

# Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation report

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***Report for the National Co-ordinating Centre  
for NHS Service Delivery and Organisation  
R & D (NCCSDO)***

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prepared by

Chris Naylor  
Jan Wallcraft  
Chiara Samele  
Angela Greatley

Address for correspondence

Angela Greatley  
The Sainsbury Centre for Mental Health  
134-138 Borough High Street  
London  
SE1 1LB

E-mail: [Angela.Greatley@scmh.org.uk](mailto:Angela.Greatley@scmh.org.uk)  
Telephone: 020 7827 8300  
Fax: 020 7827 8369

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## Acknowledgements

We would like to express our gratitude towards the many individuals and organisations who assisted with the consultation. This includes both those who contributed as participants – over a thousand people in total – and those individuals in statutory services and voluntary sector organisations who helped us to recruit participants. It would not have been possible to conduct the consultation without the enthusiasm and helpfulness of others.

# ***Executive Summary***

In 2005 the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO) commissioned the Sainsbury Centre for Mental Health (SCMH) to conduct a consultation exercise to identify medium to long-term priorities for mental health research and development (R&D) in England.

Commissioned as part of the NCCSDO's Patient and Carer-Centred Services Research Programme, the consultation was expected to include all relevant stakeholders, and in particular, service users and carers.

In conjunction with the consultation, the NCCSDO also commissioned SCMh to conduct a literature synthesis to examine existing work relating to service user and carer centred mental health services, and research priorities for mental health. The results of this literature synthesis can be found in the separate report *Research priorities for patient-carer centred mental health services: A synthesis of the literature and policy documents*.

The findings from this consultation and the separate literature synthesis are drawn together in the Overview Report, which also situates the findings within the current policy context. It is recommended that this consultation report is read in conjunction with the Overview Report.

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## **Aims and objectives**

The overall aim was to establish the medium to long-term priorities for service user and carer-centred mental health R&D in England. For the purposes of the consultation, 'service user and carer-centred' was taken to refer to services that prioritise the needs, wants and preferences of individual service users and carers, and which involve them both in their own care, and at the organisational level.

The objectives of the study were as follows.

- To identify all the key stakeholders.
- To identify and collate relevant information in clear and accessible language that will be presented to stakeholders at the start of the consultation, explaining the task, including a proposal for dissemination of interim findings and final research priorities.

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- To design and carry out a stakeholder consultation exercise, with particular emphasis on traditionally excluded groups.
- To collate and analyse the information received from the consultation.
- To translate the findings into priority areas for research and to ensure these are fed back to those who have participated in the consultation to be validated.

## Methods

Three broad stakeholder groups were included: mental health service users; carers; and professionals working in mental health or related sectors. To reach a consensus between these diverse stakeholder groups we used an adapted Delphi method. This involved three distinct stages.

- 1 Exploration** of service users' and carers' views regarding how services could be more centred on them and their needs and aspirations.
- 2 Development** of research areas based on these views – aimed at professional stakeholders who work in mental health and related sectors (including workers with personal experience of service use/caring).
- 3 Prioritisation** of the developed research areas – aimed at all stakeholders.

In each stage, semi-structured questionnaires were distributed via NHS Trusts, Primary Care Trusts, the National Institute for Mental Health in England (NIMHE), voluntary sector organisations and various professional and service user/carers networks.

The Delphi exercise was supplemented with a series of focus groups and in-depth one-to-one interviews. These were conducted with service users and carers from 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.

Across the three stages of the consultation, over 800 stakeholders were involved. Approximately half of these were service users or carers; the other half being mental health professionals of various kinds (there was of course some overlap here – a number of the professional participants having also had personal experience of service user or caring roles).

### ***Findings: research priorities***

The consultation identified 12 priority research areas. These are given below in alphabetical order. The main report elaborates on the work required within each of these areas.

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- 1 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
- 2 GPs and primary care  
Research is needed to improve the support provided within primary care for people with mental health problems, and to improve the early detection of mental health problems within primary care
- 3 Medication and 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
- 4 Mental health within the criminal justice system  
Research is needed to improve the quality of mental health care available within the criminal justice system and other secure settings, and the ability of police and other staff to deal competently with mental health issues.
- 5 Non-medication based interventions.  
Research is needed to improve access to effective non-medication based interventions
- 6 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
- 7 Prevention and promotion  
Research is needed to enable the development of preventative interventions, and interventions which promote mental well-being in the general population
- 8 Services for people in crisis  
Research is needed to improve the quality of services for people in crisis
- 9 Social inclusion and the role of mental health and 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.
- 10 Supporting and empowering family members and carers  
Research is needed to enable services to give better support, information and advice to family members and carers.
- 11 User and carer involvement in service planning and delivery

Research is needed to enable meaningful and representative involvement of service users and carers in planning and delivering services, including through user-led services

12 Workforce issues

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

The emphasis placed on each of these areas differed between stakeholder groups, but there was a strong consensus around the importance of 'GPs and primary care'; 'prevention and promotion'; 'non-medicine based interventions'; and 'social inclusion and the role of mental health and social care services'. Service users gave top priority to 'services for people in crisis', while carers gave top priority to 'supporting and empowering family members and carers'. We would like to stress however that the overwhelming feedback from participants was that all 12 research areas should be considered as priorities.

## ***Cross-cutting issues***

The consultation also identified three cross-cutting issues, of importance to all mental health research. Again, these are elaborated upon in the main Report.

1 Putting research into practice and disseminating findings

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'. Suggestions were made as to how a more efficient system for implementing research findings might be constructed.

2 Wider use of qualitative research methodologies

Several of the research areas generated in the consultation may be more amenable to qualitative exploration than quantitative techniques such as Randomised Controlled Trials. In order to meet this need for high quality qualitative studies, appropriate methodologies will have to be developed, researchers will need to be adequately trained in these methodologies, and the outputs from such studies will need to be more accepted by the academic community and policy community.

3 Service user and carer-centred outcome measures

Improved measures of service user and carer-centred outcomes will be needed both for research purposes (e.g. in evaluation of effectiveness studies) and for delivery of service user and carer-



centred services. These outcome measures would emphasise attainment of life goals of importance to the individual service user, rather than reduction in symptoms.

## ***Conclusion***

The consultation generated 12 research areas which should be prioritised if mental health services are to become more centred on the needs and aspirations of the people who use them, and their families and carers. It has also highlighted three crucial over-arching issues relating to the way in which research is conducted and put into practice. These three issues must also receive attention, in order for research to deliver the improvements sought by service users, carers and professionals.

# **The Report**

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## **Section 1 Introduction**

In 2005 the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO) commissioned the Sainsbury Centre for Mental Health (SCMH) to conduct a consultation exercise to identify medium to long-term priorities for mental health research and development (R&D) in England.

Commissioned as part of the NCCSDO's Patient and Carer-Centred Services Research Programme, the consultation was expected to include all relevant stakeholders, and in particular, service users and carers.

In conjunction with the consultation, the NCCSDO also commissioned SCMh to conduct a literature synthesis to examine existing work relating to service user and carer centred mental health services, and research priorities for mental health. The results of this literature synthesis can be found in the separate report *Research priorities for patient-carer centred mental health services: A synthesis of the literature and policy documents*.

The findings from this consultation and the separate literature synthesis are drawn together in the Overview Report, which also situates the findings within the current policy context. It is recommended that this consultation report is read in conjunction with the Overview Report.

### **1.1 Background**

The National Service Framework for Mental Health (DH, 1999) identified a patchy evidence base underpinning mental health services, and highlighted the need for investment in research to support the NHS modernisation agenda.

To ensure any research conducted is relevant and useful to those with a stake in mental health services, it is crucial that all stakeholders, including people who use services and their families and carers, are able to influence the national research agenda. This perspective is in-keeping with Government policy initiatives such as Shifting the Balance of Power (DH, 2001) the NHS Plan (DH, 2000) and Section 11 of the Health and Social Care Act (HMSO, 2001), which stress the importance of involving service users and carers in planning services.

## **1.2 Aims and objectives**

This consultation was commissioned in recognition of the need to identify research priorities for mental health, and with the intention of allowing all stakeholders to contribute to the priority setting process. The overall aim was to establish the medium to long-term priorities for service user and carer-centred mental health R&D in England.

The objectives of the study were as follows.

- To identify all the key stakeholders.
- To identify and collate relevant information in clear and accessible language that will be presented to stakeholders at the start of the consultation, explaining the task, including a proposal for dissemination of interim findings and final research priorities.
- To design and carry out a stakeholder consultation exercise, with particular emphasis on traditionally excluded groups.
- To collate and analyse the information received from the consultation.
- To translate the findings into priority areas for research and to ensure these are fed back to those who have participated in the consultation to be validated.

## **1.3 Structure of the report**

The report is split into the following sections.

- **Methodology:** critically describes the methods used to identify and consult all relevant stakeholders.
- **Findings:** describes the outputs of the various stages and components of the consultation. In order to make the priority-setting process as transparent as possible, we include extensive detail on the outputs of each stage, explaining the process leading to the development of our final research priority areas.
- **Conclusions:** summarises the key research priorities to emerge from the consultation, drawing particular attention to priority areas with the broadest consensus across stakeholder groups, and priority areas of particular importance to each group of stakeholders.

## **1.4 Terminology**

By **mental health services**, we refer to all services involved in providing support for people with mental health problems – i.e. not just specialist NHS services but also primary care services (e.g. General Practitioners) and services provided by social services and voluntary/community agencies. We use the term '**service user**' throughout this report to designate a person who has personal

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experience of accessing this diverse range of services. We are aware that some prefer other terms, such as 'survivor', but we feel that since the consultation concerned mental health services, and our objective was to hear from people who have used these services, 'service user' was the clearest and most appropriate term to use.

**Other key terms and abbreviations**

**BME groups:** Black and Minority Ethnic groups.

**Delphi method:** A method for working towards a consensus between diverse stakeholders using a series of questionnaires, adapted for use in this consultation (see section 2.2).

**NIMHE:** National Institute for Mental Health in England.

**SCMH:** Sainsbury Centre for Mental Health.

**Service user and carer-centred:** the literature synthesis carried out in parallel with this consultation highlights the lack of precision with which this term is used in the literature, and the need for a standard definition. For the purposes of the consultation we adopted the following definition: The term 'Service user and carer-centred' refers to services that prioritise the needs, wants and preferences of individual service users and carers, and which involve them both in their own care, and at the organisational level.

**Stakeholder:** anyone with an interest in mental health services, be it personal or professional. We consulted three broad stakeholder groups: service users; carers; and people who work in mental health (see section 2).

## Section 2 Methodology

The consultation involved three main stakeholder groups: service users; carers; and professionals. These groups were defined as below.

- *Service user*: anyone who has accessed a specialist mental health service in England, or who has sought help for a mental health problem from a GP or the voluntary sector. 'Mental health' does not here include learning difficulties, although people with learning difficulties and additional mental health problems were consulted. Similarly, people with substance misuse problems were only consulted if they had additional mental health problems.
- *Carer*: anyone who feels their life is affected by the mental health of a family member, partner or other close individual.
- *Professional*: people who work in mental health or a related field, in various capacities (see Appendix F for a complete list).

### **2.1 Overall design of the consultation**

Our remit was to identify research priorities for service user and carer-centred services. We therefore considered it important to begin with an exploration of service users' and carers' views regarding how services could be more centred on them, their needs and aspirations. The consultation then went on to identify the research required to underpin these changes, by consulting all relevant stakeholders.

Other key concerns in designing the consultation were as follows.

- The research priorities should be generated and developed by stakeholders themselves, rather than have stakeholders choose between candidate research priorities generated by the research team at the beginning of the process. This entailed the use of qualitative methodologies.
- The process should give all stakeholders power in determining the outcomes. This entailed giving particular attention to existing power imbalances and marginalised groups.
- The consultation should be open to all relevant stakeholders. It should involve as many and as wide a range of people as possible.

To address these concerns, we designed a process with three key components.

- 1 Adapted 'Delphi' exercise: the majority of stakeholders were consulted using a series of questionnaires which could be completed on paper or using a web-based form. These questionnaires were sent to targeted individuals and groups, and were also made publicly available.
- 2 Focus groups: a series of focus groups were conducted with service users and carers from 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.
- 3 Expert Group: we recruited an Expert Group including 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.

The Delphi exercise and focus groups were conducted in parallel – the focus groups being used in the later stages of analysis to identify areas that did not emerge from the Delphi.

Further details on these components are given in sections 2.2 and 2.3 (details concerning the Expert Group are included in the 'Adapted Delphi exercise' Section 2.2).

## **2.2 Adapted Delphi exercise**

The Delphi method (McKenna 1994, Hasson *et al.* 2000, Keeney *et al.* 2001) provides a way of working towards a consensus between diverse stakeholder groups, without the consensus position being imposed by the more powerful or influential groups. Participants complete several questionnaires in successive rounds. In each, they are given anonymised feedback on the responses to the previous round, and asked to consider this feedback while completing the new questionnaire. As the rounds progress, participants tend to converge towards a consensus position.

We adapted the standard Delphi method in order to (a) involve as many and as broad a range of stakeholders as possible and (b) ensure the process was 'data-driven' – by which we mean that we wanted the candidate research priorities to be generated and developed by the stakeholders themselves, rather than set by the research team at the beginning of the process. A three stage methodology was designed to incorporate these features.

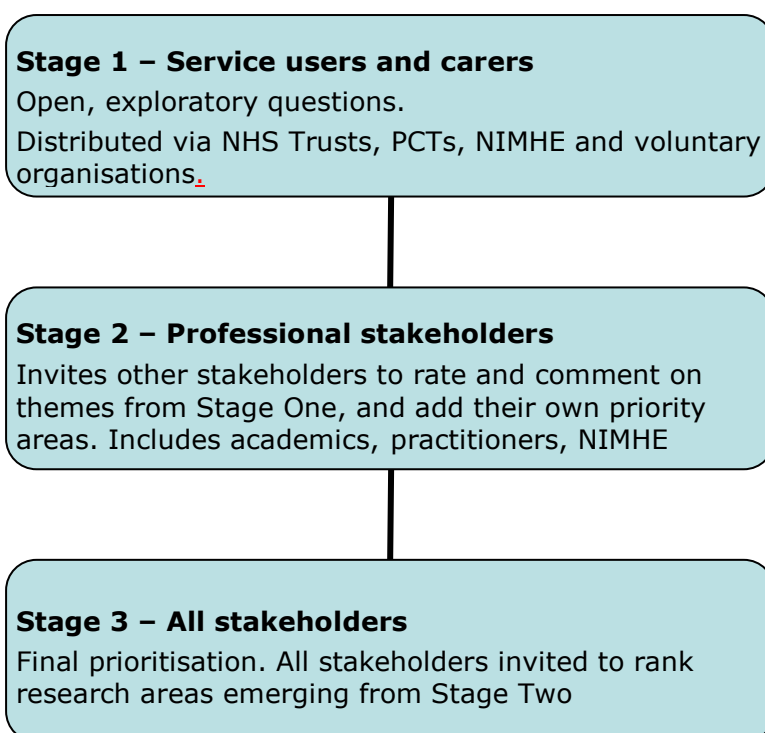
## **Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report**

- 1 **Exploration** of service users' and carers' views regarding how services could be more centred on them, their needs and aspirations.
- 2 **Development** of research areas based on these views – aimed at professional stakeholders who work in mental health and related sectors (including workers with personal experience of service use/caring).
- 3 **Prioritisation** of the developed research areas – aimed at all stakeholders.

These three stages are illustrated in Figure 2.1 below, and elaborated upon in the following sections.

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**Figure 2.1 Three stages of the adapted Delphi method**



### **Stage One Consultation with service users and carers: exploration of research priorities**

The purpose of the first stage was to explore service users' and carers' views of how services could be more centred on them and their needs and aspirations, and to begin translating these views into areas for research.



### **Questionnaire development**

We developed a semi-structured questionnaire for this purpose containing questions to cover three main topic areas:

- a How could mental health services be more centred on service users' and carers' needs and aspirations.
- b How could other services (e.g. housing) be more centred on the needs of mental health service users/carers.
- c What research needs to be carried out to develop services in these ways.

The questions used were developed in an informal focus group comprised of service user researchers, and subsequently piloted with a group of carers. They are presented in full in Appendix A.

Two versions of the questionnaire were created – a paper-based version and a web-based version (created using Keypoint Version 5).

### **Questionnaire distribution**

The questionnaire was distributed to service users and carers via a number of channels (see Appendices D and E for complete lists).

- (i) National Institute for Mental Health in England / Care Services Improvement Partnership

The questionnaire was sent to Service User and Carer leads in the eight NIMHE Regional Development Centres (RDCs). We considered it important to involve service users from diverse ethnic backgrounds, and therefore also sent it to the Race Equality leads for each region. These leads then distributed the questionnaire by a variety of means.

- Service user / carer networks associated with the RDC e.g. NIMHE West Midland Carers Network.
- Other local service user / carer groups and organisations.
- Bulletins and mailing lists for professionals who may be interested in passing the questionnaire on to service users and carers e.g. Care Services Improvement Partnership (CSIP) Eastern's 'Whole Life Bulletin'.

- (ii) Primary and secondary mental health services

We approached people directly through statutory services (primary and secondary) provided by nine selected NHS Trusts and PCTs (see Appendix E for a complete list). To ensure national coverage, we selected one from each of the eight NIMHE regions and a second in London (one north; one south). The trusts were chosen so as to include a range of different trusts (e.g. with different 'star ratings') covering both rural and urban areas, and ethnically diverse and socially deprived areas. As one of the stakeholder groups we aimed to reach was asylum seekers and refugees with mental health problems,

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we ensured some of our trusts contained significant asylum seeker and refugee populations.

Across these trusts, a comprehensive range of teams and services were recruited, to cover service users from all age groups and with a wide range of mental health issues. Teams were invited to take part in the research by telephone. Where requested, an SCMh researcher travelled to the team base to discuss the research with team members. A total of 45 teams agreed to take part (see Appendix E)

These teams were provided with an agreed number of questionnaire packs to hand out or post to service users and carers. These packs included an explanatory covering letter to the service user/carers, information sheet, consent form and freepost envelope for return. Teams also received an information sheet aimed at staff involved in distributing the questionnaire, so they would be able to answer questions from service users and carers.

### **(iii) Voluntary sector organisations**

We contacted most major national charities likely to have an interest in mental health (including those not solely devoted to mental health). In addition, several smaller, local service user and carer organisations and charities (e.g. local branches of MIND) contacted us, having seen our publicity (see 'Web-site publicity and snowballing'), to request copies of the questionnaire. Again, different organisations were able to assist in different ways.

- By passing paper copies of the questionnaire on to service users/carers they are in touch with (e.g. Big Issue, No Panic, UK Coalition of People Living with HIV and AIDS, PACE).
- By spreading the questionnaire via postal/email networks (e.g. Together UK's Supporting Carers Better Network, Mindlink, Diverse Minds).
- By advertising the consultation on web-based forums (e.g. Mental Health Foundation, Help the Aged, Phobics Society).
- By publicising the consultation among their volunteers (e.g. SANEline volunteers' mailing list).

