

# Do different stakeholder groups share mental health research priorities? A four-arm Delphi study

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## Abstract

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**Background** Despite considerable investment in research priority setting within diverse fields of healthcare, little is known about the extent to which different stakeholder groups share research priorities. Conflicting priorities may jeopardize stakeholder engagement in research.

**Objective** To identify the research priorities of different stakeholder groups within mental health care and examine the extent and nature of agreement between them.

**Design** Using a Delphi technique, we conducted parallel consultation processes within four different stakeholder groups. Each group process consisted of three rounds.

**Setting and participants** The study was carried out within a mental health and learning disabilities trust in southern England. Participants were recruited from the following groups: mental health service users (34), informal carers (26), mental health practitioners (35) and service managers (23).

**Findings** There were striking differences between the four groups in respect of their ability and willingness to make priority decisions. These differences notwithstanding, there was considerable overlap in respect of their research interests. All groups identified and attached high importance to issues relating to the promotion of independence, self-esteem and recovery. The quality of in-patient care, the place of psychological therapies and the relationship between physical and mental health also emerged across the board.

**Conclusions** The confluence of four different stakeholder groups around a number of clear themes is highly encouraging, providing a framework within which to construct a research agenda and suggesting that mental health research can be built on solid partnerships.

## Introduction

Public involvement is central to the Department of Health (DoH) strategy for modernizing the English National Health Service (NHS) and improving the quality of care it provides.<sup>1,2</sup> It also plays a vital part in the NHS Research and Development (R&D) programme, which, since its inception in 1991, has sought increasingly to involve both NHS staff and the users of health services in the systematic identification and setting of research priorities.<sup>3</sup> Identifying and prioritizing research topics is one of the most important contributions that people can make, because it helps researchers to ask the right questions in the right way and thus ensures that research is relevant, widely accessible and influential in terms of both policy and practice.

As a DoH-funded R&D department in an NHS Trust, working in partnership with the local university, we undertake a combination of externally funded and in-house research. This has historically been focused around a number of themes that were based on the interests of members of the department. We wanted to know whether the research we were conducting and our plans for future programmes of research were in line with the expectations of our local stakeholders. Like the authors of the report, cited above:<sup>3</sup>

we subscribe to the belief that research agendas should reflect the needs and values of the people who use and pay for health services, and that this is unlikely to be achieved without directly involving some of these people.

We therefore embarked on a Trust-wide consultation exercise, with the aim of involving a range of stakeholder groups in the setting of a local research agenda. In doing so, we hoped to promote a Trust-wide sense of ownership of and commitment to research activity, to embed R&D firmly within the culture of the organization and to ensure that our research addressed local needs as well as national strategic priorities.

Previous articles in this journal have described public involvement in setting research agendas in physical health care.<sup>4-7</sup> Our agenda-setting

exercise was conducted within the context of mental health care. Devon Partnership NHS Trust provides mental health and learning disabilities services to a resident population of 850 000 people. As an academic department, our activity is limited to mental health research, and so this exercise was restricted to those connected with mental health services.

We recognized that our stakeholders included frontline clinical staff and managers, as well as the users of our services and their informal carers, and that these various groups might have very different ideas about what issues were important. Little is known about the extent to which different stakeholder groups share research priorities, since previous consultation exercises have either focused on a particular group<sup>4-12</sup> or amalgamated different groups within a single agenda-setting exercise.<sup>13-15</sup> The question is an important one, as conflicting priorities may jeopardize stakeholder engagement in research. Our aim was to identify the research priorities of different stakeholder groups within mental health care and to examine the extent and nature of agreement between them. We therefore conducted four discrete but identical consultation exercises in parallel. Here, we report the results of these separate exercises and comment on the degree of overlap between them.

