

# In Our Experience

USER-FOCUSED MONITORING OF  
MENTAL HEALTH SERVICES  
in Kensington & Chelsea and  
Westminster Health Authority

By Diana Rose, Richard Ford, Peter Lindley,  
Libby Gawith & The KCW Mental Health  
Monitoring Users' Group

© The Sainsbury Centre for Mental Health 1998

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photo-copying, recording or otherwise without the prior permission of the publisher.

ISBN: 1 870480 34 1

Published by

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

0171 403 8790



# Contents

	Summary	3
<b>1</b>	Introduction	5
<b>2</b>	Methods	7
<b>3</b>	Results I - Knowledge of Mental Health Services, Involvement & Satisfaction	11
<b>4</b>	Results II - CPA & Quality Care	15
<b>5</b>	Results III - The Wider Community	17
<b>6</b>	Results IV - Qualitative Analysis	19
<b>7</b>	Vignettes - The Interviewees	21
<b>8</b>	Discussion	25
<b>9</b>	Conclusions	29
<b>10</b>	The View from the Inside - The Interviewers	31
<b>11</b>	Bibliography	35



# Summary

The ground-breaking project reported here represents a partnership between Kensington & Chelsea and Westminster Health Authority (KCW) and The Sainsbury Centre for Mental Health. It demonstrates that people with severe and enduring mental illness can have a voice in decisions about the mental health services they receive. It further shows that people with mental health problems can, with appropriate training and support, elicit the views of others with severe mental health problems. This report describes a set of interviews with 58 randomly selected mental health service users with severe and enduring mental health problems. The users were interviewed about their knowledge of the services available, their satisfaction with services and different mental health professionals, and their perceptions of the gaps in services. The interviews were carried out by 8 other local service users. The interviewers were trained and supported throughout this work. This project has developed user-focused monitoring as a method. A great deal of feedback has been received and we have assurances that services will change in line with the users' views expressed in this project.





# 1 Introduction

This report describes a set of interviews with people with severe and enduring mental health problems. The interviews aimed to find out their views on, and satisfaction with, the services they receive. The interviews are part of a wider user-focused monitoring project which was commissioned in 1996 by Kensington & Chelsea and Westminster Health Authority (KCW HA). The Sainsbury Centre for Mental Health has been carrying out user-focused monitoring in KCW over the past eighteen months.

The Centre now plans to disseminate and extend this approach and this report represents the first step in this process. Although focusing on the work done in Kensington & Chelsea and Westminster Health Authority, we believe the report has lessons for widening the scope of user-focused monitoring in the UK.

In the project, we sought to involve local users both as evaluators and as interviewees. In order to achieve this, a user group from KCW was convened. The group numbers 12, meets monthly and has been trained to carry out interviews and site visits. The group has now accomplished 58 interviews with a group of users perceived as the most vulnerable in KCW. The purpose of this report is to describe the process and results of users interviewing users. The project co-ordinator is likewise a service user.

A word needs to be said about some common images in society of mental health service users, particularly of those with the most serious difficulties. These images tend to be negative and stress dangerousness and mental incapacity (DoH, 1996). It is not readily appreciated that mental illness does not preclude a rational, balanced view about issues such as the services that are on offer and their acceptability to those who use them. We took as our starting point the view that interviews with people with serious and enduring mental health problems can give rise to fruitful and valid findings which have implications for policy.

Goffman (1963) was the first to suggest that a psychiatric diagnosis is a 'master status' in that it swamps any other aspects of the person with the diagnosis. The diagnosis comes to define them, to be perceived as the whole of what they are. If it can be difficult to see that users of mental health services are *people* first and foremost, it may be equally difficult to accept that users of psychiatric

services can play a central part in service evaluation, by taking the role of interviewers and site visitors. Although, this is common in some parts of North America, (Campbell, 1989) it is unusual in the UK (see Beeforth *et al.*, 1994; Rose, 1996).

We were given many warnings about the consequences of users interviewing users but were confident that the process and its results would lead to many lessons being learned. We hope this report achieves its aim of demonstrating that training users of mental health services to interview other users is a valid path to follow and that the project described here will encourage more user-focused evaluation by others.