### **(iv) Service user research groups**

We informed various service user research groups of the consultation and shared the questionnaire with them. These included:

- Institute of Psychiatry's Service User Research Enterprise (SURE)
- Mental Health Research Network's Service User Research Group in England (SURGE)
- 'Shaping Our Lives' National User Network.

(v) Web-site publicity and snowballing

We advertised the consultation on the Sainsbury Centre for Mental Health website home page and invited people who visit the website to complete the questionnaire. We also used snowballing techniques (Salganik *et al.* 2004) by encouraging participants to inform others of the project and become involved in distributing the questionnaire.

### **Analysis**

The content of responses was analysed through detailed reading and coding of data to draw out the main themes. This thematic analysis was done with the aid of computer software (QSR NVivo 2.0). Thematic analysis is particularly useful for deriving information of more general use from personal accounts of experience (Boyzatis 1998).

Broad research areas were then defined which encapsulated the emerging themes, and a content analysis was performed to establish the frequency with which text coded under each area occurred in the data.

To accommodate the variety of responses received we included within the analysis a process for translating responses into research priorities. While some responses were already in the form of research ideas, others were in the form 'treatment X should be more available' or 'services should be more Y'. In the case of the former, these statements were translated into a need for research around the use and effectiveness of treatment 'X'. In the case of the latter, these statements were translated into a need for research around the approaches and barriers to making services more 'Y'.

The translation process was validated by Stage Three, in which we returned to participants from stages one and two with the list of research priorities emerging from the consultation, and asked them to rate and comment upon these (see 'Stage Three'). We considered this a crucial component in validating our analysis.

### **Expert Group meeting**

A meeting of our Expert Group was held to assist with the analysis process and the design of the Stage Two questionnaire. The group discussed the translation process, the face validity of the emerging research areas, and how best to present the emerging areas of research to professional stakeholders. Group members also undertook a mock-translation of selected responses, in order to explore possible approaches to this process.

## **Stage Two: consultation with professional stakeholders: refinement of Stage One research areas**

The purpose of the second stage was to consult all other stakeholders, comprising of a wide variety of professional groups, in order to develop and add to the research areas generated by service users and carers in Stage One. These stakeholders ranged from practitioners and user/carer involvement workers to academics and commissioners involved in mental health services. We included people working in the mental health field who also had personal experience of service use or caring roles.

### ***Questionnaire development***

Based on the responses from Stage One, a questionnaire was designed which presented the key emerging areas for research. The questionnaire described each area and gave respondents the opportunity to (a) comment on each area and suggest the types of research studies needed within each; (b) rate each area in terms of importance; and (c) suggest other research areas they believed should be prioritised.

The areas were presented in order of the frequency with which they appeared in responses to Stage One. This was explained in the questionnaire, so that respondents had an indication as to which research areas were emerging as important to service users and carers. (See Appendix B for the Stage two questionnaire).

### ***Questionnaire distribution***

As in stage one, a variety of distribution methods were used, namely: (i) direct invitation; (ii) distribution via relevant mental health networks and forums; and (iii) adverts on websites and email bulletins.

#### **(i) Direct invitation**

Invitations to participate were emailed to 691 individual professional stakeholders. These individuals were identified by various means including: seeking nominations from the Expert Group and other expert contacts (e.g. in the Department of Health); obtaining membership lists for key mental health groups (e.g. the Mental Health Task Force); and searching target organisations' websites for relevant individuals (see Appendix F for full details on how we identified stakeholders within each professional sub-group).

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### **(ii) Networks and forums**

A number of networks and forums were used to distribute the questionnaire, including:

- The Mental Health Research Network
- Social Perspectives Network
- Prison Health Research Network
- Mental Health Foundation's 1-in-4 forum
- Together UK's Supporting Carers Better network
- NIMHE Development Worker networks
- Strategic Health Authority Clinical Governance Leads network.

### **(iii) Adverts**

Adverts were placed on the following websites and in the following bulletins.

- The Royal College of Psychiatrists
- Mental Health Foundation
- Mental Health Specialist Library
- Sainsbury Centre for Mental Health
- British Psychological Society research digest
- SITRA Housing Bulletin
- CSIP Whole Life Bulletin
- Mental Health Foundation news bulletin.

These adverts contained a hyperlink to the online questionnaire.

## **Analysis**

The analysis focused on two purposes of Stage Two.

- 1 To refine the research areas emerging from stage one – reducing them in number, and also specifying more fully what research may need to be done within each.
- 2 To add any new priority areas to those already identified.

As in Stage One, the qualitative responses were analysed thematically, with the aid of computer software (QSR NVivo 2.0). The translation system described earlier was again needed to convert some qualitative responses into research priorities. Descriptive statistics (frequencies, means) were compiled for the quantitative ratings data automatically by our survey publishing software package (Keypoint Version 5).

Both the qualitative and quantitative analyses contributed to the process of developing and adding to the research areas emerging from Stage One.

### ***Expert Group meeting***

The Expert Group again assisted with the analysis process and with the creation of the next questionnaire. A meeting was held in which the group discussed the preliminary findings from the analysis, and how the research areas should be developed in light of it. The group also discussed the format of the final stage questionnaire.

## **Stage Three: prioritisation of research areas with all stakeholders**

The purpose of the final stage was to give all stakeholders an opportunity to rate the research areas emerging from Stage Two, in order to establish which areas are important to whom, and which have the greatest consensus behind them. This stage also allowed us to validate our analysis of responses to stages one and two, by presenting the results of the analysis to the respondents from these stages.

### ***Questionnaire development***

The questionnaire gave a brief description of the research areas to emerge from Stage Two, and came with an appendix which included a fuller list of possible research questions within each area. Respondents were asked to rate each area in terms of importance, on a scale of one to seven. The questionnaire also included a space for comments (see Appendix 3 for Stage Three questionnaire).

We asked respondents to identify themselves as having used services personally, having cared for someone who has, and/or as a person who works in mental health or a related field. Respondents were allowed to select more than one option, but in some parts of the analysis we had to assign respondents to a single category (see 'Analysis').

### ***Questionnaire distribution***

All respondents to stages one and two who indicated they would like to contribute to a further stage were sent the final questionnaire directly. In addition, we sent the questionnaire to focus groups participants (see section 2.3) who had indicated they would like to be involved. We also made the third stage open to new respondents, utilising the same networks, forums and websites as previously to publicise the consultation.

### ***Analysis***

The quantitative ratings data allowed us to explore which research areas are most important to different stakeholder groups. To do this, respondents first had to be classified either as a service user, a carer OR a professional, as we considered it inappropriate to count twice the

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views of a person who is both a service user and a professional (for example). We devised the following categorisation system.

- If a respondent had personal experience of service use this was privileged, and the respondent was categorised as a service user regardless of their other roles as a carer and/or professional.
- If a respondent had personal experience being in a caring role, this was privileged above their professional experience, and the respondent was categorised as a carer unless they also had personal experience of service use.
- Those categorised as 'professionals' in the quantitative analyses were therefore those professionals with no expressed personal experience of service use or caring roles.

We used statistical tests to look for significant differences between the ratings scores of different groups of respondents (as the data were not normally distributed, non-parametric tests were used: Mann-Whitney U and Kruskal Wallis).

We also carried out a cluster analysis (Everitt *et al.* 2001). This type of analysis attempts to uncover groups or clusters of individuals who respond similarly – and differently from individuals in other clusters. There are many types of cluster analysis (again see Everitt *et al.* 2001). Here, a 'k-means' method was used. The k-means technique divides data into a number of groups or clusters specified by the user. The question arises as to the 'optimal' number of groups for any data set. In the case of this study, a variety of indicators suggested looking at the three group solution. The cluster analysis enabled us to explore the 'patterns' of individual responses in the quantitative data and try to identify what factors influence these responses.

Qualitative data gathered from the open-ended comments section in the questionnaire were examined using a content analysis.

## **2.3 Focus groups with marginalised groups**

A key concern in designing the consultation was that it should be as inclusive as possible (see Section 2.1). We did not anticipate reaching all groups of service users and carers in the questionnaire-based Delphi exercise, and therefore considered it crucial to supplement it with an outreach exercise. This consisted of a series of focus groups and in-depth interviews with marginalised stakeholder groups. These groups were conducted in parallel with the Delphi exercise, with the following aims.

- 1 To identify any new priority research areas not already identified by the Delphi exercise.
- 2 To explore particular issues for marginalised groups within the priority research areas identified by the Delphi exercise.

With the help of the Expert Group, we identified stakeholder groups whom we anticipated may not return the questionnaire in large numbers.

- Young service users and their parents.
- Older people.
- People from Black and minority ethnic (BME) groups.
- People diagnosed with personality disorder.
- Refugees and asylum seekers.
- Ex-offenders.
- People without stable housing (referred to below as homeless).
- People with learning difficulties.

### **Participant recruitment**

We recruited people from the stakeholder groups listed above by contacting specialist services aimed at these client groups provided by the nine NHS Trusts and PCTs involved in the Delphi exercise (see Appendix E). We also recruited via specialist voluntary sector organisations and service user groups. The organisations and groups involved were asked to distribute an information sheet to all clients/members, informing them of the purpose of the consultation and inviting them to participate. We aimed to recruit between five and eight participants for each group, and also offered people the option of taking part in an in-depth, one-to-one interview, if preferred. In all, 20 focus groups and five in-depth interviews were conducted (see Appendix G for a complete list).



### ***Topic guide development***

The topic guide was based on the questionnaire used in Stage One of the Delphi exercise (see Appendix A). This was designed to be open and exploratory, and covered a range of issues concerning:

- what mental health services participants had used
- how these services could be more centred on them
- how other public services could be more centred on them
- what mental health research they think should be done to improve services
- what were the main things they hoped to see change.

### ***Conducting the groups***

The focus groups and interviews were carried out by experienced researchers, most of whom had personal experience of service use or as carers. In most of the groups there was also a co-facilitator to keep notes and attend to practical concerns.

The groups were tape recorded and transcribed in full. The facilitator and/or co-facilitator kept notes and wrote a summary report after the group. In two cases, consent was not gained to record the group and so the analysis was based on the notes and summary report.

Several groups contained people for whom English was not their first language and in two cases the focus group was conducted with the assistance of an interpreter.

Participants were informed of the purpose of the consultation, and were given a small amount of money to reimburse them for their time and travel expenses.

### ***Analysis***

The content of the focus groups was analysed through detailed reading and coding of transcripts and summary reports, to draw out the main themes. Thematic analysis is particularly useful for deriving information of more general use from personal accounts of experience (Boyzatis 1998).

The aim of the analysis was to find out how far the data from the focus groups and interviews simply reiterated the findings emerging from the Delphi exercise, how much it added detail and depth to those findings, and to what extent new themes were emerging. The 11 research priority areas emerging from the second stage of the Delphi exercise (see Section 2.2) were therefore used as analytic categories to analyse each set of interviews and focus groups within a particular demographic group.

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The themes emerging on repeated readings of the transcripts were noted in the margins and compared to the 11 key research areas derived from the second stage of the Delphi exercise. Where they corresponded to those areas, the sub-topics arising were also noted. Where they did not correspond, new themes were generated and these were used to re-analyse the focus groups.

## Section 3 Findings

The adapted Delphi exercise identified 11 priority research areas. The focus groups corroborated the importance of these areas, but also highlighted the need for one further area – mental health in the criminal justice system. The final 12 areas (in alphabetical order) are:

- care pathways and transitions between services
- GPs and primary care
- medication and side effects
- mental health in the criminal justice system
- non-medication based interventions
- person-centred care planning
- prevention and promotion
- services for people in crisis
- social inclusion and the role of mental health and social care services
- supporting and empowering family members and carers
- user and carer involvement in service planning and delivery
- workforce issues.

We also identified three cross-cutting issues of importance to all research.

- 1 Putting research into practice and disseminating findings
- 2 Wider use of qualitative research methodologies
- 3 Outcome measures.

This section explains how these research areas and cross-cutting issues emerged from the consultation, and also presents details from a quantitative analysis exploring how different stakeholder groups rate the research areas differently.

For a full description of the 12 areas and three cross-cutting issues, please refer to the Conclusions Section – in particular, table 4.1.

### ***3.1 Findings from the adapted Delphi exercise***

This section presents the results from each of the three stages of the adapted Delphi exercise, and explains how the results from each stage contributed to the next. The results presented in the Stage One and

Stage Two sections will be of interest to those wishing to understand the process leading to the formulation of the 11 priority research areas to emerge from the Delphi exercise. We include as much detail on this in order to make the process as transparent as possible.

The Stage Three section presents the overall rating scores for each of the 11 research areas (Table 3.5), and also includes further analyses comparing the responses of different stakeholder groups, age groups and so on.

### **Stage One: consultation with service users and carers: exploration of research priorities**

We received 266 responses from service users and carers to our first stage questionnaire. Table 3.1 shows the characteristics of respondents and the NIMHE regions where they were based. The majority of respondents were service users. Carers were also represented, and there included a small number of respondents who were both service users and carers.

Most respondents were between the ages of 25 and 64 years. There were relatively small numbers of younger and older respondents. There were also relatively small numbers of people from Black and Minority Ethnic (BME) groups. This was anticipated, and compensated for through a separate series of focus groups with young people, older people, people from BME groups and other marginalised groups (see Section 2.3).

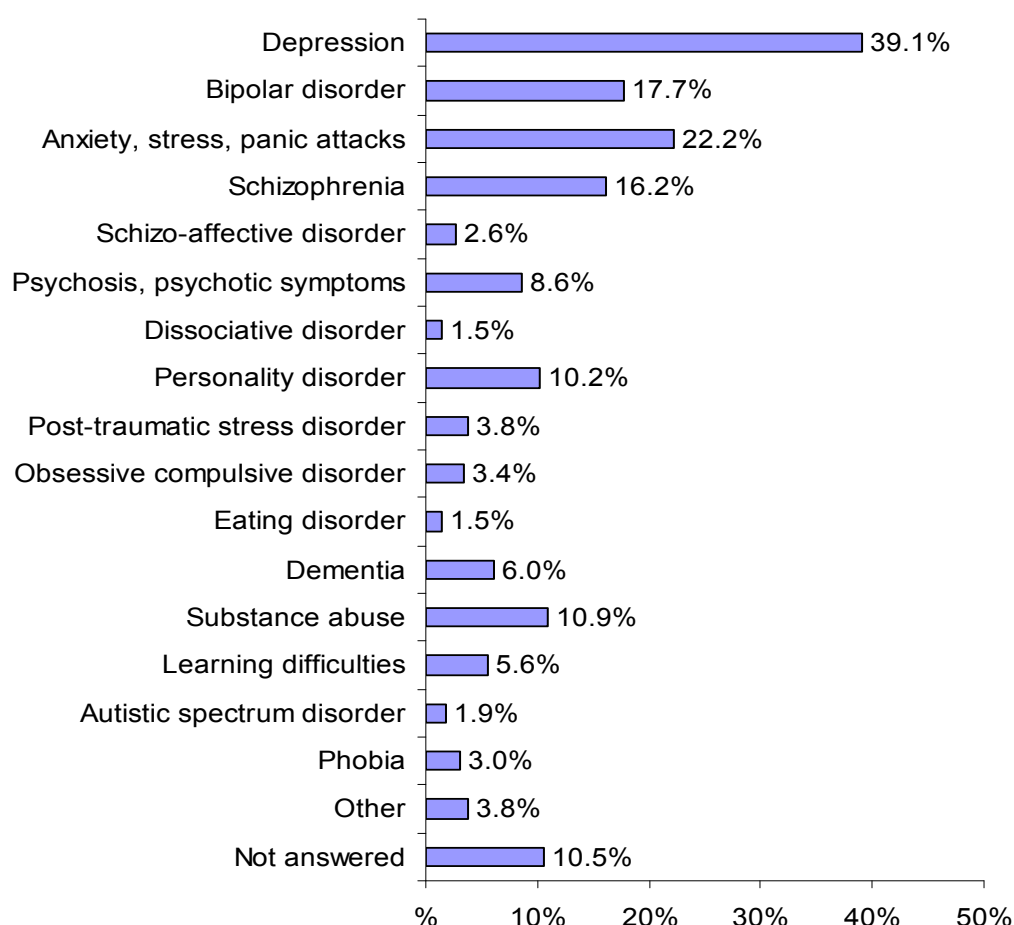
There appeared to be a relatively even distribution of respondents across the eight NIMHE regions, but with the lowest number of responses from the East Midlands.

**Table 3.1: Characteristics of Stage One respondents**

		<b>Number of respondents</b>
<b>Respondent type</b>	Service user	159
	Carer	75
	Both	23
<b>Gender</b>	Female	143
	Male	116
<b>Age group (years)</b>	0-24	24
	25-44	113
	45-64	92
	65+	24
<b>Ethnic group</b>	White British	207
	White other	17
	All other ethnic groups	34
<b>NIMHE region</b>	North East	42
	North West	29
	East Midlands	16
	West Midlands	38
	Eastern	25
	London	47
	South East	31
	South West	25

Figure 3.1 presents the distribution of these respondents across different diagnostic categories. These categories are based on respondents own descriptions of their mental health problems. Depression featured in these descriptions most commonly. Many described themselves as bipolar, schizophrenic, or said they had problems anxiety, stress and/or panic attacks. Substance abuse problems were also commonly reported, as were diagnoses of personality disorders. The figure shows that people with a range of problems contributed to Stage One. Some areas were under-represented however, notably people with eating disorders (this group was more highly represented in the complementary focus groups).

**Figure 3.1 Diagnostic categories of stage one respondents**



Percentage of respondents in each diagnostic category (respondents allowed to be in multiple categories).

Detailed coding of responses produced 149 individual thematic codes. These themes were quite particular, e.g. 'food on acute wards'. Each had between one and 75 extracts of text coded under it. The codes were arranged into broader thematic areas. Twenty-five areas were sufficient to accommodate all but the most idiosyncratic codes – codes which occurred infrequently and which bore little thematic relation to other codes (e.g. 'voluntary euthanasia'). The 25 broad areas are listed in Table 3.2, in order of the frequency with which they occurred in responses:

**Table 3.2 Twenty-five priority research areas to emerge from Stage One**

1	Acute inpatient wards	14	Marginalised groups
2	Choice and involvement	15	Amount of contact between service users and staff
3	Psychological therapy	16	Recovery and social inclusion
4	Family and carers	17	Other forms of treatment (dietary, complementary etc.)
5	Holistic, individualised treatment	18	Integrated services
6	Sources of support in the community	19	GPs and primary care
7	User involvement, user-led services	20	Early intervention, prevention and promotion
8	Nature and causes of mental health problems	21	Discharge from inpatient units
9	Medication and side effects	22	Travelling to appointments
10	Stigma, discrimination and attitudes	23	Implementational research
11	Employment		
12	Getting help when it's needed		
13	Alternatives to acute wards		
			Benefits*
			Housing*

\* Issues around housing and benefits were mentioned very frequently. They were, however, mentioned explicitly in the questionnaire – whereas the other 23 areas were generated spontaneously by service users and carers. 'Housing' and 'benefits' were therefore excluded from the order-of-frequency, both in the table above and in the Stage Two questionnaire (see Appendix B).