## Methods

We conducted a three-round Delphi survey, a technique which has a long history of use within health contexts as a systematic way of canvassing opinions and achieving consensus on priorities both for service development<sup>13,16</sup> and for research.<sup>8,10-12,14,15,17,18</sup> A Delphi survey is a structured group process in which a series of questionnaires is sent to a panel of people recruited on the basis of their knowledge, experience and interest in the issue under investigation. Participants are asked to identify, and subsequently either rate or rank, issues of importance to them. The process takes place over a number of 'rounds' of data collection and

feedback. After each round, the results are analysed, tabulated and fed back to participants, who are invited to revise their opinion in the light of them, with the aim of achieving consensus within the group on what are the most important issues. Consensus is operationalized statistically, using a measure of the spread of responses, e.g. standard deviation or inter-quartile range (IQR).

The Delphi technique has a number of advantages over other methods of consultation and consensus development. It can include large numbers of participants dispersed over a wide geographical area. It allows participants to respond individually and anonymously, avoiding many of the problems associated with workshops or focus groups, where strong characters or the 'majority view' can dominate and where the group's response to a particular idea may be determined by the status of its proponent, rather than its inherent merit. The method also offers participants the opportunity in private to review and revise their opinions in the light of others' responses, something that they may be reluctant to do in a public forum. Disadvantages of the technique include potential attrition between rounds, absence of the stimulation and cross-fertilization of ideas that occur when people meet face to face, and the possibility that anonymity may encourage carelessness on the part of participants because they are not publicly accountable for their views. We bore these potential problems in mind when deciding to undertake a Delphi exercise within our organization.

We identified four discrete stakeholder groups within our NHS Trust: service users, informal carers, mental health practitioners and service managers. We recognised that these groups might have very different ideas about what was important and that their differences would not be apparent if participants from all four groups took part in a single consensus-building exercise. We therefore conducted four separate Delphi surveys simultaneously, each consisting of three rounds. Each group generated its own list of research topics. These were analysed separately and then fed back to and rated by the group from which they came. This enabled us to

identify each group's research priorities and then to look for commonalities and differences between the four groups.

### Participants

We aimed to recruit a minimum of 25 participants in each group, so as to involve at least 100 stakeholders in total. The inclusion of larger numbers would have been beyond the limits of our resources. Service users and carers who had expressed an interest in research and development were identified through the Trust's Patient Advice and Liaison Service (PALS) and its Patient and Public Involvement Manager, and were invited to participate. Visits were also made to service user and carer groups across the whole area served by the Trust to explain the nature of the consultation and invite people to take part. Those willing to participate were asked by the project worker to complete the first questionnaire there and then. At each subsequent round, the project worker again attended group meetings and asked participants to complete the questionnaire on the spot. The project worker offered help to individuals who had difficulty in filling in the questionnaire but did not enter into any discussion that might influence the participant's suggested research topics or subsequent ratings. Those service users and carers who did not attend group meetings received their questionnaires by post or e-mail.

Practitioners and managers who had shown an interest in or commitment to research (e.g. all grant holders, those with projects registered with the R&D department and known champions of evidence-based practice) were invited to participate and to extend the invitation to their colleagues. The practitioners' group included members of five professions involved in mental health care: psychiatrists, psychiatric nurses, occupational therapists, clinical psychologists and approved social workers. The Trust's only pharmacist was on extended leave during the study period. Efforts were made to restrict the managers' group to those with little or no contact with patients, to see whether patient contact had any effect on research priorities. Health

practitioners' and managers' questionnaires were distributed by electronic or internal mail.

The importance of completing all three rounds was emphasized at the outset. To minimize attrition, the project worker maintained regular contact with participants in all four groups throughout the study via e-mail, telephone and face-to-face communication.

### Round 1

A standard one-page questionnaire was distributed to participants in all four groups with the following instruction: 'Please list up to five topic areas relating to mental health which you think should be priority areas for research'.

### Development of Round 2 questionnaires

Responses from each stakeholder group were analysed separately and used to construct a different Round 2 questionnaire for each group. There was wide variation in the style of responses to Round 1, ranging from very broad areas such as 'personality disorders' or 'access to services' to highly specific research questions.