# 2 Methods

## Sampling

Random sampling was used to select interviewees. The population consisted of all those on the top tier of the CPA in the three Trusts in KCW (1,000 users). Two hundred were randomly sampled using the statistical package SPSS.

There were difficulties with the database. Fifty-five of the sample were not known to the Trusts, had been discharged, lost contact or died. This left a sample of 145.

The selected group was contacted via their keyworkers. These were sent a letter describing the project with a letter enclosed for the selected users. By the completion of the interviewing, 36 users had not been contacted because of insufficient liaison with their keyworkers. This left a sample of 109.

There was a high refusal rate. Of those who were successfully contacted, 51 refused and 58 accepted. Two things can be said about the refusals. First, in working with the most seriously disabled people, there is likely to be low motivation. We offered a £5.00 payment, but mental health professionals did say that users were 'over researched'. The second point is that users may not have been clear about what was being asked of them. Nearly all the refusals came via keyworkers, as indeed, did the acceptances.

Why randomly sample? Our intention was not to do large amounts of inferential statistics, for which we would need the backing of a random sample. Rather, we considered this to be the best way of contacting people who would not be reached by other methods. That is, the aim was to include users who were isolated and would not have been included had we approached people at services such as day centres, which the isolated group do not attend, or by 'snowballing' which requires at least a minimal social network.

Finally, we compared those who were interviewed with those who refused for Parkside and North West London Mental Health Trusts (the numbers were too small to warrant this for Riverside). There were no significant differences between the participants and the refusers on demographic characteristics, on how well the top tier of the CPA was implemented, or risk and vulnerability

profiles. So, it can be argued that there is no distinguishing feature that marks off those who refused from those who were interviewed.

## **The Interview**

We used a semi-structured interview schedule aiming to cover users' knowledge about mental health services, their levels of satisfaction with services and different mental health professionals and their perception of gaps in services. Some of the questions were forced-choice or scales and some were open-ended. The interview schedule took between forty minutes and one and a half hours to complete.

This interview focuses on community mental health services. It was initially drafted by the Quality Assurance Team at The Sainsbury Centre. The schedule then went through three drafts in the process of which the user group adapted it to suit the local circumstances of an inner city, multi-cultural locality like KCW. The schedule was extensively discussed by the group who thereby gained some 'ownership' of it. We would anticipate that further use of the schedule would likewise require it to be customised to local circumstances.

The final draft was completed after each member of the user group had done a pilot interview. Most of the pilot interviews were conducted at a drop-in centre in South London, but four took place in a work project in KCW.

## **The Interviewers**

The KCW Mental Health Monitoring Project centrally includes a group of twelve people who use, or have in the past used, mental health services in KCW. The group was convened by explaining the project at local user group meetings and at local services, and asking for volunteers. Two of the 12 were contacted by word of mouth.

In the case of the KCW group, half are on the top tier of the CPA in one of the three Trusts from which the Authority purchases services. Whilst some are active in local user groups, they are mostly regular users of services with a wide knowledge of what it is like to be a mental health service user in the Authority. We believe that user-focused monitoring should involve ordinary service users and not only the most vociferous and articulate.

This KCW group has been meeting monthly since October 1996. They have been introduced to the ideas of monitoring and evaluation and trained in interviewing and site visiting skills. The interview training was centred on role play using the schedule finally employed and one other which was used to



interview staff in The Sainsbury Centre. This was to enable the user interviewers to get used to interviewing strangers.

Between May 1997 and September 1997 eight of the users conducted interviews with those selected. For varied reasons, four of the twelve did not carry out any interviews, though they did do a pilot interview.

Using 8 interviewers raises issues of inter-rater reliability. Each of the interviewers was accompanied once by a member of staff from The Sainsbury Centre. Moreover, it was always clear from the interview protocols who the interviewer had been. We arranged debriefing sessions and the interviews were discussed by the group at their monthly meetings. Taking these points into account, our judgement is that all but one of the interviewers were consistent in their approach to the task.

## The Group Interviewed

As stated earlier, 58 people were interviewed. They were selected from the top tier of the CPA and so we would expect them to have a high level of psychological and social disability. Table 1 below shows the demographic and social characteristics of the group.