Descriptions of each of the 25 areas – including possible research questions emerging from responses – were presented to professional stakeholders for development in Stage Two. We do not consider it useful to give a detailed description of the 25 areas here, since they were developed considerably in Stage Two.

## **Stage Two Consultation with professional stakeholders: refinement of Stage One research areas**

The second stage of the consultation was targeted at professional stakeholders who were asked to rate and comment upon the priority areas identified by service users and carers in the first stage. Responses were received from 436 professionals. Practitioners were the most well represented group, followed by academics (see Table 3.3). In addition to responses from individuals, we also received collective responses from the British Psychological Society, the National Institute for Clinical Excellence (NICE) and the Economic and Social Research Council.



**Table 3.3 Characteristics of Stage Two respondents**

		<b>Number</b>
<b>Professional group</b> (respondents allowed to be in more than one category)	Academic	110
	Practitioner	265
	<i>Psychiatrist</i>	48
	<i>Psychologist</i>	51
	<i>Nurse</i>	102
	<i>Other<sup>1</sup></i>	64
	Health service - senior roles <sup>2</sup>	61
	Health service – other roles <sup>3</sup>	12
	DH/NIMHE	24
	Voluntary sector	52
	Social care	33
	Other	24
<b>Main client group(s) or area(s) of interest</b> (respondents allowed to be in more than one category)	Adults	62
	Children and adolescents	50
	Older adults	48
	Forensic mental health	25
	Drug/alcohol abuse	15
	People with learning difficulties	44
	Carers	15
	Black and minority ethnic groups	13
	Women	8
	Interested in all client groups	169

<sup>1</sup> *‘Other practitioners’* included general practitioners, occupational therapists, counsellors, support workers, STR workers, graduate primary care mental health workers, pharmacists.

<sup>2</sup> *‘Health service – senior roles’* included medical directors, directors of nursing, clinical directors, heads of services, R&D directors /managers, commissioning managers, clinical governance managers.

<sup>3</sup> *‘Health service – other roles’* included project managers, co-ordinators, Patient Advice and Liaison Service Officers (PALS).

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To a large extent, the ratings scores agreed with the frequency measure used in Stage One. 'Acute care', 'choice and involvement' and 'psychological therapies' were all in the top five highest rated areas. They were joined, however, by 'early intervention, prevention and promotion' and 'recovery and social inclusion', which were not among the most frequently mentioned areas in service users' and carers' responses to Stage One. The scores are given in full in Appendix I. We do not wish to focus on them here as the results from the stage three give a fairer comparison of different stakeholder groups' priorities.

The qualitative data from the open-ended questions fell into three types.

- 1 Comments on each research area – its importance, coherence, and relation to other areas.
- 2 Specific ideas for research studies.
- 3 Wider comments regarding mental health research in general.

On the basis of the comments and criticisms regarding the 25 research areas, we combined and redefined several of the research areas, and abandoned two areas entirely. This process left us with the nine areas listed below. For a description of this refining process and the data it was based on, please see Appendix H.

- 1 GPs and primary care.
- 2 Medication and side effects.
- 3 Non-medication based interventions.
- 4 Person-centred care planning.
- 5 Prevention and promotion.
- 6 Services for people in crisis.
- 7 Social inclusion and the role of mental health and social care services.
- 8 Supporting and empowering family members and carers.
- 9 User and carer involvement in service planning and delivery.

These nine areas were supplemented with two new areas which had not emerged from the service user and carer consultation, but which emerged from this stage as important. These were:

- 10 Workforce issues.
- 11 care pathways and transitions between services.

In part, these areas reflect concerns which were not present in service users' and carers' responses. However they also contain some of the same concerns framed in new ways e.g. service users' and carers'

concerns regarding acute inpatient wards was framed by some professional respondents in terms of staffing and training requirements for acute wards.

As well as allowing us to redefine and refocus some of our research areas, the analysis of professional stakeholders' comments also allowed us to specify the areas more fully. We found that Stage Two complemented Stage One in the sense that professional stakeholders had many suggestions regarding research that would need to be done in order to address the areas of concern raised by service users and carers. We used this knowledge – supplemented by knowledge within the Expert Group and the SCMH research team – to create an outline of particular research projects that may need to be done within each research area. These are presented in full in the Conclusions Section.

Finally, we also identified three themes prominent in responses to Stage Two which were not isolatable research areas so much as issues of pertinence to all research.

- 1 Putting research into practice and disseminating findings.
- 2 Wider use of qualitative research methodologies.
- 3 Outcome measures.

We regarded these as highly important cross-cutting issues applicable to all mental health research, and so warranting special attention. For a full discussion of these areas, please see Section 4.7.

### **Stage three: prioritisation of research areas with all stakeholders**

The 11 areas listed above were presented in a random order in the stage three questionnaire. Two versions of the questionnaire were distributed with the areas given in different orders, to minimise any effects of question order on the results.

A total of 651 people responded to the questionnaire. As shown in Table 3.4, this included 479 people who were currently employed in mental health or related fields, 220 people with personal experience of service use, and 139 people who care for someone who has used mental health services. Note that there is some overlap here – with many people falling into more than one of these three categories.

Most respondents were White British, aged between 25 and 64 years, and there were twice as many females as males. In the case of age there was a slightly more even distribution among service users and carers than among professionals who, unsurprisingly, were almost exclusively between the ages of 25 and 64.

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There was a fairly even distribution of respondents across the eight NIMHE regions, but with the lowest number of responses from the East Midlands.

**Table 3.4. Characteristics of respondents to Stage Three**

	<b>Service users</b>		<b>Carers</b>		<b>Professionals</b>		<b>All respondents</b>	
	Number	%	Number	%	Number	%	Number	%
<b>Gender</b>								
<b>Female</b>	127	58	93	67	301	63	399	61
<b>Male</b>	64	29	35	25	162	34	204	31
<b>Age group</b>								
<b>0-24 years</b>	13	6	4	3	12	3	22	3
<b>25-44 years</b>	78	35	28	20	191	40	225	35
<b>45-64 years</b>	101	46	81	58	246	51	324	50
<b>65+ years</b>	12	5	18	13	5	1	28	4
<b>Ethnic group</b>								
<b>White British</b>	182	83	118	85	393	82	534	82
<b>White other</b>	16	7	14	10	49	10	61	9
<b>All other ethnic groups</b>	12	5	5	4	24	5	33	5
<b>NIMHE region</b>								
<b>North East</b>	37	17	19	14	69	14	98	15
<b>North West</b>	37	17	16	12	79	16	101	16

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<b>East Midlands</b>	16	7	7	5	35	7	54	8
<b>West Midlands</b>	22	10	27	19	53	11	75	12
<b>Eastern</b>	23	10	14	10	44	9	66	10
<b>London</b>	30	14	22	16	86	18	104	16
<b>South East</b>	20	9	14	10	50	10	64	10
<b>South West</b>	24	11	14	10	48	10	63	10
<b>Overall total</b>	220		139		479		651	

(respondents allowed to be categorised under several columns where appropriate)

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### **Quantitative analysis**

Table 3.5 below lists the mean rating scores for the 11 research areas to emerge from the Delphi exercise. All areas were rated highly, scoring between five and six on a scale of one to seven. Nonetheless there was a modest but highly significant (in the statistical sense) preference for certain areas – as demonstrated by a one-way 'ANOVA' test ( $p < 0.001$ ).

Interestingly, the two highest scoring areas overlap to some extent – in that they both include looking at ways of intervening early to avert the development of mental health problems. The 'GPs and primary care' area includes research around how mental health problems can be identified by GPs at the earliest possible stage, and treated within primary care without referral to specialist services. The 'Prevention and promotion' area includes research examining preventative interventions to decrease the prevalence of mental health problems.

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**Table 3.5 Stage Three mean rating scores (for all 651 respondents)**

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<b>Research area</b>	<b>Mean score (out of 7)</b>
GPs and primary care	5.67
Prevention and promotion	5.65
Non-medication based interventions	5.63
Social inclusion	5.54
Crisis services	5.49
Person-centred care planning	5.41
User/carers involvement	5.27
Carers support and empowerment	5.12
Medication and side effects	5.09
Care pathways and transitions	5.02
Workforce issues	4.96

Priority areas listed in descending order of mean rating.

### **Analysis by respondent type**

Table 3.6 illustrates the rank order of the 11 areas for different groups of respondents. There is much similarity: service users, carers and professionals all rated the 'GPs and primary care', 'prevention and

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promotion', 'non-medication based interventions' and 'social inclusion' areas highly. There were, however, statistically significant differences in the following areas.

- 1 Crisis services: service users rated this higher than any other research area. For carers and professionals it was mid-table ( $\chi^2=17.01$  df2,  $p<0.001$ ).
- 2 Carer support and empowerment: carers rated this as their top area. Service users and professionals rated it lower ( $\chi^2=25.19$  df2,  $p<0.001$ ).
- 3 Medication and side effects: service users and carers rated it higher than professionals, for whom it was the lowest priority ( $\chi^2=15.51$  df2,  $p<0.001$ ).
- 4 User/carers involvement: service users and carers rated this higher than professionals ( $\chi^2=9.56$  df2,  $p=0.008$ ).

Note that in this and the following sub-analyses, respondents were classified either as a service user, a carer OR a professional.

**Table 3.6 Comparison of the priorities of service user, carers and professionals**

<b>Service users (n=220)</b>	<b>Carers (n=95)</b>	<b>Professionals (n=322)</b>
Crisis services	Carers	Prevention
GPs	GPs	GPs
Non-medication	Social inclusion	Non-medication
Prevention	Person-centred	Social inclusion
Social inclusion	Prevention	Person-centred
Person-centred	Crisis services	Crisis services
Involvement	Non-medication	Carers
Medication	Involvement	Involvement
Care pathways	Medication	Care pathways
Workforce	Care pathways	Workforce
Carers	Workforce	Medication

Priority areas listed in descending order of mean rating for each group. 'n' = Number of respondents.



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In addition to the differences between service users, carers and professionals there were also statistically significant differences between the different sub-groups of professionals who completed the questionnaire, in the following research areas.

- 1 Social inclusion: academics, senior health service professionals and social care workers rated this among their top priorities. Practitioners rated it lower ( $X^2=16.08$  df5,  $p=0.007$ ).
- 2 User/carer involvement: senior health service professionals and social care workers rated this highly, whereas practitioners rated it as their lowest priority ( $X^2=12.42$  df5,  $p=0.029$ ).

The mean scores given to the 11 areas by each professional sub-group are presented in Appendix J.

### ***Analysis by gender***

There was only one significant difference between male and female respondents. Males tended to rate the 'medication and side effects' area lower than females ( $U=34666$ ,  $p=0.015$ ).

### ***Analysis by ethnicity***

Due to the low number of respondents from black and ethnic minority groups, we divided our respondents into three crude ethnic categories: White British, White other, and Black and Minority Ethnic (BME) groups. Again, there was a statistically significant difference in just one research area – 'services for people in crisis'. This was rated higher by BME respondents than by White respondents.

### ***Analysis by age***

For the purposes of this analysis, respondents were categorised into one of three age groups: 0-24 years, 25-64 years or 65+ years. It would not be valid to conduct a single analysis across all stakeholder groups, since the age groups differ markedly in their composition (0-24 comprising mainly service users, 65+ comprising mainly service users and carers). A single analysis on age would therefore be contaminated by the differences between the stakeholder groups. We therefore conducted separate analyses looking at the effect of age on rating scores amongst service users and carers individually. The effect of age among professionals was not examined because these stakeholder groups were almost entirely in the 25-64 years age bracket.

Among service users, age had a significant effect on the following research areas.

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- 1 GPs and primary care: under 25s and over 64s both rated this higher than service users in the 25-64 years age bracket ( $\chi^2=14.69$  df2,  $p=0.001$ ).
- 2 Care pathways and transitions: young service users rated this higher than service users over the age of 25 ( $\chi^2=8.88$  df2,  $p=0.012$ ). It seems most likely that this is attributable to the reference to 'improving the transition from child and adolescent to adult services' contained in this research area.
- 3 Person-centred care planning: this was rated higher by service users over the age of 25 than by young service users ( $\chi^2=12.51$  df2,  $p=0.002$ ), perhaps because of the terminology involved (e.g. 'care plan', 'direct payment', 'advance directive').

Among carers, age had a significant effect on the following research area.

- Workforce issues: this area was rated high by carers in the over 65+ years bracket ( $\chi^2=9.45$  df2,  $p=0.002$ ), than by carers below this age.

### **Sub-analysis by region**

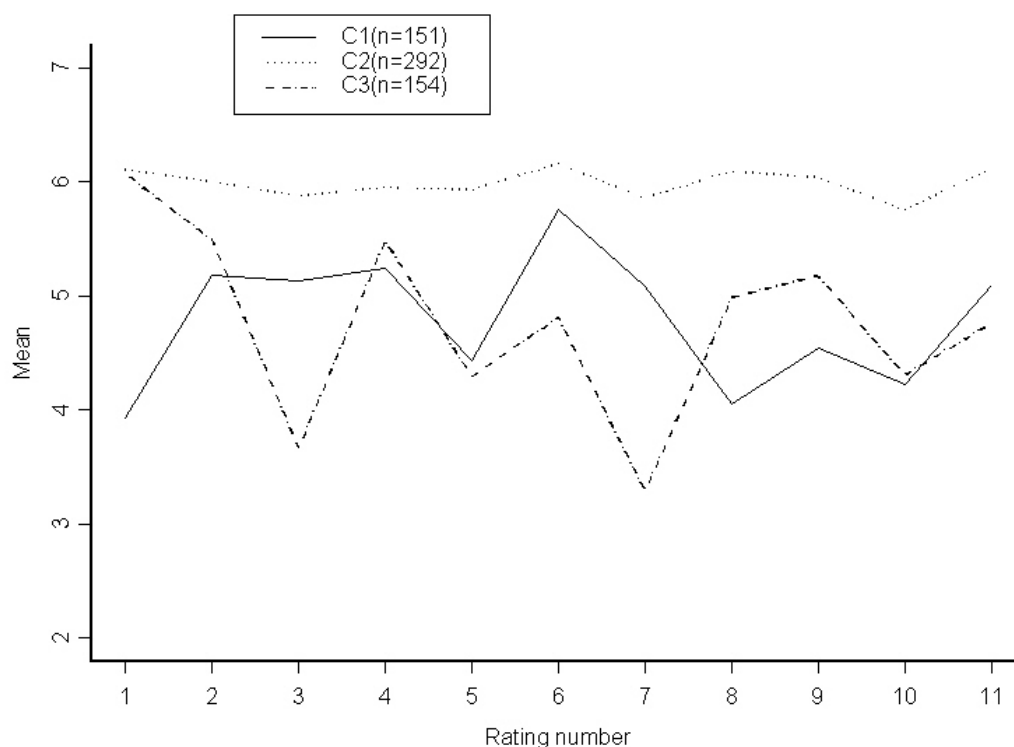
There were no significant differences between responses from the eight regional areas (North East, North West, East Midlands, West Midlands, Eastern England, London, South East, South West).

### **Cluster analysis**

A cluster analysis provides a way of exploring the factors influencing respondents' answers, by uncovering groups or clusters of individuals who respond similarly and differently from individuals in other clusters (see Methodology).

Our analysis divided the respondents into three clusters of people; within each cluster individuals have similar patterns of response on the 11 questions and different patterns from individuals in the other clusters. A variety of indicators suggested the three group solution would be most appropriate for our data. The graph below gives the mean rating scores across the 11 research areas for each of the three clusters, and illustrates how the pattern of responses differed between these clusters (C1, C2 and C3).

**Figure 4.1: Mean ratings scores over the 11 research areas, for each of the 3 clusters to emerge from cluster analysis**



**Key**

1	Social inclusion	7	Care pathways
2	Prevention/promotion involvement	8	User/carers
3	Medication and side effects care planning	9	Person-centred
4	Non-medication based interventions	10	Workforce issues
5	Carers	11	Crisis services
6	GPs and primary care		

There is one group (Cluster 2) that consistently rated all of the research areas highly. This group accounts for 49 per cent of our sample. The two remaining groups differ markedly in their ratings patterns. Both give high priority to 'prevention and promotion' and

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'non-medication based interventions', but whilst Cluster 1 also prioritises 'GPs and primary care', 'care pathways' and 'medication and side effects', Cluster 3 gives priority to 'social inclusion', 'person-centred care planning' and 'user/carers involvement'. A possible interpretation is that Cluster 1 is more 'service-focused' – their priorities are how services relate to each other, the role of primary care and the use of medication – while Cluster 3 is more focused on inclusion and empowerment of the service user. Table 3.8 shows the composition of these three clusters in terms of the three main stakeholder groups.

**Table 3.8 Composition of the three clusters identified by cluster analysis**

Percentage of people in each cluster accounted for by each of the three main stakeholder groups				
	<b>Cluster 1</b>	<b>Cluster 2</b>	<b>Cluster 3</b>	
Service user	36	34	31	
Carers	9	20	11	
Professionals	55	46	58	
Total	100	100	100	

Looking across the rows of table 3.8, there is a more or less even distribution of people across the three clusters. Put another way, the responses within a stakeholder group are not particularly homogeneous, and knowing which stakeholder group a person belongs to is unlikely to allow an accurate prediction of how they will rate the 11 research areas.

The only notable association between stakeholder group and cluster membership is in a slight over-representation of carers in cluster 2. This is the least 'interesting' of the clusters in that it contains people who rated all of the research areas highly.

We also looked at the composition of the three clusters in terms of age, ethnicity, gender, location and different professional sub-groups, and found that in these variables too, there is an even distribution of people in different groups (e.g. different age groups) across the three clusters.

The even distribution of stakeholders across the three clusters has important implications. In the quantitative analyses presented in the previous section, we illustrated that different stakeholder groups differ

slightly in their research priorities. However, the cluster analysis illustrates that this conceals two important facts.

- 1 Within any given stakeholder group – service users, for example – there is much variation between individuals' priorities.
- 2 If we divide people who took part in the consultation according to their responses, we find that three clusters of people exist with markedly different priorities, and that these clusters defy the boundaries between different stakeholder groups, age groups, genders and so on.

### ***Analysis of open-ended comments***

A content analysis was also conducted on the 'comments' box of the final questionnaire, to draw out any important points. The majority of respondents (58 per cent) declined to add anything to the comments box. However, we present a brief summary of the content of responses below.