Each group's responses were analysed by two members of the project team. Each independently read and re-read all the suggested topics, used open coding to establish themes running through the data and sorted the responses accordingly. They then compared and collated their results. Where there was disagreement over the interpretation of individual responses, other members of the R&D team were consulted. In some cases, the project worker identified and contacted the participant to clarify exactly what s/he had in mind. Discussion continued until agreement was reached on the meaning of each item and its relationship to others. This was a dynamic, iterative and time-consuming process, taking several hours to sort and synthesize each group's responses. In the process, long responses were summarized, exact duplicates were removed and broadly similar responses were amalgamated. The methodological literature is unclear as to the extent of qualitative analysis that should be carried out on the Round 1

responses. Some studies have condensed their Round 1 topics into a small number of very broad categories and asked participants to rate the latter.<sup>15</sup> This has the advantage of generating a brief questionnaire for use in subsequent rounds, but sacrifices detail, forces participant-generated ideas into researcher-generated categories and removes the possibility of giving different ratings to individual items within each category. We took a decision to present as many of the original suggestions as possible, in order that respondents could easily recognize their own ideas and discriminate between items that were closely related but different. Our goal was to produce a Round 2 questionnaire for each group that listed a manageable number of easily understood, one-line research topics, expressed as far as possible in the language of the original.

The resulting questionnaires were piloted on members of the R&D team before being issued to participants in the appropriate group. Participants were asked to rate each topic using a five-point Likert-type scale, with 5 denoting the highest priority and 1 denoting the lowest.

### Development of Round 3 questionnaires

Round 2 responses from each stakeholder group were again analysed separately. For each group, descriptive statistics were produced, including the median response and the IQR for each research topic. The median was chosen to represent the typical value given to each item by participants as the distributions were skewed. Measuring the degree of consensus among group members is a fundamental aim of the Delphi process. In common with other studies,<sup>18</sup> the level of consensus for each item was derived from the IQR, a measure of the spread of responses generated by taking the difference between the 25th and 75th percentiles.

For each group, the Round 3 questionnaire consisted of the same set of items as in Round 2, with the median response shown alongside each item. Items were also colour-coded to indicate the degree of importance attached to them by the group in the previous round. Participants were invited to consider the group's response and then

re-rate each item in the light of this new information. If their rating differed by more than two points from the median, they were encouraged to comment on their reasons for this.

### Analysis of Round 3

At the close of Round 3, the median rating for each item was again calculated and used to indicate the importance attached by the group to the item: the higher the median, the higher the priority. Items with a median of 4 or 5 were thus defined as very important. The reverse is true for consensus: items with a final IQR of 1 or less were defined as having achieved a high level of consensus.

## Results

### Response rates

The numbers recruited from each stakeholder group and the response rates for each round of the Delphi process are shown in Table 1. Altogether 118 participants were recruited and 106 completed Round 3. The overall response rates, taking all four groups together, were 92% for Round 1, 91.5% for Round 2 and 90% for Round 3. The carers emerged as the most committed group, with 100% response rate in all three rounds.

### Carers' priorities

Table 2 shows the distribution of medians and consensus scores for all four groups. Carers' responses were very tightly bunched at the top

end of the scale, with an unusually large number of items rated as 'highest priority' and a very high level of consensus. They exhibited the highest level of agreement in Round 2 and attained an even greater level in Round 3, particularly on the items they rated as highest priority.

A total of 17 out of 68 items (25% of their topics) received a final median rating of 5 with a final IQR of 0. No items received a median rating of less than 3, indicating that none was considered low priority. The items that achieved the highest ratings and consensus scores are shown in Table 3. A longer list of highly rated items for this and all groups is available from [WEB PAGE TO ADD]. Topics rated most highly by carers fell broadly into the following categories:

- Issues relating to carers' lives (e.g. respite and practical support needs, carers' health and wellbeing, information needs, communication between carers and professionals).
- The quality of inpatient and residential care environments and the need for safe alternatives to hospital.
- Strategies for preventing and managing crises (including access to crisis services).
- Promoting service users' independence, self-esteem and recovery (including access to jobs, social skills training and use of service users as experts).
- Causes, detection and treatment of mental illness/disorders, particularly psychological and creative therapies.
- Public education and challenging stigma.
- Workforce issues (e.g. staff motivation, staff retention, workloads).