**Table 1 : The characteristics of the group of users of the CPA top tier interviewed for the KCW Mental Health Monitoring.**

<b>Feature of the Group (N=58)</b>	
Age (mean in years)	42.7 yrs
Gender - percent male	64%
Black or ethnic minority group - percent	62%
Inpatient in last year - percent	64%
Current inpatient or living in hostel	44%
Contact with police because of mental health problem	73%
No. of years using mental health services - mean	11.3 yrs

Table 1 shows demographic characteristics in line with those described by Johnson *et al.* (1997) for the most deprived client group who make use of mental health services in the inner city. 64% had been an inpatient in the previous twelve months and 73% had contact with the police because of their

mental health problem. The voices of this most disabled group are rarely heard. This report attempts to remedy this.

There are three Trusts in KCW. We ran a range of statistical comparisons on variables such as demography, service use and levels of satisfaction with services. No differences were found between the users of the Trusts in these comparisons. The report therefore presents findings for the total group of 58.



# 3 Results I:

## Knowledge of Mental Health Services, Involvement & Satisfaction

All the people interviewed were on the top tier of the CPA, had a care plan and a keyworker. They would also be expected to know who to contact in times of crisis. Table 2 shows the proportions who did know about these features of their care and those who said they did not. It also shows the proportion who were unsure about whether or not they were receiving the care.

**Table 2: Users' knowledge of key elements of mental health services in KCW.**

	% know	% do not know	% not sure
Keyworker	57	33	9
Care Plan	35	41	23
CPA	39	57	4
CPA Review	16	82	2
Out of hours	38	27	38
Crisis contact	51	27	22

The level of knowledge about key services and personnel is patchy. We had contacted the users via their keyworkers but little over half knew that the person in question was their keyworker. It is of particular concern that only 51% of the group knew who to contact in times of crisis. There was a high level of uncertainty about whether psychiatric help could be received quickly and about the existence of out of hours services.

It might be said that users don't need to know terms such as 'keyworker' or 'CPA' and that they may receive a quality service without being familiar with this terminology. However, this argument can be a little patronising and care will probably be more clearly organised if users and workers speak the same language.

The question about crisis care was phrased in everyday language - 'can you get help quickly when you need it?' Some users showed us actual telephone numbers whereby they could get this type of help, but these were unusual. CPA top tier users should certainly know about crisis care, but just under half the group did not know or were unsure whether this type of help existed for them. This is particularly worrying when two thirds of the group had used inpatient facilities in the previous twelve months (see Table 1).

## Satisfaction with mental health professionals

Users were asked about their level of satisfaction with the mental health professionals involved in their care. Table 3 shows the percentages who were satisfied, who were neutral and who were not satisfied. The N column shows the number in touch with each service. Three services were received by less than 10% of the group and so are not shown in the Table because the numbers are too small to make sense. They are: OT, psychology and community support work. This, in itself, is a finding.

**Table 3: Satisfaction with a range of mental health professionals.**

Profession	N	% satisfied	% neutral	% not satisfied
Keyworker	31	64	24	12
Consultant	46	41	35	24
Junior Doctor	15	20	60	20
Social Worker	35	63	20	17
CPN	32	78	9	12
All professions	57	36	49	14

It has been argued (Elbeck and Fecteau, 1990) that user satisfaction surveys in the field of mental health tend to elicit unrealistically high levels of satisfaction on the part of those surveyed. We will take this up in the discussion but for the moment it can be noted that whilst general satisfaction rates are favourable, the group did discriminate between different professions. Moreover, asked about mental health professionals as a whole, only 36% said they were satisfied. The majority were, in fact, neutral about the help they received from mental health professionals.

## Needs Assessment and Treatment

The interviewees were asked if they thought their needs had been fully assessed. 66% said they did, 27% did not think their needs had been fully assessed and 7% were unsure. A further question asked people whether they thought their strengths and abilities had been taken into account in the needs assessment as well as their problems. 36% considered that mental health professionals took their strengths into account. 54% said they thought only their problems were considered and 10% were not sure.