By far the most common comment was that it was difficult to rate the research areas because all 11 are important. This goes some way towards explaining the finding from the cluster analysis (see previous section) that 49 per cent of respondents rated all items highly, with little discrimination. Several respondents expressed concern at the idea that some areas would be funded at the expense of others:

*'Nearly all the issues raised above should be given high priority - compared perhaps to less important issues such as investment in high-tech genetics. It may be a little disingenuous to put these options in apparent competition since all are high priorities'*

The British Psychological Society

As a result of this feedback, we decided to stress that whilst different stakeholder groups place emphasis on different areas, all of the areas listed in stage three should be considered priorities for research. We do however draw attention to those that enjoy a greater degree of consensus across the different stakeholder groups (see section 4.2).

The second most common theme in respondents' comments regarded our coverage of issues relating to young people, older people and other marginalised groups. Respondents indicated that while the concerns of these groups were referred to within several of the research areas, they would need to be made more explicit and given greater prominence in our report.

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*'Concern that most of these areas, on reading the text, appear to refer to adult services. Some mention is made about CAMHS but little in terms of Older People ... Whilst services for older peoples with mental ill-health may be implicit in your research areas above, sometimes it needs to be explicit so that it doesn't get overlooked'*

Carer

Accordingly, we ensure that the concerns of marginalised stakeholder groups are given prominence in the Conclusions Section of this report, highlighting in turn the priorities of different stakeholder groups (sections 4.3 to 4.6).

The three 'cross-cutting issues' that emerged from Stage Two were present again in the Stage Three comments. Please see section 4.7 for a full discussion of these.

The remaining responses were largely suggestions for particular research studies that should be done within each area. To avoid repetition we do not list these here – rather they are included in the full outline of the priority research areas given in the Conclusions Section.

### **3.2 Findings from the focus groups with marginalised groups**

This section presents the findings from 20 focus groups and five in-depth, one-to-one interviews. These were conducted with the following marginalised stakeholder groups whom we anticipated would not return the questionnaires for the Delphi exercise in large numbers (see Appendix G for further details):

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**Table 3.9 – Participants in focus groups and one-to-one interviews**

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<b>Stakeholder group</b>	<b>Total number of participants</b>
Young service users/parents	11
Older service users and carers	27
Black and minority ethnic groups	45
Refugees and asylum seekers	13
Ex-offenders	12
People with no stable housing	13
People with learning difficulties	6
People with personality disorders	7

This section is structured according to the two aims of our analysis.

- 1 To identify any new priority research areas not already identified by the Delphi exercise.
- 2 To explore particular issues for marginalised groups within the 11 priority research areas identified by the Delphi exercise.

### **New priority research area: mental health within the criminal justice system**

The analysis identified one new research area which was not identified by the Delphi exercise but which was a strongly expressed priority for several of the marginalised groups. This theme was 'mental health within the criminal justice system'.

The level of mental health need within the criminal justice system was expressed by one service user, reflecting on what he had observed in prison:

*'I've been in prison and I'll tell you what it is. In prison there's more people suffering from mental illness than there is in the psychiatric hospital'*

BME service user

Another gave mental health in prisons as his top priority for research:

*'In an ideal world, I think that they should investigate the people who are in prison with mental health illness. Because that does need sorting out without a doubt'*

Homeless service user

Several participants, in particular BME service users and carers and people in the ex-offender and homeless groups, pointed to a lack of awareness concerning mental health issues in the police force. One BME group decided at the end of the group that 'Educating police in the issues surrounding mental health' was one of their top three priorities for improving mental health care.

*'Police officers have no knowledge about us, mental health, culture. They have no medical knowledge or understanding to offer us support with mental health problems'*

BME Service user

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A BME carer gave further weight to this theme of mental health knowledge within the police force, by indicating that the police act as an important part of the mental health service in times of crisis:

*'when there is a problem it is so difficult to contact the service... At present I go to the police as I am not aware of any services and information'*

BME carer

Ex-offenders and homeless people discussed the support available in prisons. One issue was a lack of continuity with support provided in the community:

*'they are not getting the right medication in prison because when you go into prison and you are on whatever you were taking outside, you don't get that. You either get aspirin and water or something like that; it's pointless'*

Homeless service user

One service user who had spent time in prison felt that the level of support was not adequate and created a 'vicious circle of prison and living on the streets'. A service user in the homeless group argued that offenders with mental health problems should be diverted from prison, but felt that courts fail to give sufficient regard to psychiatric reports:

*'I think that they should make sure that people with mental illness should go to hospital not prisons ... You go to court and they say we'll remand you in custody or remand in hospital for psychiatric reports. Then when they get the psychiatrist's report, the courts don't even look at them. They just go yeah right....stand up...you will go to prison for three months and the reports are disregarded'*

Homeless service user

Accessing services after being released from prison was another problematic area. Participants reported waiting many weeks before gaining access to a GP.

Family members of people in prisons or secure units point to a lack of support for the family, and point out the need for better communication with the unit, such as a contact person or support for the family within the community:

*'In prison there should be a contact person from whom we could get information. The in-reach team don't give enough information. I don't have money to go and visit him in prison there are no community services that can help us'*

BME carer



## **Particular issues for marginalised groups**

Most of the issues discussed by focus group participants fell within the 11 research areas to emerge from the Delphi exercise. We concentrate here on presenting new issues relating specifically to these marginalised groups – rather than repeating the more generic issues which emerged from the Delphi exercise.

### **GPs and primary care**

Most of the groups echoed the concern from the Delphi exercise regarding the handling of mental health issues within primary care – that there needs to be better understanding, more choice and less reliance on medication:

*‘Sometimes they are already writing out prescriptions, before you even explain what is wrong with you’*

BME service user

In several of the groups, people suggested that for them, limited understanding of mental health within primary care was compounded by limited awareness of issues particular to them – for example, cultural awareness, or awareness of drug and alcohol issues.

*‘I think that a lot of GPs don’t really know what they are looking for, especially in diverse communities; they don’t know really how to cope with mental health. That’s one of the reasons why Caribbean men get sectioned more commonly. They get to the services very late because they haven’t had any kind of support up to that point’*

BME service user

Similarly, some of the ex-offenders had drug and alcohol issues on release from prison, and felt they were deemed ‘problem patients’ by GPs and not given adequate support for their mental health needs. Refugees and asylum seekers found it difficult to get access to primary care at all.

A group of young people listed detection of eating disorders and other mental health problems within primary care as their top priority for mental health research.

Older people’s main concern with regard to primary care was that mental health problems should not be allowed to ‘overshadow’ physical health problems:

*‘The GP doesn’t give you any help for any physical health problems you might have because they assume all your complaints are symptoms of’*

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*your mental illness. The mental health label overshadows everything else'*

Older service user

### **Prevention and promotion**

Several participants suggested preventative work should start in school, with children being taught coping strategies and life skills to make it less likely that they develop mental health problems. One BME group listed this among their top three priorities for mental health research.

There was also a suggestion that some preventative work should be focused on high-risk groups such as children in the care system and victims of abuse:

*'Young people with mental health problems have often been victims of sexual abuse, violence, mental abuse, broken homes or have been in care. They have been let down by society and need early intervention and help so that they don't end up in a life of mental illness, drugs, alcohol and street crime. Research should look into how to prevent young people from becoming lifelong service users'*

Ex-prisoner

People in the learning difficulties group wanted there to be more help for people to stay mentally well, not just help for people who have become unwell.

### **Non-medication based interventions**

Talking treatments were popular, especially with young people. However there were a number of problems reported, mainly about the lack of control over the form of therapy offered and how long it was available for:

*'By the time you start opening up, it's over, and I don't know how the CAMHS staff don't realise that...it is a long process'*

Young service user

Two young people preferred a more structured approach, involving 'homework', issues being written down or put up on a whiteboard, and planning for what would be covered in the next session.

People in the learning difficulties group believed that they were not given access to counsellors and psychologists because unfair assumptions are made regarding their capacity to benefit from counselling or therapy. They reported a resulting over-reliance on medication.

***Social inclusion and the role of mental health and social care services***

Topics within this area included stigma, housing, employment, education and the role of day services in encouraging social activity.

Young people, older people, and people in the BME and homeless groups all called for media images and public attitudes around mental health to be addressed.

*'You could have a hundred people all diagnosed the same, mental health wise, but with completely different experiences. And yet the press seem to group it up into this one form which is just biased and offensive'*

Young service user

Young people and people from BME groups both felt that it would be most effective to target attitudes among young people. Young people themselves suggested that peer training of young people by young people could be tried and evaluated. BME groups said that there should be mental health awareness provided in schools, possibly from service user perspectives.

People in the homeless group argued that while hostels can be useful in providing the skills needed for independent living, a range of options needs to be available, for example, for those not ready for fully independent living:

*'I think places like this hostel are very important. They... help to set you up for independent living, but there is one point, I mean, there may be people that are sort of like caught in the middle. I mean we were capable of moving on but there's those that aren't and are sort of in the middle. Maybe there should be like sort of a halfway house where there is not, you know, a twenty-four hour problem'*

Homeless service user

With the exception of young people, all groups discussed the importance of employment or some form of educational or vocational activity. Comments from older people and people with learning difficulties highlighted that they should not be overlooked in the drive to support people with mental health problems into employment. Several older people reported benefiting from opportunities provided by the voluntary sector to learn new skills and gain qualifications. People with learning difficulties listed amongst their priorities 'having a job, like local, sheltered work' and the opportunity 'to earn the same as everyone else'. The opportunity to engage in some form of activity

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was also an issue for asylum seekers, who are not able to work while their case is under review:

*'if you are not allowed to work or find something to keep you busy, you end up always worrying and thinking about things, then you get ill. So that is the cause of our difficulties, if we are allowed to do something, volunteer work, anything, to keep us busy, it would improve our lives'*

Asylum seeker

Several participants appreciated group activities organised by day centres but there was concern in some cases regarding cultural appropriateness and how centres can avoid exacerbating stigma and social exclusion:

*'we create stigma by everyone being in the same place in a day centre'*

Older service user

*'I was the only black person there. I felt uncomfortable going and never went back'*

BME service user

### **Services for people in crisis**

With respect to crisis services, compulsory treatment was a key issue for people in the BME and personality disorder groups. Some described a coercive atmosphere going beyond the use of necessary force:

*'Their attempts to control you go beyond compulsory treatment – it's a game for them, they laugh as they inject you'*

BME service user

*'You get horrible side effects from forced injections. You are treated worse than an animal'*

Service user with a diagnosis of personality disorder

One young person described the distress encountered on being restrained and medicated while sectioned to an adult ward:

*'These two blokes literally grabbed me, put me in restraint, ran me down the corridor, and told me, "Look, we've given you something to calm you down". I said, "I don't need something to calm me down. You need to let me out"... You get a sixteen-year old who comes into an adult unit. Let's just think, oh, I know what we'll do. We'll give her some medication to calm her down. Why don't you just listen to her and talk to her?'*

Young service user

A second issue concerned the placing of different groups of people together on acute wards. People with personality disorder felt unsafe on wards with actively psychotic patients. People with learning difficulties argued that specialist wards would also be more suitable for them.

### **Person-centred care planning**

The need for a more collaborative partnership between professionals and individual service users was one of the strongest themes to emerge from the focus groups, and was discussed across the range of service user groups consulted. This kind of partnership, they argued, is necessary because service users know most about themselves.

*'Ok, they are the psychiatrist, they know about medicine, but I am the patient, I know about my health, my own self and my body'*

BME service user

Participants felt that they could not be helped adequately unless treated as an individual. One young person wanted it written in large letters on doctor's walls: 'NOT EVERYONE'S THE SAME'.

Flexible, collaborative care planning requires that service users are given information and choice. Many of the groups said they did not know what services existed, or who to contact to find out. Where options had been offered, people reported feeling better supported:

*'My GP said..."you can join CAMHS if you want, and if it doesn't work out, then you can come back to me"...I didn't feel like I was just pushed from one person to another. I felt he was really trying to get me what was best for me'*

Young service user

The focus groups suggest that attitudes towards people with mental health problems may be one thing that precludes this way of working. BME group members said that professionals do not treat mental health clients as having the same capacity or individuality as the physically ill. One suggested that it may be assumed that a person using psychiatric medication is not a person worth talking to:

*'Not many people, when you are under the mental health act, actually give a damn. Some people would walk in, see you, and knowing that you are on medication rather than come to you to ask what is wrong with you and what's going on in your life, they are going to read the notes that are written down'*

BME service user

This attitudinal barrier may be particularly problematic in the case of people with learning difficulties. These participants said that staff could be highly condescending, for example by talking to the person accompanying the service user rather than to the service user themselves. One said that staff on inpatient units, 'treat us like children'.

### **User/carers involvement in service planning and delivery**

Several of the young people consulted had been involved at the service level via a consultation day, and found it helpful to realise that the service providers agreed with many of their frustrations and that it was only lack of funding that was preventing the improvements they wanted. They felt that efforts should be made to involve even younger people, from 10 - 12 years. Older people also expressed the desire to be more involved in service planning, and suggested that consultation days would be a useful way of doing this.

### **Carer support and empowerment**

Participants in both service user and carer groups felt that better support for carers would be beneficial for all. They suggested that more carer support groups and centres need to be available, including culturally sensitive centres for carers from BME groups.

*'I want to see some research... around the wellbeing of the carers as well. Trying to find out carers own mental health well-being while they are in an active role of caring and maybe after one or two years'*

BME service user

Carer support also emerged as a particularly important area for older people, with one group listing as their highest priorities 'more help for the carers', 'more training courses for the carers' and 'more information and respite' for carers.

### **Medication and side effects**

Most of the groups discussed problems with medication, side effects, and the need for good information and choice.

*'I had to fight for years to get my medication changed. A medication, that wasn't doing anything for me, making me more ill and sluggish. Felt it was making me more unable to cope with the issues in my life'*

BME service user

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The issue of information regarding medication was particularly important to people with learning difficulties. They reported being given no explanation on exactly what the tablets are, what the side effects might be, or how the service user can distinguish between side effects and symptoms of illness. At present, the conversation tends to end with the moment of prescription.

*'I am often not sure if I'd feel any better for not taking tablets – I want to know if they are really of benefit'*

Service user with learning difficulties

### **Workforce issues**

An important issue for older people was staff training in inpatient and residential units – particularly with regard to physical healthcare needs such as incontinence:

*'I feel that it is down to the training and the nurses aren't fully aware of what they are really expected and of course a lot of the people in the hospital are incontinent and in a state where they can't control themselves at all. They really need more care than they are actually getting'*

Older carer

Some felt that dementia was not always understood and catered for, and that more training was needed on how to care for people with dementia.

## Section 4 Conclusions

This section summarises the findings from both methodological strands of the consultation – the Delphi exercise (section 3.1) and the focus groups with marginalised stakeholders (section 3.2). It focuses on the priorities of the different stakeholder groups included in the consultation, and areas of consensus. For a summary of the priority research areas to emerge from the consultation, please see table 4.1.

### **4.1 Overview of findings**

The consultation identified 12 research areas which should be prioritised if mental health services are to become more service user and carer-centred. Eleven of these emerged from the Delphi exercise conducted with all stakeholders, with one further area added to these on the basis of the analysis of focus groups conducted with marginalised groups.

The 12 areas are summarised in table 4.1 (in alphabetical order) and described fully in the subsequent sections. We have not identified any one of these areas as being of top priority, for three reasons.

- 1 We would like to stress that all 12 areas are priorities. This is in line with recommendations from stakeholders who took part in the consultation, who felt that research in all areas is needed and that it would be a mistake to prioritise some at the expense of others (see Findings).
- 2 As the 12 areas arose from two different methodological strands in the consultation, it is not possible to compare all areas on the same basis.
- 3 The difference between the scores for each of the areas is small (although statistically significant, and hence not likely to be attributable to chance) – again this suggests that all 12 areas should be considered as priorities.

It is possible, however, to identify which areas have the broadest consensus behind them, as this we do, in Section 4.2.

In Sections 4.3 to 4.5 we describe the variation between the priorities of our three main stakeholder groups: service users; carers; and professionals. The three groups displayed certain differences in



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emphasis. However it should be said that there was as much variation within these three groups as between them. This study does *not* demonstrate a simple tension between, for example, service users and carers on the one hand, and professionals on the other. Our analysis suggests that a person's status as a service user, carer, or professional is not the main factor which determines their priorities (see section on cluster analysis).

Section 4.6 presents research priorities for certain marginalised groups. Most of the issues pertaining to these groups lie within the 12 broad research areas. In some cases, however, we also highlight a small number of issues outside of the 12 priority areas.

Section 4.7 presents three cross-cutting issues identified by the consultation. We consider these to be highly important issues of relevance to all research done in this field.

**Table 4.1 Priority research areas to emerge from the consultation (in alphabetical order)**

	<b>Aim of research area</b>	<b>Stakeholders to whom it is of most importance</b>
<b>Care pathways and transitions between services</b>	To ensure people are able to move between different parts of the mental health system in a way which is acceptable and efficient	Health service staff, young service users
<b>GPs and primary care</b>	To improve the support provided within primary care for people with mental health problems, and to improve the early detection of mental health problems within primary care	All stakeholder groups
<b>Medication and side effects</b>	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	Service users generally, but particularly older service users and young service users
<b>Mental health in the criminal justice system</b>	To improve the quality of mental health care available within the criminal justice system and other secure settings, and the ability of police and other staff to deal competently with mental health issues	Service users from Black and Minority Ethnic (BME) groups, ex-offenders, homeless people
<b>Non-medication based interventions</b>	To develop effective psychological, occupational and creative therapies, and other non-medical approaches such as those based on diet and exercise, which are accessible and acceptable to all groups of service users	Service users, academics and practitioners
<b>Person-centred care planning</b>	To enable services to adopt a flexible, collaborative approach in which people are involved in planning their own care, e.g. using CPA care plans, advance directives, direct payments, 'WRAP' plans	People in senior health service roles, carers, service users (according to focus group results)
<b>Prevention and promotion</b>	To develop interventions which tackle the causes of mental health problems, and which promote mental well-being in the general population	All stakeholder groups (except for older service users)
<b>Services for people in crisis</b>	To improve the quality of services for people in crisis – both in hospital and in community-based alternatives	Service users

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<b>Social inclusion and the role of mental health and social care services</b>	To explore how various services (e.g. day centres, housing services, employment services, community mental health teams) can help people who use mental health services to become more involved in wider society	Academics, people in senior health service roles, carers, service users (esp. those from BME groups)
<b>Supporting and empowering family members and carers</b>	To enable services to give better support, information and advice to family members and carers	Carers, older service users
<b>User and carer involvement in service planning and delivery</b>	To enable meaningful and representative involvement of service users and carers in planning and delivering services	People in senior health service roles
<b>Workforce issues</b>	To clarify the workforce, skill mix and team working arrangements required to allow services to become more user and carer-centred	Older service users, academics, practitioners

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## **4.2 Key priorities**

The strongest consensus across stakeholder groups exists for research in the areas 'GPs and primary care', 'prevention and promotion', 'non-medication based interventions' and 'social inclusion'. These are described more fully below.