**Table 1** Composition of sample and response rates for each round

Stakeholder group	Number recruited ( <i>n</i> )	Round 1		Round 2		Round 3	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Service users	34	29	85	27	79	25	74
Carers	26	26	100	26	100	26	100
Mental health practitioners*	35	31	89	34	97	33	94
Service managers	23	23	100	21	91	22	96
Total	118	109	92	108	91.5	106	90

\*Included psychiatrists, psychiatric nurses, clinical psychologists, occupational therapists and approved social workers.



**Table 2** Distribution of median ratings and consensus scores for each stakeholder group

	Median rating	No of items	Consensus (IQR)	No of items
Carers (total no of items: 68)	5	41	0	19
	4	23	1	42
	3	4	2	4
	2	–	3	3
	1	–	4	–
Service users (total no of items: 57)	5	25	0	5
	4	25	1	31
	3	5	2	20
	2	2	3	1
	1	–	4	–
Health practitioners (total no of items: 107)	5	1	0	1
	4	28	1	62
	3	65	2	44
	2	12	3	–
	1	1	4	–
Managers (total no of items: 84)	5	1	0	8
	4	35	1	56
	3	43	2	20
	2	5	3	–
	1	–	4	–

The request to rate items in Rounds 2 and 3 appeared to cause real difficulty for many carers. The following comments were made by carers and appeared to be typical of the group:

I can't differentiate between all these priorities [...]. Every benefit is bound to invoke a 5 because we want the best for our loved ones.

They are all important and all relevant without distinction.

Two carers attempted to extend the top end of the scale by adding 'VERY' and 'VERY, VERY' to some of their '5' ratings.

A further problem emerged within this group. Carers' topics differed markedly in character from those put forward by the other groups. While many carers did propose potentially researchable ideas, many of their completed Round 1 questionnaires had the character of 'wish lists'. They seemed to contain urgent pleas for service developments and interventions that would make life easier for them or their relatives, and revealed a profound sense of isolation. For example:

Immediate access to help in a crisis - we are frequently left to cope with a deteriorating situation. Over weekends there are no local GPs or crisis team.

Better respite for carers, more frequent breaks and social events. After all, the NHS would not expect its staff to work full-time, 7 days a week, 52 weeks a year without a break or a payment (or perhaps they would!)

Carers should be listened to at an early stage. They are experts on family members and don't ask for help unless it's really necessary.

Thus, it would appear that many carers had difficulty not only in prioritizing, but also in differentiating between research and care issues.

### Service users' priorities

The service users were slightly more successful at prioritizing. In this group, five out of 57 items (9% of topics) received a final median rating of 5 with an IQR of 0. A high level of consensus was therefore achieved, but on far fewer topics than in the carers' group. There was limited consensus lower down the scale, with no IQRs of 0 below a median score of 5. Eleven items improved both their priority ratings and consensus levels between Rounds 2 and 3.

The five top scoring items are shown in Table 3. Topics suggested by service users were remarkably similar to those put forward by carers, but with a far greater number of items on the general theme of promoting independence, self-esteem and recovery. Within this theme, there were numerous topics relating to service users' involvement in their own care, in training and mentoring and in service planning and delivery. Issues relating to the quality of inpatient care and the need for safe alternatives ('sanctuaries') again featured prominently, as did crisis prevention, talking therapies and healthy lifestyles.

Like some of the carers, some service users had difficulty in identifying researchable topics and used the Round 1 questionnaire as an opportunity to make requests for service improvements, such as:

Being able to talk to visitors privately when in hospital.