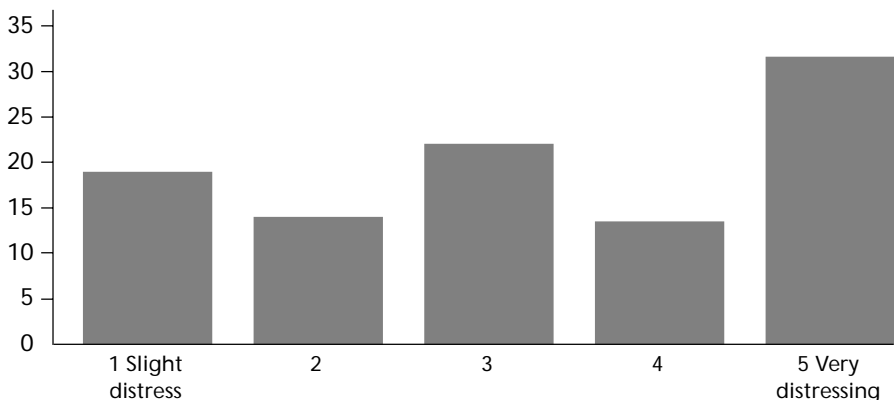
We asked how long the person had to wait for their first appointment. While 49% said they were seen 'almost straight away' a further 29% said they had to wait 'too long'.

The major treatment used by the group was medication. Only 1 person was not on some form of psychotropic medication. 35% said they were given a choice as to how to take their medication. This is a low figure but, at the same time, 79% of those who had an injection were happy with the way it was given in terms of respect and sensitivity.

68% of the group thought the medication helped but there was also a good deal of worry about side effects. 70% reported having side effects from the medication and 60% said they were not given enough information about this.

We asked those who experienced side effects to rate the level of problem caused on a scale of 1-5. Figure 1 shows the percentages endorsing the different levels of distress. In addition, 22 people (38%) rated themselves as overmedicated.

**Figure 1: Percent of users endorsing levels of distress (from 1-5) associated with the side effects of medication.**



In the interviews, discussions of psychotropic drugs were not limited to the specific questions on medication. We will take this up later but, at this point, will present some figures for treatments which are an alternative to, or complement for, medication.

It has already been seen that OT and psychology services were used by a very small proportion of the group. We asked the interviewees whether they had enough access to talking therapies. Table 4 shows the results.


**Table 4: Opinions about access to talking therapies.**

	<b>% endorsing</b>
Enough access to talking therapies	30%
Not enough access to talking therapies	51%
Don't want talking therapies	19%

Table 4 shows that over half the sample thought they had insufficient access to talking therapies. As we shall see later, many users talked throughout the interview about their desire for talking treatments.

## **Involvement**

It is becoming accepted amongst some psychiatric professionals that users should be involved with setting up the arrangements for their care and treatment. The interview included some questions about involvement in this way. The results showed that there is a very low level of perceived user involvement in this group. As we have seen, the majority thought their strengths and abilities were not taken into account when designing care. They felt that the focus was solely on their problems. Consistent with this, a minority (21%) said they had been involved in drawing up their care plan and nobody considered that they were involved in the CPA review process.



# 4 Results II:

## CPA & Quality Care

These interviews are part of a monitoring process which also includes a detailed and regular look at the operation of the Care Programme Approach in KCW. The CPA is the government's recommendation for the organisation of care in mental health services. The CPA includes needs assessment, having a keyworker, having regular contact with relevant professionals, having a care plan and regular reviews. Given this concern, we were interested to know whether the users felt they had all the elements and whether knowledge about CPA was associated with better care.

Firstly, we looked at the different elements of the CPA to see whether if one element was present in the user's opinion, the others were too. This was not, on the whole, the case.

If a user was aware of the CPA process then they were significantly more likely to know about their next CPA review. However, there was no relationship between knowing about CPA and knowing that there is an allocated keyworker or a care plan or thinking one's needs had been properly assessed.

This supports what was said before about patchy knowledge of services. There is a great deal of confusion on the part of this group about how their care is being managed. There are two possible reasons for this. The most likely is that CPA is new to most Trusts in KCW and that it is still not fully implemented. For instance, users' confusion about who is their keyworker is reflected in the varied use of this term in services. Nurses in hospital wards are sometimes called 'keyworker' but are unlikely to be the CPA keyworker. The same goes for workers in other services such as day hospitals and hostels. When services use terminology in a variable way, it is little wonder that users are unclear.

The other possibility is that the Care Programme Approach is just a paper exercise and, even when properly implemented, does not provide a coherent framework for care, at least from the users' perspective.