### Priority area 1: GPs and Primary Care

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

Respondents called for research into:

- 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'
- 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.

### Priority area 2: Prevention and Promotion

Research is needed to enable the development of preventative interventions, and interventions which promote mental well-being in the general population. Respondents called for research into:

- 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?

### Priority area 3: Non-medication based interventions

Research is needed to improve access to effective non-medication based interventions. Respondents called for research into:

- adapting and evaluating psychological therapies and other interventions to make them suitable for all client groups

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- identification of the key processes common to effective therapies so that therapeutic input can be made more flexible while 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 and exercise
- effectiveness of self-management techniques.

Priority area 4: Social Inclusion and the role of mental health and 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.

Respondents called for research into:

- 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 schools, the workplace and within 'hard' groups e.g. JobCentrePlus staff, housing officers
- practical steps and methodologies for services and agencies to implement the principles of social inclusion.

### ***4.3 Priorities for service users***

The four areas described above were rated highly by all stakeholder groups. The areas described in this section received particular emphasis from service users. In this section we treat 'service users' as a single group. In section 4.6 we look at particular priorities for certain groups of service users (e.g. young people, older people).

The highest priority for service users: throughout all stages of the consultation: was the quality of acute inpatient wards and other services available for people in crisis.

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### Priority area 5: 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 and 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.

In the first stage of the Delphi exercise and in the focus groups, another of service users' most frequently stated priorities concerned being involved in planning their own care.

### Priority area 6: 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.

Service users gave a higher priority than other stakeholder groups to research around medication and side effects. There was some disagreement about whether such research should be conducted using public money or funding from pharmaceutical companies.

Priority area 7: Medication and 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 and control over the type and amount of medication they use
- the role of mental health pharmacists in improving prescribing, giving people accurate information and assisting with medicines' management
- side effects of long-term medication use
- tailoring prescription to individual metabolic profile/genetic markers.

Service users also gave a higher priority than professionals to research around user and carer involvement (although professional sub-groups differed markedly in rating this area – see section 4.5).

Priority area 8: User and carer involvement in service planning and delivery

Research is needed to enable meaningful and representative involvement of service users and carers in planning and delivering services, including through user-led services. Respondents called for research into:

- 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 and effectiveness
- effectiveness of training/interventions to promote positive attitudes and behaviour regarding user/carers involvement among staff.

## **4.4 Priorities for carers**

Carers' top priority is the need to change their own role in the mental health system: specifically with regard to the support, information and advice they receive.

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Priority area 9: Supporting and empowering carers

Research is needed to enable services to give better support, information and advice to family members and carers. Respondents called for research into:

- 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 and 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?

Carers also considered research aiming to promote social inclusion and to enable service users to be involved in planning their own care to be of high importance (see previous sections).

### ***4.5 Priorities for professionals***

Professionals' responses were, in many ways, similar to those from service users and carers. They too gave high priority to 'GPs and primary care', 'prevention and promotion', 'non-medication based interventions' and 'social inclusion' (see Section 4.2 above).

Unsurprisingly, professionals (or at least, academics and practitioners) gave higher priority than service users and carers to workforce issues (although this difference failed to reach statistical significance). To an extent, this merely reflects the same problems being seen through a different lens – the focus of the 'workforce issues' area was on the workforce requirements for implementing changes covered in the other research areas:

Priority area 10: Workforce issues

Research is needed to clarify the workforce, skill mix and team working arrangements required to allow services to become more user and 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?

It is worth noting that in terms of research priorities, the gap between different types of professionals is at least as large as that between service users and professionals. Academics, senior health service professionals and social care workers rated social inclusion among their top priorities; practitioners rated it lower. Similarly, senior health service professionals and social care workers rated user and carer involvement in service planning/delivery highly, whereas practitioners rated it as their lowest priority.

The 'care pathways and transitions between services' area featured particularly highly in the lists of priorities of health service staff, relative to other stakeholder groups:

Priority area 11: 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. Respondents called for research into:

- 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.

## **4.6 Priorities for marginalised groups**

In this section we draw attention to research priorities pertaining to potentially marginalised groups of service users for whom particular issues emerged from the consultation. Most of these issues lie within the 12 priority research areas. In some cases, however, we also highlight a small number of issues outside of the 12 priority areas.

The research suggestions presented here were produced both by people within the groups under question and by other stakeholders with an interest in the needs of these groups.

### **Black and Minority Ethnic groups**

Focus groups with service users from BME groups demonstrated the need for research around the treatment of mental health within the criminal justice system. In these focus groups, those who had experience of police involvement, prisons or secure units considered improvements in this area to be of high priority:

Priority area 12: Mental health within 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 and other staff to deal competently with mental health issues. Respondents called for research into:

- 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
- 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 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 among generic mental health teams to service users with a 'forensic' label.

In the Delphi exercise, people from Black and Minority Ethnic (BME) groups gave significantly higher ratings to the 'Services for people in crisis' research area. This perhaps reflects the reported over-representation of BME groups in inpatient units, particularly among those detained for compulsory treatment (Koffman *et al.* 1997).

Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to people from BME groups need to be prioritised.

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- Care pathways & transitions between services  
Pathways through the mental health system followed by people from BME groups.
- Carer support and empowerment  
Cultural issues impacting on the involvement of families and carers within BME groups.
- Person-centred care planning  
How to address attitudes within services regarding service users from BME groups, in order to promote collaborative working.
- Workforce issues  
Ethnic diversity within the mental health workforce.

### **Children and young people**

Several professional respondents considered there to be a 'shameful' lack of research attention paid to the mental health of children and young people.

In the Delphi exercise, young service users rated the 'Care pathways' research area highly. This is likely to be attributable to the reference to the transition from child and adolescent to adult services. Young people also rated 'GPs and primary care' significantly higher than adult service users (aged 25-64) suggesting the quality of primary care is of particular importance to them.

Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to children and younger people need to be conducted.

- Care pathways and transitions between services  
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.
- Carer support and empowerment  
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 and young people.
- GPs and primary care  
Detection of eating disorders within primary care.

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- Medication and side effects  
Long-term safety of childhood psychiatric medication.  
More precise definition of dosages.
- Non-medication based interventions  
Making therapies more effective, accessible and acceptable for young people e.g. using self-administered therapies and narrative therapies.  
Effectiveness of dietary-based interventions for young people diagnosed with Attention Deficit and Hyperactivity Disorder or an eating disorder.
- Person-centred care planning  
How young people can be meaningfully involved in decisions around their care?
- Prevention and promotion  
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 to promote positive 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 and other high risk groups.
- Services for people in crisis  
How inpatient units can be made more suitable for young people.  
Alternative models for young people – e.g. intensive home treatment models.
- Social inclusion and the role of mental health and social care services  
How mental health services can work with schools and colleges to ensure young service users are not excluded from education.

### **Older people**

The service received by older people for mental health problems – particularly by those with a dementia – was described as 'terrible', and a high priority for research.

Service users and carers aged 65 and over rated the 'GPs and primary care' and 'Workforce issues' areas highly. The latter was also born out in focus groups, where older people discussed concerns about staff skills regarding physical health care needs and dementia.

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Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to older people need to be prioritised.

- Care pathways and transitions between services  
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.
- GPs and primary care  
How to support the physical health needs of older people with mental health problems.  
Improving the detection and treatment of depression and anxiety in older adults with a dementia – ensuring dementia does not 'overshadow' other, treatable problems.
- Medication and side effects  
Effects and side effects of medication on older people, particularly around the issue of 'polypharmacy' – interactions between medications taken in combination.
- Non-medication based interventions  
Making therapies more accessible for older people with cognitive impairment.
- Person-centred care planning.  
How older people with cognitive impairment can be meaningfully involved in decisions around their care?
- Prevention and promotion  
Effectiveness of interventions to prevent dementia.
- Services for people in crisis  
How acute inpatient units can be made more suitable for older people, especially those with a dementia.
- Social inclusion and the role of mental health and social care services  
Evaluation of residential options for people with dementia including enhanced care at home, live-in support workers, overnight respite, supported housing.  
Effectiveness of vocational activity (e.g. volunteering) in maintaining older peoples' mental health.

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- Workforce issues  
Skills needed for staff on inpatient wards/residential units to meet the needs of older adults e.g. relating to dementia and physical health.

### **Women**

The experience of women within the mental health service was described as 'often overlooked'. Several respondents voiced the opinion that the Department of Health's Women's Mental Health Strategy (DH, 2003) has not yet translated into significant changes in service provision.

Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to women need to be prioritised:

- Medication and side effects  
Effects and side effects of medication on women – this was not always being tested systematically.
- Prevention and promotion  
Preventative interventions and mental health promotion initiatives for women around the time of childbirth.
- Services for people in crisis  
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.

A further issue considered important, but outside of our 12 main research priority areas, is the needs of women coping with children while experiencing mental health problems or being in a caring role for someone else with mental health problems.

### **People with learning difficulties and/or autistic spectrum disorders**

Several respondents stressed that there is a 'tremendous' lack of research and evidence-based practice pertaining to the mental health of people with learning difficulties and/or autistic spectrum disorders, and that a co-ordinated effort to address this could yield considerable improvements:

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*'A network support approach from the SDO programme with clear targets for topics and outputs to be achieved could make a big difference with a relatively small amount of investment.'*

Academic

Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to people with learning difficulties need to be prioritised:

- Carer support and empowerment  
Effectiveness of informal carer interventions and role-modelling, and provision and uptake of respite services.
- GPs and primary care  
Improving detection of mental health problems within primary care – ensuring learning difficulties/ASD do not 'overshadow' these.
- Medication and side effects  
Inappropriate prescription of anti-psychotics for people with learning difficulties/ASD.
- Non-medication based interventions  
Making therapies accessible for people with learning difficulties/ASD.
- Person-centred care planning  
How people with learning difficulties/ASD can be meaningfully involved in decision about their care.
- Prevention and promotion  
Mental health promotion strategies for people with learning difficulties.
- Services for people in crisis  
Generic Vs specialist inpatient units – experimental evaluation looking at differences in outcomes/length of stay/readmissions.

Respondents also highlighted other issues requiring research in this field, outside of our 12 priority areas.

- Measuring the met and unmet mental health needs of people with learning difficulties.
- Capacity and willingness of mainstream mental health services to meet the needs of individuals with learning difficulties/ASD.
- Effectiveness of alternative models of service provision.

## **Refugees and asylum seekers**

Mental health problems are highly prevalent within refugee and asylum seeker populations. Within the priority research areas already outlined, stakeholders considered that the following pieces of research work relating to refugees and asylum seekers need to be prioritised.

- GPs and primary care.  
Effective means of delivering primary mental health care to refugees and asylum seekers.
- Social inclusion and the role of mental health and social care services.  
Effectiveness of vocational activity (e.g. volunteering) in maintaining the mental health of asylum seekers who cannot work.

Respondents also highlighted the need for research looking at assessment processes and support within asylum seeker detention centres, and co-ordination between mental health services agencies working with refugees and asylum seekers.

## **Homeless people**

In focus groups with people of experience of sleeping rough or living without stable accommodation, a key issue was mental health in the criminal justice system. For some of these participants, mental health problems, offending and homelessness formed a 'vicious circle'. Other research issues within the 12 priority areas included the following.

- Prevention and promotion  
Preventative interventions targeted at the children living without stable accommodation.
- Social inclusion and the role of mental health and social care services  
Housing options – how homeless people with mental health needs can be supported into independent accommodation.

Respondents also suggested that research should explore how services would need to be organised in order to be accessible to homeless people.

## **Lesbian, gay and bisexual people**

Several respondents suggested that sexual minority groups often fail to register alongside other forms of minorities (for example, in the National Service Framework for Mental Health) despite comprising at



least six per cent of the population and despite the suggestion of significant mental health needs posed by higher suicide rates.

Research suggestions included:

- mental health needs of these groups
- staff attitudes towards service users from these groups – the impact of prejudice.

### **Deaf people**

Several respondents highlighted the status of Deaf people as a distinct cultural minority with particular mental health needs. Within the priority research areas already outlined, stakeholders considered that the following pieces of research work need to be prioritised.

- Non-medication based interventions.  
Adapting psychological therapies for Deaf people.
- Person-centred care planning.  
Ways of enabling Deaf people to participate in planning their treatment.

Respondents also highlighted the need for research looking at the following.

- 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.

## **4.7 Cross-cutting issues: priorities for all research**

In addition to the research areas described above, there were three themes prominent in responses which were not isolatable research areas so much as issues of pertinence to all research. We regarded these as highly important cross-cutting issues worthy of special attention.

### **Putting research into practice and disseminating findings**

A frequently expressed notion was that current mechanisms for putting research into practice are inadequate, and that this inadequacy 'devalues research'. Respondents stated that in the case of some of service users' and carers' priority areas (e.g. psychological

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therapies) adequate research had already been conducted, but not acted upon.

*‘The only question we should be asking now is “why are our research findings not being acted upon?”’*

Practitioner

*‘I have been horrified by how little note policy often takes of the research evidence’*

Academic

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

- 1 make research relevant to real practice
- 2 base policy on research evidence
- 3 base management decisions on research evidence
- 4 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.

### **Wider use of qualitative research methodologies**

A second over-arching theme concerned methodology – in particular, the use and acceptance of qualitative methodologies. Respondents argued that many of the research areas generated by service users and carers would be more amenable to qualitative exploration and

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sociological approaches than Randomised Controlled Trials (RCTs) or other quantitative techniques. For example, two respondents considered that personal narrative research into the causes of mental health problems has yielded more useful indications of how preventative interventions should be targeted than the larger volume of quantitative biological research.

There were some exceptions to this – in particular, five respondents expressed the opinion that ‘non-medication based interventions’ should prove their efficacy in RCTs before being invested in. But for many of the emerging research priorities (e.g. research looking at collaborative care planning, user involvement, medication use or the interface between different services) it was considered that qualitative methodologies would be more appropriate.

There was a concern that in order to meet this need for high quality qualitative studies, appropriate methodologies would have to be developed, researchers would need to be adequately trained in these methodologies, and the outputs of qualitative studies – and in particular, qualitative analysis of user narratives – would need to be more accepted by the academic community and policy community.

*‘There needs to be development and training in appropriate research methodologies. As an academic journal editor and reviewer I am keenly aware - for example - of how it is almost impossible to place user accounts of their experiences in the academic and professional press’*

Academic

*‘I would like to see qualitative research techniques becoming more important in the field of mental health and for NICE [National Institute for Clinical Excellence] to incorporate such studies into the evidence-base’*

Practitioner

Increased collaboration with sociologists and researchers from other disciplines with a tradition of qualitative research may provide one way of increasing capacity.

A variety of methodological approaches will be required if research is to contribute to the development of service user and carer-centred mental health services – and the relative merits of both qualitative and quantitative techniques will need to be recognised.

*‘I would appeal for a serious discussion of the validity of the ‘hierarchy’ of research types which has been used by some to assert that RCTs are the most reliable form of research and expert testimony is the least. Each research type has its strengths and weaknesses, and is better*

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*used for one thing than another. By combining the various strengths of different types we will achieve a far greater likelihood of developing services and supports that can adapt to meet individual needs'*

NIMHE Programme Lead

### **Outcome measures**

The final cross-cutting theme concerned the need to develop improved measures of service user and carer-centred outcomes. These outcome measures would be needed in evaluation of effectiveness studies in several of the emerging research areas – for example, in evaluating therapies or different forms of services for people in crisis.

It was suggested that more relevant outcome measures would emphasise attainment of life goals of importance to the individual service user, rather than a reduction in symptoms. It was also considered that promoting the routine use of outcome measures could have wider advantages:

*'the goals of mental health care become more transparent (and hence amenable to debate), it makes clinical governance possible, it allows rational decision-making about taking people on and discharging them from the service, it allows expectation management, and it leads to a rational recruitment strategy in which people are recruited for what they can do rather than for their professional background'*

Academic

## **4.8 Priorities in context**

The 12 research priorities identified by the consultation are highly congruent with current policy agendas and previously recognised gaps in the evidence base. This section discusses each area in relation to this wider context.

### **GPs and primary care**

Primary care is the site where most mental health problems are dealt with and has also been the focus of much of the Labour Government's health care modernisation strategy. Consistent with this, it emerged as the highest priority area in our consultation. Stakeholders called for research examining the best ways of providing support and early detection of problems in primary care (clearly there is some overlap here with the second highest scoring area, 'prevention and promotion' – see below). The newly introduced Graduate Primary Care Mental Health Workers should be well-placed to play a part in developments

in this direction. The role involves delivering low intensity cognitive behavioural therapy to people with common mental health problems; sign-posting and facilitating self-help strategies; and providing additional support in prevention (DH, 2000).

Primary care features in *Our Health, Our Care, Our Say* (DH, 2006) as the key site through which the goal of better prevention through early intervention would be met. Choice and flexibility are emphasised, e.g. choice of GP; flexibility in access to primary care services including convenient appointment times and longer opening hours; also ensuring that primary care meets the needs of particular groups such as offenders, young mothers and people with disabilities.

## **Prevention and mental health promotion**

Mental illness prevention and mental health promotion received the second highest rating overall. These areas have been grossly neglected in research terms considering their potential to reduce significantly the burden of suffering and the vast health care costs for treating mental health problems. The Strategic Report of the Mental Health Funders' Group (2005) demonstrated that only two per cent of all funding for mental health research was earmarked for prevention and promotion. Mental health promotion was highlighted in 'The National Service Framework – Five Years On' (DH, 2004d) as one of three critical gaps in the evidence-base identified by a review of NHS Research & Development work (DH, 2002).

Prevention and health promotion are highly related to the recent focus on public health. In a critique of the Department for Health's Public Health White Paper (DH, 2004a), the Mental Health Foundation highlighted a lack of understanding about the role of mental health from a public health perspective (MHF, 2005). They identified the need for a 'public mental health' approach. It was also noted that mental health prevention has not been included in the National Prevention Research Initiative and argued that mental health prevention research should be prioritised within the Health Development Agency.

The European Commission (EC, 2005) launched a debate concerning the relevance of mental health for the European Union (EU), setting out the need for a strategy and to establish research priority areas at EU level. The focus of this Green Paper included promoting the mental health of the population and addressing mental ill health through preventive action across all age groups, including infants, children and older people.

Clearly, prevention and promotion in mental health are gaining increasing attention. The Institute for Public Policy's 'Mental Health in the Mainstream' (Rankin, 2005) argues that while the current policy environment is largely supportive of a public health approach to mental health, what is lacking is a clearly defined national strategy.

## **Non-medication based interventions**

We identified a demand for more research around alternatives to medication – another familiar call. For many years, critiques of the mental health system emerging from the service user movement have pointed to an over-reliance on medication and lack of alternative options, and there are signs that this demand is gathering momentum. Professor Lord Layard has recently argued that a massive expansion in the availability of evidence-based psychological therapies is needed to meet what he describes as 'Britain's biggest social problem' (Layard, 2005). A review of choice in mental health conducted by the Care Services Improvement Partnership (CSIP) identified the need for easier care pathways towards evidence-based psychological therapies – including therapies not widely available at present such as dialectical behavioural therapy.