**Table 3** Top scoring items for each stakeholder group

Research topic	Median	IQR
<b>Carers</b>		
*Impact of mental illness on the health and lives of carers	5	0
*Respite and practical support for carers	5	0
*Residential care/supported living: effectiveness and adequacy of provision	5	0
*Access to crisis services, especially out of hours	5	0
Alternatives to hospital; safe environments or sanctuaries for people to recover in	5	0
How to improve communication between carers and health professionals	5	0
Factors affecting carers' and professionals' motivation and effectiveness	5	0
Service users' and carers' understanding of diagnosis; access to information	5	0
Aftercare following an acute episode	5	0
Putting care plans into practice	5	0
Effective methods of preventing crisis	5	0
Helping service users to recognise onset of crises and seek help early	5	0
Early detection of mental disorders (e.g. at school)	5	0
Length of time between first onset of symptoms and diagnosis	5	0
Public education about mental health	5	0
Causes and triggers of serious mental disorders	5	0
Implementing available research evidence and cost of not doing so	5	0
<b>Service users</b>		
How to find meaning and purpose in everyday life; battling hopelessness	5	0
Alternative places to go when ill or recovering; sanctuaries	5	0
Crisis prevention	5	0
Challenging stigma; changing public attitudes towards mental illness	5	0
Which aspects of services do service users perceive as enhancing or undermining their personal autonomy and dignity?	5	0
<b>Health professionals</b>		
Quality of in-patient environment and care	5	1
Brief psychological interventions: what components are helpful?	4	0
<b>Managers</b>		
Admissions to hospital: how are decisions taken?	5	1
What do patients see as central to recovery?	4	0
Effective self-management packages for chronic mental illness	4	0
Good customer service skills: impact on service users, staff & visitors	4	0
Performance monitoring: impact on service delivery and patient experience	4	0

\*Items that retained the same top-priority rating and IQR between Rounds 2 and 3 and that may therefore be regarded as the most highly rated by carers.

Separate tables giving further information about each group's high scoring items are available as supplementary material.

Others put forward questions that were existential rather than empirical in nature and that powerfully conveyed the day-to-day struggles that they face, for example:

Battling hopelessness: what really is the point to life?

#### Health practitioners' priorities

The scoring pattern was altogether different for health practitioners, who were both more sparing with their top ratings and less inclined to agree on priorities. Only one item out of 107

(0.9%) received a final median score of 5 ('Quality of in-patient environment and care'), and its IQR was 1, indicating less than total consensus. Nevertheless, it emerged clearly as the winning topic. There was full consensus (a final IQR of 0) on only one item, which received a median rating of 4 ('Brief psychological interventions: what components are helpful?'). Overall, consensus improved slightly between Rounds 2 and 3.

Health practitioners' priorities again centred on the quality of in-patient care, carers' support

needs and service user involvement in care. The Wellness and Recovery Model was highly rated, as were many items relating to recovery, such as the role of work and meaningful activity. In addition, practitioners showed a marked interest in psychological interventions, in suicide and self-harm prevention and in service interface issues (between physical/mental health and between primary/secondary care).

### Service managers' priorities

The managers' median scores were again bunched around the middle of the priority scale. Out of 84 items, only one (1.2%) achieved a median rating of 5 ('Admissions to hospital: how are decisions taken?'), with an IQR of 1, indicating less than full consensus, but nonetheless a clear winner. Full consensus (an IQR of 0) was achieved on eight items with median scores of 3 and 4. Median scores and IQRs both improved slightly between Rounds 2 and 3.

Table 3 shows the highest scoring items for this group. Managers' responses appeared to be slightly more closely aligned with those of service users and carers than did those of the practitioners. A number of items relating to recovery, self-management and the maintenance of positive mental health received strong ratings, as did those on understanding and resolving crises. There appeared to be less interest in the quality of in-patient care and more emphasis on keeping people out of hospital in the first place. Like the mental health practitioners, managers also attached importance to the physical/mental healthcare interface and to suicide prevention. Communication between NHS personnel and service users and carers was again rated as important, as were a number of organizational and workforce issues and their impact on care.

### Common themes and cross-group agreement

Because the consultation exercise was conducted separately with each of the four stakeholder groups, we have no statistical measure of overall consensus on research priorities. Our original plan was to merge the four groups at the end in a

combined fourth round to see if inter-group consensus could be reached, but we were unable to find a valid process for doing so.