In this connection, we looked next to see if having a keyworker or being aware of CPA was related to other aspects of the service. The variables chosen here were satisfaction with mental health professionals as a group, feeling that strengths and abilities count as much as problems and thinking that mental

health services were an aid to progress. None of these relationships approached statistical significance. Once again this could be due to poor implementation of CPA or it may reflect on the usefulness of the CPA as such.

Access to talking therapies was associated with overall satisfaction with mental health professionals and, satisfaction with needs assessment was also related to access to talking therapies. Believing one has sufficient access to talking therapies therefore has stronger links with other satisfaction variables than is the case for CPA.

Talking therapies and medication are not alternatives in the view of those studied. They appear to be separate forms of treatment and can as easily be complementary as alternatives. Nonetheless, feeling overmedicated is associated with low levels of satisfaction with mental health professionals and with how far the user thinks that staff help him or her progress.





# 5 Results III:

## The Wider Community

People on the top tier of the CPA receive social as well as medical help. They are also members of the wider community.

People often receive help with both benefits and housing. We asked the users whether they had ever received such help and how satisfied they were with their current situation.

**Table 5: Percentage satisfaction levels with housing and finance.**

	<b>N</b>	<b>Satisfied</b>	<b>Neutral</b>	<b>Dissatisfied</b>
Housing	38	22%	48%	30%
Finance	43	51%	35%	14%

It is clear that users who use these services are happier with the help they receive with their finances than with their housing. As shown in the next section, housing problems appeared often in the open-ended questions.

Nearly half the sample (48%) knew about local work projects such as St Mary's Abbott Rehabilitation Team (SMART), Many Hands and Birthday Bakers. However, only 9 people actually used these projects. In addition, two people had full-time jobs. This means that 47 of the 58 were completely outside the labour market.


We asked the users if they felt safe in the community. This question about safety and threats to safety was asked separately about other users, staff, neighbours and the public generally. Table 6 shows the results.

**Table 6: Perceived safety with different groups in the KCW sample.**

	<b>Feels safe</b>	<b>Feels unsafe</b>
Other users	60%	40%
Staff	71%	29%
Neighbours	68%	32%
General public	63%	37%

Although the proportions of people perceived as threatening are fairly evenly distributed between the groups, this is not because one third of the sample perceived *everybody* as a threat. On many occasions, users selected only one or two groups as unsafe. It is nevertheless worrying that between 30% and 40% of the sample find aspects of their environment to be unsafe for them.

The final community group investigated was the police. As already stated, 73% of the sample had come into contact with the police as a result of their mental health problem. Of these, 56% felt the police were disrespectful and 46% thought that too much force had been used. Less than half of this group (42%) found the police helpful (cf Rose, 1996).



# 6 Results IV:

## Qualitative Analysis

The interview schedule had space for comments and suggestions appended to each set of formal questions. These suggestions were coded using a form of content analysis (Jovchelovitch, 1995). Four themes were identified as the main concern of the group of users. One was the issue of access to talking therapies, discussed above. A significant number of people mentioned this throughout their interview and others mentioned it once or twice. However, care is needed in using the term 'talking therapies'. Whilst some interviewees specifically mentioned psychotherapy or counselling, for others it appeared that formal talking therapy was not the point. What the user wanted was someone to talk to. In other words, there was a sense of isolation and desire for social contact.

A second theme has also been discussed already and this is the issue of overmedication. There were users who made this the focal point of the interview and often were very distressed about side effects. In respect to this, several said that they simply weren't listened to when complaining about the unwanted effects from psychotropic medication. Nevertheless, distressing side effects did not prevent the user from agreeing that there was some benefit from the medication.

Another prominent theme was housing. Many people, including some living in hostels, were very unhappy with their housing arrangements. They also felt that they were given insufficient help in improving their housing. Again, housing was critical for people in acute wards with no fixed address. There were four people in the sample who had been in hospital for more than a year and had no address to move on to. The housing problems ranged from physically inadequate housing (damp, no heating, no cooker) to trouble with neighbours. There were three younger people in the sample living with their parents who said this was not their choice.

Finally, a small number of users (n=7) felt completely let down by services. They painted a picture of being abandoned by mental health professionals (and society) and said no-one ever visited, or if they did it was for a matter of minutes. These are people in a position which is opposite to the usual concern about mental health service users. They were not 'hard to engage', they wanted to engage with services, but felt neglected.