## **Social inclusion and the role of mental health and social care services**

Research aiming to tackle social exclusion, stigmatisation and discrimination was the area rated fourth overall. The notion of social inclusion has been central to the Government's social policy agenda, but it has been argued that limited progress has been made in the case of mental health (Rankin, 2005).

Addressing the exclusion of people on the basis of mental health problems would involve changes to a wide range of services from day care to employment. The main theme to emerge from the consultation was about the need for services to assist people in becoming more involved in wider society. There is also more to be done to prevent people with mental health problems being excluded in the first place. A Green Paper (DH, 2005a) set out a vision for social care for all adults over the next 10-15 years. A central theme was the need to maintain people's independence, and to ensure better partnership working between Primary Care Trusts, voluntary and independent sectors. Some mention is made of preventing problems and ensuring the NHS and social care work together on a shared agenda to maintain people's independence. The research agenda for this area could also look at how people with mental health problems can be prevented

from losing their employment, housing and social support particularly at the early stages of their illness; and could develop and evaluate services that are the most effective in achieving this.

## **Services for people in crisis**

Improving crisis services both in the community and in inpatient settings was the most important issue for service users responding to the consultation. This concurs with previous studies such as the Sainsbury Centre for Mental Health's 'Acute Solutions' (SCMH 1998) and 'Acute Care 2004' (SCMH 2004) and Mind's 'Ward Watch' (Mind 2004) which have argued that acute inpatient care is an area in dire need of attention.

'The National Service Framework (NSF) – Five Years On' (DH, 2004d) identifies inpatient care as one of the key areas where more research is needed in relation to the targets laid out in the NSF, and mentions that work is currently being funded in this area by the NHS Service Delivery Organisation – specifically, on 'alternatives to admission, ward observation, inpatient care of young people and staff morale'.

## **Person-centred care planning**

Person-centred planning, as identified in our consultation, was defined as a flexible, collaborative approach in which people are involved in planning their own care. This has been another important theme in recent government policy – for example in the NHS Improvement Plan (DH, 2004e), which has the goal of 'putting people at the heart of public services'. The emphasis in the Improvement Plan is on flexible services, with staff delivering more personalised and user-friendly care. Within mental health a number of approaches, such as personal care plans, advance directives, direct payments and Wellness and Recovery Action Plans (WRAP) still require research to assess their implementation and outcomes.

## **User and carer involvement in service planning and delivery**

Service user involvement in mental health has received considerable attention in the literature (see the Literature Synthesis conducted in parallel with this report). Many authors have asserted the importance of such involvement (Perkins and Goddard, 2004). However, implementation within services has been slow, despite examples of

good practice, and involvement has not automatically led to improvements in services. This has been highlighted by the report on patient and public involvement - 'Getting over the wall' (DH, 2004b). The literature synthesis stresses the need for evaluations to show the ways in which involvement can be effective in instigating service improvements.

## **Supporting and empowering family members and carers**

Carers featured in two of our priority areas, (a) around involvement in service planning and delivery, and (b) in terms of empowerment of carers and family members. The specific concerns of the latter were around better support, information and advice. These are areas that mirror the three main elements of the Strategy for Carers (DH, 2004c).

- 1 Information: where carers are informed of the new charter on long-term care services, setting new standards and information on good health.
- 2 Support: where carers are involved in planning and providing services and can consult with local caring organisations.
- 3 Care: ensuring that carers own health needs are met, that services are available for the person being cared for, and the opportunity exists for respite from caring, with a special grant to enable this.

'The National Service Framework (NSF) – Five Years On' also highlights carers, identifying the area as one where more research is needed to meet the NSF targets. Research currently being funded by the NHS Service Delivery Organisation includes 'what is important to carers' quality of life, the range of respite services available, the usefulness of carer assessments and good practice in sharing information between health professionals and carers' (DH, 2004d).

## **Medication and side effects**

Medication has long been a contentious topic for service users. It featured in responses to our consultation primarily in terms of calls for more research ensuring that medication is used in an effective and acceptable way, and that side effects are minimised as far as possible. In part, this is a question of research examining longer-term side effects and the effects of 'poly-pharmacy' – the prescription of multiple types of medication particularly common for older service users. However it also relates to the current policy agenda around 'choice'. CSIP's report on choice in mental health identifies the need for the



provision of information to service users to assist them in making choices about medication options (CSIP, 2006). Research is needed to establish best practice in this area.

## **Care pathways and transitions between services**

Many stakeholders, particularly health service professionals and younger service users, were concerned with how service users can move efficiently through different parts of the mental health system. Recent policy (CSIP, 2006) focuses on care pathways and access issues, emphasising choice of care options and professionals. The well-recognised difficulties in moving from adolescent to adult services – particularly the limited provisions made for 16-17 year olds – is an important component of the Public Service Agreement (PSA) Target for Child and Adolescent Mental Health Services (DH, 2004f).

## **Workforce issues**

The 'workforce issues' area called for research exploring the skills mix and team working arrangements required to enable services to become more user and carer centred. Policy in this area – as set by the NHS Plan (DH, 2000), for example – has largely concentrated on increasing the workforce capacity rather than shaping the workforce to become more service user and carer centred. However, 'New Ways of Working for Psychiatrists' (DH, 2005b), did attempt to provide a best practice guidance to deliver person-centred care across mental health services for all age groups. It focused on the need for consultant psychiatrists to embrace change, and test effective ways of meeting the needs of service users and their families; and greater clarity in staff roles.

## **Mental health in the criminal justice system**

The main aim of current policy on offenders is the reduction of repeat offending, particularly through providing offenders with skills training and assistance in gaining employment (HMSO, 2005). Despite the clear importance of this, the research priorities emerging from our work also highlight the continued need to improve the quality of mental health care within the criminal justice system. This includes looking for ways in which the police, prison and other relevant staff can become more able to assist offenders with mental health problems through training and improved resources within prisons and other secure settings. The recently established, Department of Health funded 'Prison Health Research Network' should provide an infrastructure to support such work, and has mental health among its five workstreams.

## **4.9 Limitations of the consultation**

### **Sampling**

A principle objective of the consultation was to be as inclusive as possible – giving all stakeholders, and in particular those from marginalised groups, an opportunity to contribute. Our series of focus groups allowed us to achieve this goal to some extent. Through these, a diverse range of service users and carers were able to contribute to the generation of research priorities. The focus groups did not, however, allow stakeholders from marginalised groups to evaluate or comment upon the final list of priorities to emerge from the consultation. Ideally, we would have conducted a second series of focus groups at a later stage in the consultation process. However, the time required to recruit people from such marginalised groups meant that this was not feasible. As a consequence, although the stakeholders who contributed to the generation of our research areas were representative of a wide variety of backgrounds, the stakeholders who took part in the final prioritisation were less so.

We would also like to acknowledge that it was not possible to include representatives from all socially excluded or marginalised groups. For example, we have not been able to give due attention to the concerns of those marginalised on the basis of physical impairment (on this subject, we would draw the reader's attention to the work of Morris (2004) for the Joseph Rowntree Foundation). Some groups, such as pre-lingually Deaf people, were only represented in the consultation by professionals working with them – ideally we would have liked to include such people in focus groups using interpreters. Furthermore, some of the groups that were consulted were represented by a small number of individuals – only one focus group was conducted with people with learning difficulties, for example. Although the goal of the focus groups was to generate range rather than ensure statistical representation, this remains a limitation.

A further cause for concern is the low response rate to the questionnaires, especially in round one, in which over 2000 questionnaires distributed to various organisations produced 266 responses. While this would be of great concern within epidemiological research, we do not feel it represents as great a threat to the credibility of a public consultation, and we are reassured by the even balance of responses in terms of region and gender, and the range in terms of diagnostic categories.

In terms of the balance of respondents from different stakeholder groups, it might be noted that in the final stage the number of

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'professionals' (479) exceeded the number of service users (220) and carers (139). For this reason we have reported the priorities for each group separately, and have drawn attention to similarities and differences, rather than presenting a simple overall rank order which would be determined to a great extent by the balance of stakeholder groups in the sample.

Of the professionals included, there was an under-representation of GPs and social care workers (particularly GPs). It would have been interesting to receive greater input from these groups given that two of our highest priority areas concern primary care and social inclusion.

### **Analysis**

A final limitation concerns the process by which we moved from complaints about existing services to ideas for research. Not all respondents expressed their hopes for improvement in terms of research questions, and if we were to use this data we had to establish some translation process. Such a process could only ever be imperfect – for example, a complaint about access to therapy might be translated into several different research questions – but on balance we considered this preferable to not using this data at all.

## **4.10 Conclusion**

This consultation has generated 12 research areas which should be prioritised if mental health services are to become more centred on the needs and aspirations of the people who use them, and their families and carers. It has also highlighted three crucial over-arching issues relating to the way in which research is conducted and put into practice. These three issues must also receive attention, in order for research to deliver the improvements sought by service users, carers and professionals.

It should be acknowledged that many of the research areas generated by the consultation are not novel. They are highly congruent with current policy agendas and previously recognised gaps in the evidence base – as discussed in section 4.8. However, we feel that this consultation adds several things to the debate around the national research priorities.

- 1 It identifies those areas where the consensus and will for change is strongest.
- 2 It involves service users and carers in the prioritisation process to an extent not previously achieved.
- 3 It examines whether the emerging research agenda adequately meets the needs of various marginalised groups.
- 4 While the broad themes identified may be familiar, within each we also present a number of more focused suggestions to emerge from the consultation. Many of these will be less familiar.

It is advised that the recommendations presented here are taken in conjunction with those emerging from the parallel Literature Synthesis. The two sets of findings are brought together in the Overview Report.

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## **Appendices**

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### **Appendix A: Stage One questionnaire**

Mental health services should become more focused on the hopes and experiences of the people who use them and their families and carers

This survey aims to help that goal become a reality. It is being funded by the Department of Health but conducted by an independent charity, the Sainsbury Centre for Mental Health.

We would like your views on what mental health services would be like if they were more focused on the people who use them and their families and carers – on their experiences, hopes and aspirations. By 'mental health services' we mean any services involved in mental health care, including family doctors or GPs.

Taking part in this survey gives you the opportunity to influence the future of mental health services. The results will affect what research is funded over the next 5 to 10 years. Services can often only be improved if the right research is done first – so it is important that the people who fund research hear your voice.

Your views will make a difference.

If you would like any help completing the questionnaire, or would like more information, please call XXXXX

You can also complete the questionnaire online at  
<http://keypoint.scmh.org.uk/webform.htm>

All your responses are completely confidential.



**Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report**

**Mental Health Services**

Could mental health services be more focused on you and what you want? If so, please describe how. You can write up to 5 ideas below (not necessarily in priority order). Please write as clearly as possible.

1
2
3
4
5

**Other Services**

Health services are not the only thing which can make a difference to a person's quality of life. Other things like housing, employment, education, benefits and social care can also be important. Could things in any of these areas be improved for people in your situation? If so, please describe how below.

1
2
3
4
5

***What could mental health services do for you?***

If mental health services were helping you in the way you would like them to, how would that improve your life?

1
2
3
4
5

**Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report**

**Areas for research**

One thing that can stop services from improving is a lack of knowledge about what works, or what might be helpful for people. Sometimes research is needed to find out more. For example, if a person has an idea about how to improve services, research can help people decide whether the idea will work or not. Research can also show whether or not a particular service is helping the people who use it.

What things would you like to see researched?

1
2
3
4
5

## **Personal details**

### **The following questions are for monitoring purposes only**

1. Which of these is true for you?

- ☐ I use or have used mental health services  
☐ A family member or someone I care for uses mental health services

If you have used services yourself, please answer the following questions about yourself. If a family member or someone you care for uses services, please answer the following questions **about that person**.

2. Sex ☐ Female  
☐ Male

3. Age .....

4. Region of England

- |                                        |                                      |
|----------------------------------------|--------------------------------------|
| <input type="checkbox"/> North-East    | <input type="checkbox"/> East Anglia |
| <input type="checkbox"/> North-West    | <input type="checkbox"/> South East  |
| <input type="checkbox"/> East Midlands | <input type="checkbox"/> South West  |
| <input type="checkbox"/> West Midlands | <input type="checkbox"/> London      |

5. Ethnic group (tick ONE only)

White

- ☐ White British  
☐ White Irish  
☐ Any other White background

Black or Black British

- ☐ African  
☐ Caribbean  
☐ Any other Black background

Mixed

- ☐ White and Black Caribbean  
☐ White and Black African  
☐ White and Asian  
☐ Any other Mixed background

Asian or Asian British

- ☐ Indian  
☐ Pakistani  
☐ Bangladeshi  
☐ Any other Asian background

Chinese or other ethnic group

- ☐ Chinese  
☐ Any other ethnic group (please specify).....

6. Please briefly describe the kinds of mental health problems experienced by you or the person you care for

.....

.....

7. What types of individuals or teams have you or the person you care for received mental health services from in the past 2 years? (tick as many as you want)

- ☐ GP
- ☐ Counsellor / therapist
- ☐ Community Mental Health Team
- ☐ Inpatient ward
- ☐ Services for people with learning disabilities
- ☐ Forensic service
- ☐ Older people's service
- ☐ Services for drug / alcohol problems
- ☐ Others (please list)

.....

.....

8. Please tick any of the following that apply to you or the person you care for

I have or he/she has...

- ☐ ...been detained under the Mental Health Act (sectioned)
- ☐ ...used mental health services based in a prison
- ☐ ...no permanent home

I am or he/she is...

- ☐ ...living in the UK as a refugee or asylum seeker

What happens next?

**Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report**

The Sainsbury Centre for Mental Health will collect the responses to this questionnaire from people across the country, and produce a second questionnaire based on them. In the second questionnaire, people will be able to look at the sorts of responses made by other people, and discuss them. This will all be done anonymously – nobody will be named in the questionnaire.

After the second questionnaire there will be one more, shorter questionnaire. The point of having several questionnaires is to give people the chance to discuss other people's ideas. Research has shown that this is a good method for making decisions – allowing many people to join the discussion, without anyone actually having to meet.

You do not have to take part in these further questionnaires, but if you would like to, please give some contact details. We can send the questionnaires to you by post or by email. Your details will be held confidentially and will only be used for this study.

I am happy to be contacted ☐  
or I do not wish to take part in the rest of the study ☐

Name .....  
Address .....  
.....  
Telephone .....  
Email .....

We can also send you feedback about the results of the study  
Please send me the results of the study ☐

Thank you for completing this questionnaire. Your views are important, and we appreciate you taking the time to share them.

Please return by 31<sup>st</sup> January 2006 to:

XXXXX

Please contact us if other people you know would like to take part in this survey.

## Appendix B Stage Two questionnaire

### ***Service user and carer-centred services research priorities: Consultation with all stakeholders***

#### ***The purpose of the consultation***

This questionnaire is part of a major consultation funded by the NHS Service Delivery and Organisation R&D programme. It is aimed at anyone with a professional interest in mental health. Service users and carers are being consulted separately.

The purpose of the consultation is to identify the research needed to enable services to become more service user and carer-centred. By 'service user and carer-centred', we refer to services which prioritise the needs, wants and preferences of individual service users and carers, and which involve them both in their own care, and at the organisational level. The consultation aims to give all stakeholders an opportunity to influence the national research agenda in this area.

#### ***How to complete this questionnaire***

**Part one** of the questionnaire presents the results of the consultation so far:

25 priority research areas that have been generated by over 400 service users and carers. You can rate each of these areas, and comment on them.

**Part two** invites you to add your own priority areas.

**You are not expected to complete every question.**

The results from this questionnaire will form the basis of the final stage of the consultation, in which all stakeholders – service users, carers and professionals – will be asked to prioritise the final list of research areas.

The deadline for returning this questionnaire is **7<sup>th</sup> May 2006**

It can also be completed online at  
**<http://keypoint.scmh.org.uk/stage2.htm>**

If you would like any help completing the questionnaire, or would like more information, please contact XXXXX



**PART ONE - Priorities emerging from the service user / carer consultation**

The following is a list of priority areas for future research emerging from the consultation with service users and carers. The areas are listed **in order of frequency, highest first** – i.e. more service users wrote about conditions on acute inpatient wards than any other area. Please note that the last two areas, 'benefits' and 'housing' are not included in the frequency sequence because we asked about them directly, whereas the other areas were generated entirely by service users and carers, when asked open questions about improving services and research.

For each of the 25 areas there is a description, followed by some examples of possible research questions taken from the service user and carer consultation. **These examples are not exhaustive**, they are given purely to illustrate possible research questions.

**Instructions**

- 1 Please rate each area on a scale of 1 to 5 according to how important you think it is that research is done in this area **(5 being most important)**.
- 2 In the blank space, please describe any specific research questions that need addressing within an area. You can also use the space to add any other comments about the area e.g. why you feel it is an important one. Please do not feel obliged to add research ideas / comments for every area.