Nevertheless, there were some clear themes cutting across all four groups. Viewing the four-arm exercise as a whole, highly rated items can be seen to fall into the following broad categories:

- Promoting independence, self-esteem and recovery.
- Appropriate care environments.
- Preventing and managing crises and relapse.
- The place of talking and creative therapies.
- Relationship between physical and mental health.
- Service user involvement in and perspectives on care.
- Health and wellbeing of carers.
- Communication between service users, carers and health professionals; access to information.
- Workforce issues.

These are illustrated by selected items from each of the groups in Table 4.

## Discussion

### Key findings

Striking differences in the ability of different stakeholder groups to identify and prioritize research topics emerged as an unexpected and important finding in this study. These differences notwithstanding, there was considerable overlap in respect of their interests. All groups identified and attached high importance to the promotion of independence, self-esteem and recovery. Concern with the quality of in-patient care, the place of psychological therapies and the relationship between physical and mental health also emerged across the board.

Of the four stakeholder groups, carers emerged as the most committed to the project and the most united in their views, with 100% response rates and very high levels of consensus throughout. They also consistently rated the greatest number of items as 'highest



**Table 4** Common themes across four stakeholder groups (showing selected items from each group)

	Carers	Service users	Mental health practitioners	Service managers
Promoting independence, self-esteem and recovery	How to promote and assist recovery Role of carers in recovery What enables or prevents people from fulfilling their potential and living healthy lives? Effect of work on recovery Role of social skills training in recovery	Different ways of promoting recovery Battling hopelessness: finding meaning & purpose in everyday life Importance of meaningful activities to recovery Employment and educational opportunities	The Wellness & Recovery Model Meaningful daily activity for people with severe mental illness	What do patients see as central to recovery? Interventions to help service users return to work
Appropriate care environments	Alternatives to hospital: 'sanctuaries' Safety in inpatient units Provision of meaningful activity in hospital Provision of residential care & supported living	Alternative places to go when ill or recovering: 'sanctuaries' Improving the inpatient environment Access to meaningful occupation while on wards	Quality of inpatient environment and care Alternatives to hospital Reducing violence in inpatient units Boredom on acute wards Quality of life in long-stay care settings Relapse prevention in severe mental illness	How are admission decisions taken? Alternatives to admission Reasons for long stays on acute wards
Preventing and managing crises	Effective methods of preventing crisis Helping service users recognise onset of crises and seek help early Access to crisis services	Crisis prevention		What do carers/families need from Crisis Resolution Teams? When is a crisis a crisis, and for whom?
Talking and creative therapies	Benefits of talking therapies Effectiveness of creative therapies (e.g. art therapy) Use of family therapy	Effectiveness of psychological therapies Access to psychological therapies and support when therapy ends	Benefits of psychological therapies What components of brief psychological interventions are helpful?	Benefits of psychological therapies Anti-psychotic medication versus cognitive therapies
Relationship between physical and mental health	Effects of nutrition and healthy eating on mental health Link between physical illness/disability and mental health	Effects of exercise on mental health Effects of nutrition on mental health Holistic approaches to mental health	Physical health needs of people with mental illness Primary/secondary care interface	Link between physical and mental health Exercise and mental health Care of people in general hospitals who also have mental health problems

Table 4 (Continued)

	Carers	Service users	Mental health practitioners	Service managers
Service user involvement in and perspectives on care	Use of service users as experts	Involving service users in care/crisis planning How can service users have a more effective voice in the planning and delivery of services?	Service user involvement in delivery of care Service user perspectives on treatment and services Service users' beliefs about mental health problems Support and respite for carers	Effect of Wellness Recovery Action Plans on users' perceptions of care Service user and carer experiences of crisis resolution & home treatment
Health and wellbeing of carers	Impact of caring on own health Recognition of carers' role Respite and practical support needs Factors that affect motivation and caring	Respite and support for carers		
Communication; access to information	Improving communication with professionals Understanding diagnoses Access to information; confidentiality issues How to retain staff in a mental health trust Factors influencing staff motivation Workloads	Access to medical records and opportunities for service users to contribute to them Effects of staff morale on service users Mental health of health professionals		Information sharing between service users and clinicians
Workforce issues				Staff morale and mental health needs