# 7 Vignettes

## The Interviewees

(Names and some details have been altered.)

**Mr Rehman is a 43 year old man living in a bedsit in North London. He says the doctors have told him he has paranoid schizophrenia but the thing that bothers him most is his agoraphobia. We approached Mr Rehman through his keyworker, but he himself is unclear who his keyworker is. He gets most support from a Flexicarer from the local MIND. He did name his keyworker as the person to contact if he was in trouble, but he said this usually happened at night so he phoned the out of hours team. Mr Rehman has a social worker whom he finds very helpful. He has never heard of CPA or Care Management but when it was described to him he said yes, he had had a meeting like that, but couldn't go because of his agoraphobia. His sister went instead. He didn't know the outcome, didn't have a copy of his care plan, didn't know when the next meeting was planned or that he could be involved in organising it. He feels his sister has to do far too much for him. She is not well, herself. Mr Rehman wanted the doctor to come and visit him at home because he couldn't go out on account of his agoraphobia. He said he wasn't worried when people came to him. The meeting could come to him, he said, rather than take place without him. He said, too, that he would like his medication reduced. However, Mr Rehman stressed that he had few complaints about the services he receives.**

Linda Moore is 30 years old and lives in a hostel for people with mental health problems. She would like to be more independent but has been told she isn't well enough. She had her first breakdown, diagnosed as schizophrenia, at the age of 18. She frequently has spells in hospital which she finds not in the least therapeutic. Linda says the nurses have as little to do with the patients as possible and that the atmosphere is rather frightening. She gets on well with her keyworker at the hostel, although this caused us confusion in the interview because she does not know who is responsible for organising her care and how many 'keyworkers' she has. She does not know what CPA is and does not recognise it when described to her. She says the hostel is friendly enough and she does not feel isolated. She had not heard of any of the work projects in KCW but would welcome the opportunity to do something constructive with her time.


Jerome Kahn, who is 38, was interviewed in an acute inpatient unit. He has been there for a year and is trying to move out. He has been staying some nights at a hostel for a trial period but the journey is onerous. He thinks he might be getting institutionalised but he is aware of how his care is being organised. He knows when his next CPA review is to be. Mr Kahn would like to meet a girlfriend and settle down. He wants to go to college but has trouble concentrating. He has been told that this is because of his mood swings but he thinks it is not helped by the tablets he takes. He thinks the hospital has helped him but that he could have been discharged months ago had he a flat to go to.

Mary Gray is 58 and had her first breakdown two years ago. It took her completely by surprise and she is very distressed that she has a psychiatric condition. Her children are embarrassed, she says. She had to spend four months in hospital and, although she thought the staff were kind, she didn't like the regimentation at her age. She found the other patients helpful. She is not sure if she has a keyworker but says a CPN visits her every fortnight for an hour. She really can't be bothered with it but is afraid of breaking down again and needing help in the future. Her biggest disappointment in herself was that she had to be brought to the hospital by the police. She says they were disrespectful, used too much force and frightened her. She said she felt treated like an animal. She thinks psychiatric services have been 'somewhat helpful' to her but she would really rather forget the whole thing.

Jonathan Watson is one of the two people we interviewed in full-time work. He is 27 years old and a musician. He had been in hospital earlier in the year but since he does contract work he did not lose everything, as he had feared. He thinks his consultant is absolutely marvellous and his CPN is pretty good too. When asked if he had a keyworker he was a bit puzzled and said he had a 'key nurse' on the acute unit but didn't know if he had a keyworker now. He recognised CPA when it was described to him and said he had signed a paper that was probably a care plan but he hadn't really read it thoroughly. He didn't have a copy and did not know when his next CPA review would be. He knew how to get help in a crisis and was confident the consultant would do what was best if things went wrong again. He lives with his parents and thinks his mother worries about him too much.







# 8 Discussion

It is clear from most of the schedules that the user interviewers were successful in engaging the interviewees in discussion and eliciting thoughtful responses. It is also clear that some of the interviewees were very psychologically distressed. One form was peppered with comments about the user's relationship to Princess Diana, and another expressed fear that the interviewee was fatally damaged. One man said he was going to commit suicide there and then. These were not the majority, but even with these distressed users the questions about services and satisfaction with mental health professionals were responded to quite coherently. There was only one occasion when an interviewer returned the form with the comment 'I think some of this was her imagination'. We conclude that the most psychiatrically and socially disabled users can give clear responses to an interview such as the one used here.