<b>1</b>	<b>Acute inpatient wards</b>							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research looking at acute wards – how they can be made into more supportive environments so that inpatient stays have a positive impact on mental wellbeing. Service users and carers suggested more contact with staff, more therapeutic input, more activities and improvements in the physical environment.</p>								
<p>Your research ideas or other comments (optional)</p>								

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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<b>2</b>	Choice and involvement								
	<table border="1"> <tr> <th>Rating</th> <th>Least Important</th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>Most important</th> </tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at the involvement of service users in planning their own care. How can clinicians adopt a collaborative approach, in which service users can make informed choices about treatment options? How can care plans, advocacy, advance directives, patient-held records, direct payments and personal budgets be used more effectively? How can minority groups be meaningfully involved, e.g. people with learning difficulties, people from black and minority ethnic groups?</p>								
	<p><i>Your research ideas or other comments (optional)</i></p>								

<b>3</b>	Talking therapy								
	<table border="1"> <tr> <th>Rating</th> <th>Least Important</th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>Most important</th> </tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at the availability of talking therapy, and the effectiveness of it. Do waiting lists reduce the effectiveness of therapy? What is the most effective form of therapy for different groups of people? Can therapies be made more effective and accessible for potentially marginalised groups e.g. people with a diagnosis of personality disorder or learning difficulties, or for 'low functioning' individuals e.g. those with a diagnosis of Alzheimer's. Are there any adverse effects of talking therapies?</p>								
	<p><i>Your research ideas or other comments (optional)</i></p>								

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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<b>4</b>	Family and carers							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
	Research examining how family members and other carers can contribute towards planning a person's care, in a way that is beneficial to the service user and aids the clinician. What potential adverse effects of involving carers are there, and how can these be minimised? In what ways are clinicians able to support family members, with respect to both their caring role and their own emotional and physical health care needs?							
	Your research ideas or other comments (optional)							

<b>5</b>	Holistic, individualised treatment							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
	Research exploring holistic approaches to treatment, in which clinicians take account of an individual's social circumstances, physical health, strengths and goals, and devise a tailored care package aimed at increasing overall quality of life. How effective and cost effective would these approaches be? What are the barriers to this way of working? Would people benefit from being given more help with socialisation and personal relationships?							
	Your research ideas or other comments (optional)							

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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<b>6</b>	Sources of support in the community								
	<table border="1"> <tr> <th>Rating</th><th>Least Important</th><th>1</th><th>2</th><th>3</th><th>4</th><th>5</th><th>Most important</th></tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research exploring the role of day centres, drop-in facilities, support groups, help-lines and other sources of support for those living in the community. How can day centres and drop in facilities be modernised? What role can they play within a coherent, integrated community support system? Are help-lines an effective source of support?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>7</b>	User involvement, user-led services								
	<table border="1"> <tr> <th>Rating</th><th>Least Important</th><th>1</th><th>2</th><th>3</th><th>4</th><th>5</th><th>Most important</th></tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at the involvement of service users and carers at the organisational level – e.g. in the planning and delivery of services. Is this form of work beneficial for the individuals involved? What impact does it have on services? How do professionals feel about service user involvement? How can the effectiveness of user-led services be increased?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>8</b>	The nature and causes of mental health problems								
	<table border="1"> <tr> <th>Rating</th><th>Least Important</th><th>1</th><th>2</th><th>3</th><th>4</th><th>5</th><th>Most important</th></tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at the nature and causes of mental health problems. How great an influence do different environmental and biological factors have? Are different factors important for different groups of people, e.g. amongst different ethnic communities? How strong are the links between use of illegal drugs and mental illness? Will high levels of drug use amongst young people lead to higher levels of mental illness in the future? How valid are the various diagnostic categories?</p>								

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Your research ideas or other comments (optional)

<b>9</b>	Medication and side effects							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research into medication use, side effects and withdrawal symptoms. What impact do side effects have on performance in the work place or the effectiveness of therapy? Do lifestyle factors e.g. diet, smoking and exercise alter the effectiveness or side effects of medication? Could medication be better tailored to each individual's metabolic profile? Could prescribing and monitoring practices be improved – e.g. by prescribing on a 'prn' (when needed) basis, or by allowing psychologists to prescribe? What are the benefits and side effects of long-term usage? How can people be assisted in their attempts to minimise or eliminate medication use?</p>								
<p>Your research ideas or other comments (optional)</p>								

<b>10</b>	Stigma, discrimination and attitudes							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research looking at challenging negative attitudes towards mental health amongst mental health staff, staff in other public agencies, the police, prison staff, the media and the general public. Including attitudes regarding people who abuse drugs or alcohol, who self-harm or who have a diagnosis of personality disorder. Does user-led training change attitudes and practice within mental health services? How can media representations be challenged? How does the way we use mental health in everyday language affect our understanding and attitudes towards it?</p>								

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Your research ideas or other comments (optional)
--------------------------------------------------

<b>11</b>	<b>Employment</b>
<b>Rating</b>	<i>Least Important</i>   <b>1</b>   <b>2</b>   <b>3</b>   <b>4</b>   <b>5</b>   <i>Most important</i>
<p>Research examining employment issues. What helps people find employment, particularly for those who have never worked? What role can occupational therapy and higher/further education play? What support do people with mental health problems need to stay in work and meet the requirements of the work they do? What support and training do employers need in order to employ people with mental health problems?</p>	
Your research ideas or other comments (optional)	

<b>12</b>	<b>Getting help when it's needed</b>
<b>Rating</b>	<i>Least Important</i>   <b>1</b>   <b>2</b>   <b>3</b>   <b>4</b>   <b>5</b>   <i>Most important</i>
<p>Research looking at making services more responsive, so people can quickly get help when they feel they need it. How could it be made easier for people to 'dip in and out' of services, and get support when they are not in crisis? Could people who have been discharged from secondary services get quicker access to them, should they become unwell again? What scope is there for 'direct access' services? How could care teams be more accessible by phone, to give advice to service users and carers? What would be the impact of expanding out-of-hours support, and what forms of out-of-hours support would be most beneficial?</p>	
Your research ideas or other comments (optional)	

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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<b>13</b>	Alternatives to inpatient wards at times of crisis								
	<table border="1"> <tr> <td><b>Rating</b></td><td><i>Least Important</i></td><td><b>1</b></td><td><b>2</b></td><td><b>3</b></td><td><b>4</b></td><td><b>5</b></td><td><i>Most important</i></td></tr> </table>	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>		
	<p>Research into crisis teams, crisis houses and other facilities aiming to avoid the need for admission to acute wards during times of crisis. How effective are crisis teams in preventing re-admission? How long does it take to access them, and how do they deal with crises? What do crisis houses need to be like, in order to be effective in reducing the need for acute ward admission? What are the potential adverse effects of crisis houses?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>14</b>	Potentially marginalised groups								
	<table border="1"> <tr> <td><b>Rating</b></td><td><i>Least Important</i></td><td><b>1</b></td><td><b>2</b></td><td><b>3</b></td><td><b>4</b></td><td><b>5</b></td><td><i>Most important</i></td></tr> </table>	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>		
	<p>Research concerning groups that could potentially be marginalised or excluded e.g. black and minority ethnic groups, elderly people, people with disabilities or a diagnosis of personality disorder. What are the different needs of such groups? How are different groups treated e.g. with regard to the treatment options they are offered, or the use of restraint and compulsory treatment? How can cultural values and religious beliefs be taken into account? How should people with multiple needs be treated?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>15</b>	Amount of contact between services users and staff								
	<table border="1"> <tr> <td><b>Rating</b></td><td><i>Least Important</i></td><td><b>1</b></td><td><b>2</b></td><td><b>3</b></td><td><b>4</b></td><td><b>5</b></td><td><i>Most important</i></td></tr> </table>	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>		
	<p>Research looking at the amount of contact service users in the community have with care staff (in community mental health teams and primary care), in terms of both frequency of contact and longevity of relationship. Would service users benefit from more frequent, proactive contact and monitoring, and more continuity of care? If so, how could this be achieved?</p>								

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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Your research ideas or other comments (optional)
--------------------------------------------------

<b>16</b>	Recovery & social inclusion						
<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research into the recovery-based approach, in which service users are encouraged to accept their problems, adapt to them, and move on to re-engage with society and lead a fulfilling life. Do recovery plans work? What helps and hinders recovery? How do service users and professionals feel about the concept of recovery? What skills do service users need for independent living? How can local communities can become supportive environments into which people who have used mental health services can become integrated more easily?</p>							
Your research ideas or other comments (optional)							

<b>17</b>	Other forms of treatment						
<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research into dietary/nutritional interventions, exercise programmes, homeopathic medication and complementary therapies such as meditation, reflexology or use of the creative arts. How effective are complementary therapies, and what level of skill do practitioners need to have in order for them to retain their effectiveness? How do diet and exercise impact on mental wellbeing?</p>							
Your research ideas or other comments (optional)							



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<b>18</b>	Integrated services								
	<table border="1"> <tr> <th>Rating</th> <th>Least Important</th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>Most important</th> </tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at how different professionals, services and agencies work together. How could a person's care be more co-ordinated? Could communication and referral mechanisms between primary and secondary services be improved? What barriers exist between health, social care and other agencies, and how could they be addressed? How could statutory services be better integrated with voluntary sector services?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>19</b>	GPs and primary care								
	<table border="1"> <tr> <th>Rating</th> <th>Least Important</th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>Most important</th> </tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking at the support people receive within primary care for mental health problems. Could primary health care staff be trained to spot mental health problems at an earlier stage? What impact does making mental health specialists (e.g. counsellors) available in GPs' surgeries have on the service user and on the culture within the surgery? How adequate is the service received by those supported solely within primary care?</p>								
	<p>Your research ideas or other comments (optional)</p>								

<b>20</b>	Earlier intervention, prevention and promotion								
	<table border="1"> <tr> <th>Rating</th> <th>Least Important</th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>Most important</th> </tr> </table>	Rating	Least Important	1	2	3	4	5	Most important
Rating	Least Important	1	2	3	4	5	Most important		
	<p>Research looking into intervening at the earliest stages of mental health problems, or preventing them from arising at all. What can be done during the first episode of illness? Can services for children and adolescents (e.g. for ADHD) prevent other problems later in life? Would counselling for young people with disabilities prevent later mental health problems? How can positive mental wellbeing be promoted within schools, vulnerable groups and the wider population?</p>								

**Research Priorities for Service User and Carer-Centred Mental Health Services:  
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Your research ideas or other comments (optional)
--------------------------------------------------

<b>21</b>	Discharge and post-discharge							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research into the support received after discharge from hospital, and the process leading up to discharge. How frequently are people monitored after discharge? Are their housing needs and other social circumstances adequately considered at the point of discharge? To what extent is discharge influenced by non-clinical considerations e.g. limited beds?</p>								
Your research ideas or other comments (optional)								

<b>22</b>	Travelling to appointments							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research looking at difficulties service users have in travelling to appointments. What alternative options are available for people who have difficulty using or affording public transport, or for those in rural areas with limited public transport? Could home visiting be expanded for these people? Could services be based in more accessible community settings?</p>								
Your research ideas or other comments (optional)								

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<b>23</b>	Implementational research							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research looking at how research and policy is put into practice. How can research have the greatest impact in the real world? Why is research evidence and even legislation not always acted upon? How can we bring our various bits of knowledge from research together more?</p>								
<p>Your research ideas or other comments (optional)</p>								

<b>n/a*</b>	Benefits							
	<b>Rating</b>	<i>Least Important</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<i>Most important</i>
<p>Research looking at how the benefits system impacts on people with mental health problems. How can assessment and review procedures cater better to people with mental health problems? How can the system be changed so that it is easier for people to return to work if they want to?</p>								
<p>Your research ideas or other comments (optional)</p>								

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n/a*	Housing										
Rating		Least Important	1	2	3	4	5	Most important			
Research looking at housing issues for people with mental health problems. How can mental health services help people find adequate housing? What is the impact on mental wellbeing of the concentration of service users in certain housing areas? How can housing associations and departments take better account of mental health needs?											
Your research ideas or other comments (optional)											

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\*The 'benefits' and 'housing' areas have not been included in the frequency sequence because we asked about them specifically, whereas the other priority areas were generated spontaneously by service users and carers

***Research Priorities for Service User and Carer-Centred Mental Health Services:  
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When rating research priorities people take various factors into account e.g. the size of the problem, the potential for finding viable solutions, the extent of existing research. Please describe what factors were important to you when deciding how to rate the above 25 areas.

***PART TWO - Other research priorities***

What other areas need to be researched to allow services to become more service user and carer-centred? By 'service user and carer-centred', we mean services which prioritise the needs, wants and preferences of individual service users and carers, and which aim to involve them both in their own care, and at the organisational level.

Please use the space below to describe your own research priorities – particularly, any priorities relating to your own area of expertise or interest. Continue on a separate sheet if necessary.

**Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report**

Personal details

Name .....

Organisation .....

Job title .....

Professional background / training .....

Client group(s) you work with / are interested in .....

If you would like to be involved in the final stage of the consultation, please leave contact details below. You would be sent a short questionnaire asking you to rank the final list of research priorities.

Address .....

.....

Telephone .....

Email .....

We can also send you the results of the study in summer 2006

Please send me the results of the study ☐

Thank you for completing this questionnaire. We appreciate you taking the time to share your views.

Please return by 7<sup>th</sup> May 2006 to:

XXXXX

## Appendix C Stage Three questionnaire

### **Service User & Carer Centred Services Research Priorities**

#### **Consultation: Final Stage**

##### ***Who this questionnaire is for***

This questionnaire is the final part of a major consultation funded by the NHS Service Delivery and Organisation R&D programme. It is aimed at anyone in England with personal experience of mental health services and/or with a professional interest in the area.

##### ***The purpose of the consultation***

The purpose of the consultation is to identify the research needed to allow services to become more service user and carer-centred. By 'service user and carer-centred', we refer to services which prioritise the needs, wants and preferences of individual service users and carers, and which involve them both in their own care, and at the organisational level. The consultation aims to give people an opportunity to influence the national research agenda in this area.

##### ***How to complete this questionnaire***

The questionnaire describes 11 areas in which research work may need to be done, if services are to become more user and carer-centred. These areas are based on the earlier stages of the consultation, in which we received suggestions from over 400 service users and carers and another 400 people who work in mental health and related fields.

**The 11 research areas are listed in a random order.**

Please rate each area on a scale of 1 to 7, according to how important you think it is that research work is done in that area. You should give '7' to the area(s) you think are most important for research, and '1' to the area(s) you think are least important. You may feel that all 11 areas are important, but please try to decide which are *most* important to you. It may be helpful to read through all 11 areas before making your ratings. **Please rate all 11 areas.**



***Research Priorities for Service User and Carer-Centred Mental Health Services: Consultation Report***

**If you would like more details on the 11 areas before rating them, please read the 'appendix' at the end of the questionnaire.**

The deadline for returning this questionnaire is **7<sup>th</sup> July 2006**

It can also be completed online at <http://keypoint.scmh.org.uk/stage3.htm>

If you would like any help completing the questionnaire, or would like more information, please contact XXXXX

### **1 Social inclusion and the role of mental health & social care services**

Aim: to explore how community-based services can help service users to become more involved in wider society. Researchers could look at...

- how various services & organisations can work together to promote social integration
- the effectiveness of a range of social support & recovery-based interventions
- addressing stigma within the workplace, the Police, housing officers etc.

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **2 Preventing mental health problems and promoting mental well-being**

Aim: to develop interventions which tackle the causes of mental health problems within high-risk groups, and which promote mental well-being in the general population. Researchers could look at...

- risk-factors e.g. drug abuse, and interventions which aim to protect people from them
- initiatives aiming to teach children skills for looking after their mental health
- the cost-effectiveness of prevention and promotion strategies

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **3 Non-medical interventions**

Aim: to improve access to effective psychological, occupational and creative therapies, and other non-medical approaches such as those based on diet and exercise. Researchers could look at...

- developing effective therapies for all people, whatever the age, ability or ethnicity
- making therapies more accessible e.g. using computer programs or self-referral services
- approaches based on diet, exercise and self-management techniques

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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#### **4 Medication & side effects**

Aim: 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. Researchers could look at...

- ways of giving people more choice & control over the medication they use
- concerns regarding the use of medication by young children and older adults
- concerns regarding the use of medication over long periods of time

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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#### **5 Supporting & empowering family members and carers**

Aim: to enable services to give better support, information and advice to family members and carers. Researchers could look at...

- evaluating carer support/education programs
- evaluating interventions to reduce the mental and physical health impact of caring
- models for working with families from family-based therapies & the voluntary sector

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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#### **6 GPs and primary care**

Aim: to improve the support provided by GPs and other professionals in primary care for people with mental health problems, and to improve the early detection of mental health problems within primary care. Researchers could look at...

- how GPs can detect mental health problems at the earliest possible stage
- ways in which people can be helped without being referred to specialist services
- meeting the physical health care needs of people with mental health problems

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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#### **7 User and carer involvement in service planning & delivery**

Aim: to enable meaningful involvement of service users and carers in planning and delivering services. Researchers could look at...

- how people should be supported so that they can be involved in a meaningful way
- involving marginalised groups so that all people are represented
- addressing attitudes regarding user/carers involvement within services

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **8 Care pathways & transitions between services**

Aim: to make sure people are able to move between different parts of the mental health system in a way which is acceptable and efficient (e.g. in terms of minimising duplication of work). Researchers could look at...

- making the transition from child and adolescent services to adult services less difficult
- improving referral pathways from GPs & community organisations to specialist services
- how people from potentially marginalised groups move through the mental health system

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **9 Workforce issues**

Aim: to clarify the workforce, skill mix and team working arrangements required to allow services to become more service user and carer-centred. Researchers could look at...

- workforce requirements in inpatient wards & crisis teams
- combating stress and low morale within the workforce
- training and supervision arrangements required for therapies to remain effective

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **10 Person-centred care planning**

Aim: to enable services to adopt a collaborative approach in which people are involved in planning their own care, and to enable services to become more needs-led and recovery-based. Researchers could look at...

- how best to use CPA care plans, advance directives, direct payments, 'WRAP' plans etc.
- how marginalised groups can be better involved in planning their care
- addressing attitudes within services to promote collaborative working

<b>RATING (please circle one)</b>	<i>(Least Important)</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<i>(Most important)</i>
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### **11 Crisis care**

Aim: to improve the quality of crisis care in a variety of forms – both in hospital and in the community. Researchers could look at...

- how acute wards can be better linked with teams in the community
- how best to use alternatives such as home treatment teams and crisis houses
- the use of psychological therapies on acute inpatient wards

<b>RATING (please circle one)</b>	(Least Important)	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	(Most important)
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Please add any general comments you would like to make about the 11 research areas in the space below

**Personal details**

Which of the following is true for you?

- ☐ I use or have used mental health services  
☐ A family member or someone I care for uses mental health services  
☐ I work in mental health or a related field

***If you work in mental health or a related field, please give the following details about your work:***

Your name.....  
Organisation.....  
Job title.....

***The following questions are for all people to complete. They are for monitoring purposes only:***

1. Sex ☐ Female  
☐ Male

2. Age .....

3. Region of England
- |                                        |                                                  |
|----------------------------------------|--------------------------------------------------|
| <input type="checkbox"/> North-East    | <input type="checkbox"/> East Anglia             |
| <input type="checkbox"/> North-West    | <input type="checkbox"/> South East (not London) |
| <input type="checkbox"/> East Midlands | <input type="checkbox"/> South West              |
| <input type="checkbox"/> West Midlands | <input type="checkbox"/> London                  |

4. Ethnic group (tick ONE only)

White

- ☐ White British  
☐ White Irish  
☐ Any other White background

Black or Black British

- ☐ African  
☐ Caribbean  
☐ Any other Black background

**Mixed**

- ☐ White and Black Caribbean  
☐ White and Black African

**Asian or Asian British**

- ☐ Indian  
☐ Pakistani

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- |                                                     |                                                     |
|-----------------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> White and Asian            | <input type="checkbox"/> Bangladeshi                |
| <input type="checkbox"/> Any other Mixed background | <input type="checkbox"/> Any other Asian background |

**Chinese or other ethnic group**

- ☐ Chinese
- ☐ Any other ethnic group (please specify).....

If you would like to be sent the results of the study, please give contact details below:

Address .....

.....

Email .....

Thank you for completing this questionnaire. We appreciate you taking the time to share your views.

Please return by **7<sup>th</sup> July 2006** to the address below. You do not need to return the appendix.

XXXXX

## Appendix D Organisations involved in questionnaire distribution

List of organisations, groups and networks involved in distributing our questionnaires. Please note that as snowballing techniques were used, this list is not likely to be complete. It also does not list the mental health trusts involved in questionnaire distribution – these are listed in Appendix E.