priority', appearing to have some difficulty in discriminating between items and to be reluctant to rule out any topic as unimportant. The fact that a quarter of their topics scored 5 for importance and 0 for consensus is highly unusual in a Delphi study and is somewhat problematic, as we are left with no clear order of priority for this group. There are a number of reasons why this may have happened. It may be that the carers did not fully understand the purpose of the exercise; that, being less practised than clinicians and managers in making priority decisions, they found it difficult to decide on the relative importance of different items, or that they were not really interested in doing so. The nature of their topics, revealing as they do a sense of desperation and unmet need, suggests that the carers may have been more interested in advocacy and campaigning for better services than in setting a research agenda.

Service users showed greater readiness than carers to discriminate between topics and to prioritize, but again no single, top priority emerged from this group. Their suggested topics revealed a deep desire for hope, safe sanctuary and a society that allows them to play a meaningful part, indicating that they too may be more interested in care and recovery than in research.

The health practitioners failed to reach full agreement on any really high priorities. This may be due to the lack of homogeneity in this group, whose members were drawn from five different professions with very different theoretical perspectives. It may well have been easier for individual professions to reach agreement on their top priorities. However, in view of the fact that the co-ordination of an individual service user's care may be assigned more or less arbitrarily to any one of these different professions, this apparent inability of mental health practitioners to agree on what is really important perhaps warrants closer scrutiny.

Like the clinicians, managers also failed to reach consensus on what was really important, agreeing only on a number of items to which they attached middling importance. Managers are also a heterogeneous group from a wide

range of backgrounds, some of whom have 'risen from the ranks' of the mental health professions, while others may have little experience of the day-to-day realities of dealing with mental illness. However, managers' high scoring topics appeared to be rather more concrete and more readily translatable into research questions than those of the other groups. Both managers and practitioners demonstrated greater readiness to discriminate between items and to use the whole rating scale than did either service users or carers, and seemed to be more comfortable with the idea of prioritizing. This may reflect the fact that they are required to make priority decisions on a daily basis.

Overall, broader or more abstract topics (e.g. 'Crisis prevention' or 'Challenging stigma') tended to score more highly both for importance and for consensus than more concrete research ideas. This may to some extent account for the fact that there was greater agreement among carers and service users than among practitioners and managers.

The confluence of the four different stakeholder groups around a number of clear themes is highly encouraging for us as an NHS organization, and provides a framework within which to construct a research agenda, as well as to determine priorities for care.

The concept of 'recovery', in its broadest sense, appeared to link many of the highest rated items in all four stakeholder groups. The idea that recovery from even the most severe forms of mental illness is achievable has been termed the 'guiding vision' of mental health services in the 1990s and beyond,<sup>19</sup> and the Recovery Model is being widely adopted both in the UK and elsewhere.<sup>20-24</sup> This is founded on the belief that, while they may never be free of symptoms, those with severe mental health problems are, with appropriate support, nonetheless able to live on their own terms and to pursue meaningful lives in the community. This optimistic philosophy has been heavily influenced by the ideals and aspirations of the survivor movement and represents a shift in thinking from passive and disempowered 'patienthood' to active involvement and the exercise of control over one's own life. It

stresses the importance of hope, positive commitment to staying well and responsibility for self, and is closely linked with the concept of self-management. Critics of the recovery concept argue that, among other things, it lacks clarity and is too all-embracing to be of any real value,<sup>25</sup> which may be precisely why it suggests itself as a means of unifying many of our top scoring items. Moreover, the recovery model poses challenges for research, as it is essentially value-based rather than evidence-based and is not easily amenable to outcome measurement,<sup>23</sup> although some strides are now being made in the development of measures.<sup>26,27</sup> Proponents of the approach set great store by personal narratives of recovery, and the topics proposed in our Delphi study suggest that a balance of qualitative over quantitative methods may be required.

### Relationship to other work

Previous work has suggested that there may be significant differences in research priorities between mental health service users on the one hand and health professionals and funding bodies on the other,<sup>28</sup> but the reasons for this have not been explored. Our study suggests that service user and carer priorities will be coloured by their experience of local services and by the perceived adequacy of those services to meet their wants and needs. Some of their perceived priorities may be service delivery issues rather than research questions, and may point to gaps in the implementation of research evidence, rather than to gaps in the evidence base itself. Service users and carers would not necessarily be expected to have as keen an awareness as health professionals of where the gaps in the published literature lie, and it is entirely understandable if they are preoccupied with the quality of the service experience. Health professionals' and managers' priorities, on the other hand, are likely to be heavily influenced by political pressures. This is well illustrated in our study by the fact that suicide prevention was identified and prioritized by these two groups, but not by service users or carers. The National Suicide Prevention Strategy is largely directed at

clinicians and managers, who are under pressure to deliver a reduction in suicides as part of the drive to meet government targets.

While this study was being conducted, a national consultation was being carried out by the Sainsbury Centre for Mental Health, using a Delphi method to identify research priorities for service user- and carer-centred mental health services in England.<sup>15</sup> A wide range of stakeholders, including service users, carers, mental health professionals, service directors and academics, took part and together identified and prioritized broad research areas. Their top priorities emerged as:

- Primary care, including the provision of physical healthcare, for people with mental illness.
- Prevention and mental health promotion.
- Non-medication based interventions, including psychological therapies, diet, exercise and self-management techniques.
- Social inclusion.

While there may be some advantages in amalgamating the responses of all stakeholders, not least in producing a single list of priorities, it also obscures potential differences of perspective. In our study, while there was agreement on broad, overarching themes between the four stakeholder groups, subtle differences in orientation are also apparent. For instance, the provision of physical healthcare for people with mental illness was identified and rated highly by clinicians and managers, but not by service users or carers. At the same time, service users and carers produced and gave high ratings to items such as 'Effects of nutrition and healthy eating on mental health' and 'Effects of exercise on mental health', suggesting that, contrary to the prevailing view in the literature,<sup>29</sup> they are no less interested in the physical health-care agenda but express that interest in holistic and recovery-oriented terms rather than in terms of service interfaces.

### Strengths and limitations of the study

Our study was innovative in its four-arm parallel design, which allowed us to identify the priori-

ties for different stakeholder groups at the same point in time, within the context of current service provision in Devon, and demonstrates the importance of allowing the solo voices of service users and their informal carers to be heard in studies of this type.

The failure of carers and, to a lesser extent, service users to prioritize effectively may be regarded as a limitation of the study, since it limited the extent to which we were able to meet our objective. Our decision to ask participants to rate, rather than rank, items may have been partly to blame for this. Delphi studies are divided between rating and ranking, and there is little discussion of their relative merits in the methodological literature. In retrospect, we might have achieved clearer results, particularly for service users and carers, if we had asked participants in Round 3: 'Pick your top 5 (or 10) items and place them in order of importance'. On the other hand, had carers and service users felt unable or unwilling to do this, they may have disengaged from the process and failed to complete the exercise. Alternatively, using a 7- or 9-point scale might have encouraged a better spread of ratings, particularly in the carer and service user groups.

A further limitation is that some highly rated items are clearly specific to our local context, such as 'Challenges facing rural mental health services'.

### Implications

It is a mistake to assume either that all stakeholder groups have the same views or that they are able to express them through the same formal process. The commitment that carers and service users made to the study shows a genuine hunger for involvement, but the difficulty they had in making priority decisions suggests that they may need assistance if they are to make a meaningful contribution to future consultation exercises.

Our findings suggest that mental health services research can be built on solid partnerships between stakeholder groups with different knowledge and skills but common values. While members of professional and academic health disciplines may still be best placed to detect gaps

in the evidence base underpinning their practice, the 'privilege of experience'<sup>30</sup> equips service users and carers uniquely to highlight areas of potential need, and both they and managers play a key role in ensuring that research can be translated into better services and thus bring direct benefit to those who use them.

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### Supporting information

Additional Supporting Information may be found in the online version of this article:

**Table S3a.** Carers' top priorities

**Table S3b.** Service users' top priorities

**Table S3c.** Health practitioners' top priorities

**Table S3d.** Managers' top priorities

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