Action on addiction  
Age Concern  
Akwaaba Ayea (BME advocacy project)  
Big Issue  
British Psychological Society  
Carers Centre Newcastle  
Carers Leeds  
Carers Lewisham  
CHAIN Network  
Depression Alliance  
Diverse Minds BME Network  
East Kent Mental Health Carers' Forum  
East Kent Service User groups  
East London & City Mental Health Trust User Advisory Group  
Essex race equality council  
Health R&D now conference – publicized in conference pack  
Help the aged  
Independent Newham Users Forum  
James Wiltshire Trust  
London Development Centre Carers Network  
London Development Centre Service User & Carer groups  
Leeds Involvement Project  
Luton Service User Involvement Project  
Luton Service User Network  
MELLOW (BME organization)  
Mental Health Foundation's 1-in-4 forum  
Mental Health Foundation 's Us As Experts forum  
Mental Health Specialist Library  
MIND Exeter & East Devon  
Mindlink mailout  
National Phobics Society Anxiety Research Forum  
NHS Clinical Governance Support Team  
NIMHE Eastern Service User & Carers email groups



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NIMHE Eastern Whole Life Bulletin  
NIMHE North East service user groups  
NIMHE West Midlands Carers Network  
NIMHE West Midlands User Group  
NIMHE South East Service User Panel  
No Panic  
Norwich MIND  
PACE  
Parental Mental Health and Child Welfare Network – Social Care  
Institute for Excellence  
PCHA Housing Association  
Phobics Society  
Royal College of GPs  
Royal College of Psychiatrists  
Samaritans  
SANEline volunteers mailing list  
Second Step (support + Organization Organization)  
Shaping Our Lives  
SIMBA (BME service user group)  
SITRA  
Supporting Carers Better Network (Together UK)  
Service User Research Enterprise (SURE)  
Service User Research Group in England (SURGE)  
Turning Point  
UK Advocacy Network (UKAN)  
UK Coalition of People Living with HIV and AIDS  
UK Federation of Smaller Mental Health Agencies  
Young Minds

## Appendix E Trusts and services involved in Stage One

The following table lists the 9 NHS Trusts and PCTs involved in distributing the Stage one questionnaire to service users and carers.

### Characteristics of NHS Trusts and PCTs selected for inclusion in study

Trust	NIMHE Region	Key characteristics
Leeds Mental Health Teaching NHS Trust	North East	Urban, high ethnic diversity, teaching trust
Morecambe Bay Primary Care Trust	North West	Predominantly rural, with relatively large population of asylum seekers & refugees
Nottinghamshire Healthcare NHS Trust	East Midlands	Mix of urban and rural
Birmingham & Solihull Mental Health NHS Trust	West Midlands	Urban, high ethnic diversity
Norfolk & Waveney Mental Health Partnership NHS Trust	Eastern	Predominantly rural
Hillingdon Primary Care Trust	London	Urban, high ethnic diversity, high levels of social deprivation. Zero star trust
South London & Maudsley NHS Trust	London	Urban, high ethnic diversity, high levels of social deprivation. Teaching trust with wide range of services
East Kent NHS & Social Care Partnership	South East	Mix of urban and rural, with relatively large population of asylum seekers & refugees
Somerset Partnership NHS & Social Care Trust	South West	Predominantly rural

From these 9 Trusts, a total of 45 teams agreed to take part

- 7 Community Mental Health Teams (including 3 older people's teams).
- 7 Acute inpatient wards (including low and medium secure units).
- 3 Rehabilitation / recovery units.
- 3 Crisis Resolution and Home Treatment teams.
- 3 Early Intervention in Psychosis teams.

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- 3 Assertive Outreach Teams.
- 3 Forensic teams (community and prison in-reach).
- 6 Child and Adolescent Mental Health teams.
- 2 Dual diagnosis teams.
- 2 Carers teams.
- 5 Acute Community Day Services.
- 1 GP practice.

## Appendix F Identifying professional stakeholders for Stage Two

<b>Stakeholder group</b>	<b>Key roles/organisations within stakeholder group</b>	<b>How stakeholders were identified</b>
Academics	Clinical and non-clinical mental health academics in all relevant specialisms – child and adolescent, older adults, forensic, primary care, learning disabilities, health services research, social work, sociology of mental health	Nominations from the Expert Group, staff within the Sainsbury Centre for Mental Health and expert contacts in the Department of Health Mental Health Research Network (Hub Leads and Primary Care Leads) Individuals associated with other networks - Prison Health Network, Social Perspectives Network, British Sociological Association's mental health study group
Health service management	Various roles in Mental Health NHS trusts - Medical Directors, Directors of Nursing, Clinical Directors, R&D Directors / Managers. SHA & PCT Commissioners. SHA Clinical Governance Leads	Staff lists on the websites of all Mental Health NHS Trusts in England. Mental Health Task Force members Individuals involved in distributing stage one questionnaire to service users Strategic Health Authority Clinical Governance Leads network
Practitioners	Psychiatrists, clinical psychologists, nurses, occupational therapists, GPs, pharmacists	Individuals involved in distributing stage one questionnaire to service users Individuals associated with the Royal College of GP's mental health group
Department of Health	Policy, research & senior staff in Department of Health (e.g. in mental health, prison health, children's health, older people's health)	Nominations from the Expert Group, staff within the Sainsbury Centre for Mental Health and expert contacts in the Department of Health Mental Health Task Force members
NIMHE	Regional Development Centre Directors, Research Leads and Service Improvement Leads	Staff lists on the websites of the 8 NIMHE Regional Development Centres

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Other related statutory agencies	Policy, research and senior Healthcare Commission, Mental Health Act Commission, Disability Rights Commission, NICE	Nominations from the Expert Group, staff within the Sainsbury Centre for Mental Health and expert contacts in the Department of Health Mental Health Research Funders' Group members
Voluntary sector	Policy, research and senior staff in voluntary sector organisations with an interest in mental health (including those not solely devoted to mental health)	We contacted most major national charities to identify suitable individuals Nominations from the Expert Group, staff within the Sainsbury Centre for Mental Health and expert contacts in the Department of Health Individuals involved in distributing stage one questionnaire to service users
Related sectors	Staff with an interest in mental health in the housing and social care sectors, and in the DfES, Home Office and Youth Justice Board	Nominations from the Expert Group and other expert contacts Mental health task force Housing group members
Research funders	Representative from MRC, ESRC, Alzheimer's Research Trust, King's Fund, Wellcome Trust etc.	Mental Health Research Funders' Group members

## Appendix G List of focus groups and in-depth interviews

### Focus groups and in-depth interviews conducted with service users and carers from marginalised groups

	Description	Location	# attending
<b>Young service users</b>	Child & Adolescent community team (ages 10-14)	London	1
	Adolescent inpatient unit (ages 16-18)	Sussex	6
	Mind young people's project (ages 14-16)	Sussex	2
	Young person recruited through Mind advocacy worker (age 16)	Sussex	1
<b>Parents</b>	Parents of Child & Adolescent community team clients	London	1
<b>Older service users and carers</b>	Community Mental Health Team for Older Adults	London	5
	Community Mental Health Team for Older Adults	Birmingham	10
	BME Community Team for Older Adults	Birmingham	8
	Focus group recruited through Mental Health Matters	Newcastle	2
	2 one-to-one interviews recruited through Mental Health Matters	Newcastle	2
<b>Black and Minority Ethnic (BME)</b>	Carers Service	Leeds	8

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<b>Groups</b>	Local service user group	Bradford	3
	Women's support group	Bradford	7
	BME Mental Health Support Centre	Leeds	9
	Counselling/Support group for Asian Women (Mind)	London	8
	Recruited through Manchester Race and Health Forum	Manchester	10
<b>Refugees and asylum seekers</b>	Recruited through Manchester Race and Health Forum	Manchester	9
	Refugee & asylum seeker group at Mind drop-in centre	Suffolk	4
<b>Ex-offenders</b>	Ex-prisoners recruited through Revolving Doors	London	6
	Ex-prisoners using Medium Secure Unit	London	6
<b>People with no stable housing</b>	Recruited through the mental health section of a housing association	Nottingham	8
	Homeless team clients – 'rough sleepers' & people in direct access hospitals	Birmingham	5
<b>People with learning difficulties</b>	Support group for people with learning difficulties + mental health problems	London	6
<b>People with personality disorder</b>	Personality disorder inpatient unit	Birmingham	7

## Appendix H Developing the emerging research areas in Stage Two

### ***Professional stakeholder views on the research areas from stage one***

The following outlines the key criticisms and comments made by professional stakeholders in stage two, regarding each of the 25 research areas from stage one.

#### **1 Acute inpatient wards**

Research aiming to improve acute wards should not consider wards in isolation but in relation to community care and in relation to alternative crisis care such as crisis houses and home treatment teams.

#### **2 Choice & involvement**

The emphasis should be on making services needs-led and flexible rather than on an ideologically-driven focus on free choice. Research could contribute by examining tools, mechanisms and models underpinning such services.

#### **3 Psychological therapy**

The focus should be on developing accessible interventions for all, in order to create a needs-led service. Hence the area should be widened to include occupational and creative therapies and approaches based on diet and exercise.

#### **4 Family & carers**

The focus should be on 'supporting' and 'empowering' carers rather than on 'involving' them in care planning per se – as the latter can raise ethical issues and potential tensions between service users and carers.

#### **5 Holistic, individualised treatment**

The concept of 'holistic' treatment is broad and difficult to define. Many respondents felt that the notion merely describes good clinical practice, and would be hard to assess systematically. It was suggested that the key, substantive issue here is, again, how services can be needs-led and flexible.

#### **6 Sources of support in the community**

This area (looking at the role of day centres and other sources of support in the community) was felt to be too limiting. Day services



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and other localised services should be examined within the context of the wider drive to promote social inclusion and recovery.

### **7 User involvement in service planning & delivery**

Respondents felt that this has been the focus of much research already, but that there is still work to be done to make involvement more representative and effective, and more radically, in the area of user-led services. The area should also include the involvement of carers.

### **8 Nature & causes of mental health problems**

Work on the causes of mental health problems should be directed towards serving the prevention agenda. Environmental risk factors – and interventions to offset them – should be the focus. A large number of respondents felt that research is currently biased towards genetics, and that this research will ultimately prove less useful.

### **9 Medication & side effects**

Respondents were divided on this issue, more than any other. Some felt that no further emphasis should be placed on medication. Others felt that research exploring ways of minimising side effects or maximising user choice and control definitely *should* receive public funding, to avoid the conflicts of interest associated with commercial funding.

### **10 Stigma, discrimination & attitudes**

A consensus existed around both the importance and the difficulty of tackling stigma. There was some scepticism around the likely effectiveness of media-based anti-stigma campaigns. Many felt that the anti-stigma agenda would be best served by spending public money on research to promote social integration – this being the best way of changing attitudes. If money is to be spent on direct attempts to address attitudes, the weight of opinion in this consultation suggests that attitudes *within* mental health services should be the first priority.

### **11 Employment**

Respondents felt that employment is important but already high on the agenda. Some remaining gaps in the research base were suggested, but it was clear that these would be better placed within a wider social inclusion area rather than a dedicated employment area.

### **12 Getting help when it's needed**

It was felt that this area (which concerned making services responsive to users' needs) was adequately covered elsewhere. It was also suggested that it would be better to research self-management strategies than to pretend services can always be available to give

support.

**13 Alternatives to acute wards**

It was felt that this should be combined with the 'acute wards' area (see above).

**14 Marginalised groups**

Respondents felt that this should not be a separate research area – rather, research in all areas should give due consideration to the needs of marginalised groups.

**15 Amount of contact between service users & staff**

It was felt that it would be more useful to look at quality than quantity. Continuity of care was seen to be an important issue, but one that has already received recent attention from researchers.

**16 Recovery & social inclusion**

This was felt to be highly important, but it was suggested that the area should be defined as 'social inclusion' – recovery being more of a cross-cutting notion relevant to several research areas.

**17 Other treatment approaches (dietary, complementary etc.)**

A great consensus existed around the need for research into dietary and exercise-based interventions, but less so for other complementary approaches. It was suggested that given limited resources, research should focus first on approaches with the strongest link to established medical understanding.

**18 Integrated services**

This was seen largely as an issue for local management/audit rather than research. However, some issues were deemed important for research – e.g. the transition from child & adolescent to adult services – and these were included in a reconceptualised 'care pathways and transitions' area (see below).

**19 GPs & primary care**

This was seen as an area requiring further attention, despite a large body of existing research work.

**20 Early intervention, prevention & promotion**

This was seen as highly important. There were some concerns, however, around pathologising and medicalising child behaviour.

**21 Discharge from inpatient services**

It was felt that this should be combined with the 'acute wards' area (see above).

**22 Travelling to appointments**

This was the lowest scoring area. Respondents did not feel this was an

area where mental health researchers could be usefully employed.

**23 Implementational research**

Respondents felt that this area – about finding better ways of putting research findings into practice – should be framed as a cross-cutting issue rather than a separate research area

**24 Benefits**

Respondents felt there would be little use in research looking at the benefits system specifically in relation to mental health service users, given the wider plans to reform Incapacity Benefit for all types of recipient. Those specific issues which do exist are already well understood.

**25 Housing**

Several suggestions for research needed in this area were made, but it was also suggested that housing should be one component of the social inclusion research area rather than a stand-alone area.

**Refined research areas for stage three**

The following summarises how the 25 research areas from stage one were refined into nine areas for stage three, on the basis of the comments and criticisms from professional stakeholders described above.

- 'Housing', 'Benefits', 'Employment', 'Sources of support in the community' and 'Stigma, discrimination & attitudes' were combined with 'Recovery & social inclusion' under a broader research area: 'Social inclusion and the role of mental health and social care services'.
- 'Acute inpatient wards', 'Alternatives to acute wards' and 'Discharge from acute wards' were combined as 'Services for people in crisis'.
- 'Psychological therapies' and 'Other treatment approaches' were combined as 'Non-medication based interventions'.
- 'Choice & involvement' was defined more tightly on needs-led, flexible services with collaborative approaches to care planning and named 'Person-centred care planning'. This also covers the substantive parts of the 'Holistic, individualised treatment' area
- 'Nature & causes of mental health problems' was included in 'Prevention and promotion'.
- 'Amount of contact between service users and staff' and 'Travelling to appointments' were removed from the list of research areas.

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- Research ideas previously categorised under 'Marginalised groups' were re-classified under the other areas, as respondents felt that attending to such groups should be a concern within all areas rather than a stand-alone issue.
- 'Implementing research findings' was re-classified as a 'cross-cutting issue' (see below).

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## Appendix I Stage Two rating scores

Professional stakeholders' ratings of the 25 research areas emerging from stage one.

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### Mean rating scores from 436 professionals consulted in Stage Two

<b>Research area</b>	<b>Mean score (out of 5)</b>
Acute inpatient wards	4.25
Choice and involvement	4.09
Early intervention, prevention and promotion	4.03
Psychological therapy	4.00
Recovery and social inclusion	3.97
Holistic, individualised treatment	3.94
Stigma, discrimination and attitudes	3.94
Getting help when it's needed	3.89
Alternatives to acute wards	3.86
Potentially marginalised groups	3.85
Family and carers	3.84
Employment	3.83
GPs and primary care	3.83
User involvement, user-led services	3.81
Sources of support in the community	3.79
Integrated services	3.69
Nature and causes of mental health problems	3.65
Medication and side effects	3.65
Housing	3.63
Implementational research	3.63
Discharge from inpatient units post-discharge	3.61
Benefits	3.55
Amount of contact between service users & staff	3.42
Other forms of treatment	3.39
Travelling to appointments	2.78
Priority areas listed in descending order of mean rating	

## Appendix J Comparison of priorities of professional sub-groups

**Comparison of the research priorities of different sub-groups of mental health professionals (stage three)**

<b>Academics (n=43)</b>		<b>Practitioners (n=128)</b>		<b>Senior health service roles (n=58)</b>		<b>Other health service roles (n=28)</b>		<b>Voluntary sector (n=31)</b>		<b>Social care (n=19)</b>	
	Mean		Mean		Mean		Mean		Mean		Mean
Social inclusion	5.47	Prevention	5.66	Social inclusion	5.70	Non-medicat'n	6.00	GPs	5.94	Prevention	6.39
Non-medicat'n	5.42	Non-medicat'n	5.54	GPs	5.62	Social inclusion	5.71	Prevention	5.84	Social inclusion	6.33
Prevention	5.30	GPs	5.46	Prevention	5.62	Prevention	5.68	Non-medicat'n	5.84	GPs	6.00
Crisis services	5.29	Crisis services	5.29	Person-centred	5.47	Person-centred	5.63	Social inclusion	5.74	Involvement	5.89
Person-centred	5.21	Social inclusion	5.21	Involvement	5.25	GPs	5.44	Person-centred	5.74	Person-centred	5.83
GPs	5.09	Person-centred	5.13	Non-medicat'n	5.24	Carers	5.37	Crisis services	5.57	Non-medicat'n	5.78
Involvement	5.00	Carers	5.09	Crisis services	4.97	Care pathways	5.32	Involvement	5.53	Crisis services	5.22
Workforce	4.93	Workforce	5.02	Care pathways	4.96	Workforce	5.07	Carers	5.53	Carers	5.17
Carers	4.84	Care pathways	4.87	Carers	4.66	Involvement	4.92	Care pathways	5.40	Workforce	5.00
Medication	4.79	Medication	4.84	Medication	4.55	Crisis services		Workforce	5.37	Care pathways	4.78
Care pathways	4.44	Involvement		Workforce		Medication		Medication			

Priority areas listed in descending order of mean rating for each sub-group. Ratings were given on a scale of 1 to 7.

## **Appendix K – Members of Expert Group**

The following people attended one or more of the Expert Group meetings or contributed in writing.

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### **Members of Expert Group**

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<b>Name</b>	<b>Organisation/role</b>
Richard Mills	National Autistic Society
Prof Susan Benbow	NIMHE Fellow for Aging and Mental Health
Prof Glyn Lewis	Professor of Psychiatric Epidemiology
Mark Fenton	James Lind Alliance
Alison Faulkner	Service User Researcher
Dr David Goodban	National CAMHS Support Service
Dominic Walker	Social Perspectives Network
Robin Johnson	NIMHE Adviser on Housing & Mental Health
Mick Collins	NIMHE West Midlands
Vicky Nicholls	Service User Researcher
Jen Kilyon	Empathy with Carers consultancy
Grainne Fadden	Birmingham & Solihull Mental Health Trust
Dr Neil Brimblecombe	Department of Health
Carol Jenkin	Service User Researcher
Tom Dodd	NIMHE West Midlands
Elias Tsakanikos	Estia Centre
Ian Davies	Central England People First
Catherine Clarke	Carer
Elizabeth Potts	NIMHE West Midlands
Cathy Street	Young Minds
Keith Halsall	Hal Research and Consultancy
Joan Penrose	Carer
Debbie Moores	South Staffs Healthcare NHS Foundation Trust
Eddie Chaplin	Estia Centre

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**Addendum**

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