## **The Process**

We learned as much from the process of setting up and carrying out these interviews as we did from the results. The interviewees were contacted via their keyworkers. Some keyworkers were enthusiastic about the project and the idea of user-focused monitoring from the outset. We tended to interview most of the clients selected for these keyworkers. However, others were ambivalent about the whole exercise. There was worry about confidentiality and the belief that users would not be able to sustain confidentiality about other users. Some keyworkers were quite frank that they feared criticisms. Others were simply too busy to make the monitoring a priority and were lukewarm about its importance. On two occasions we were told that users' views about services would be invalidated by their psychopathology. For these two keyworkers, criticism of services is a symptom of mental illness.

From this experience, we draw several conclusions. First, that it is important to get front line staff on board with a project like this from the start. We had a committed purchaser and mostly committed managers but were remiss in selling the project and the idea of user-focused monitoring to keyworkers. We did not anticipate the level of ambivalence about users interviewing users. It is apparent that communication channels need to be clear and information thorough.

Secondly, this ambivalence raises questions about the refusal rate reported earlier. Whilst not wishing to impugn anyone's professional integrity, we remain unconvinced that all the users who refused were given complete information about what was expected of them. Some of the keyworkers definitely encouraged their clients to participate and we would probably have had a higher participation rate if more had done this.

Finally, from this experience we draw the conclusion that user-focused monitoring can sometimes pose a threat. It questions many of the assumptions about mental health service users that underpin theories about mental illness. It can also lead to fear of unjust criticism for these same reasons. We hope that this report shows that user-focused monitoring can deliver important views about services and those who work in them and that the findings presented here are not a total surprise to professionals.

In connection with the above, it has been argued by Elbeck and Fecteau (1990) that user satisfaction measures in the psychiatric field have a bias towards *positive* findings rather than the negative ones anticipated by some of the keyworkers. They believe this is due to the questionnaire or interview as a method which does not encourage critical reflection. They propose that focus groups would be a preferable method.

It is not possible to compare this study directly with others since different questionnaires were used. However, we would argue that our method did elicit varied responses, a mixture of both positive and negative. There may be two reasons for this. First, the interview contained qualitative as well as quantitative questions. The content analysis both supported and added to the findings from the forced-choice questions and scales. Second, we would argue that having users interview other users is conducive to an open and relaxed atmosphere. Another service user is independent and would not, for example, be perceived as having the power to alter the services a person receives should they voice criticism. A professional might deter an interviewee from being open about their views of services.

Throughout this report, the interviews have been described in some detail. It must be pointed out that, from some perspectives, what we have done constitutes a violation of the basic principles of the interview as a method. In particular, the objectivity of the interview was compromised by such features as sharing experience of the mental health system and tolerating long digressions that sometimes parted with reality.

This assumes that an interview *can be* objective and transparent. Writers from Cicourel (1964) to Silverman (1993) have questioned this and argued that the subjectivity of the interviewer always affects the results. Administering an

interview is not like taking someone's temperature because human beings are reactive and reflective. The consequence of this is that the researcher should be quite clear about these subjective features and build them in to any discussion of results. We believe we have been true to this perspective.

## Results

The results showed that the users interviewed were very happy with some aspects of the services they received. Keyworkers, CPNs and Social Workers were well liked and thought to be helpful. Medication was perceived as helpful by the majority of the group even while they were very concerned about side effects. This is interesting because people who use mental health services are often seen as reluctant to take their medication. The majority of this group experienced distressing side effects but at the same time persevered with the drugs because they gave at least some benefit.

Users were ambivalent about consultants and junior doctors, with some perceiving their consultants as a life line whilst others thought they simply didn't care as long as the person turned up for their regulation ten minutes every three months. Some people said they were dissatisfied with their consultant because they didn't see them often enough or for long enough. One consultant who visited people at home was appreciated, as was one who was always accessible on the phone in working hours.

Nearly half the sample did not feel they could get help quickly in times of crisis. People told of delays in seeing a professional when they were in trouble which made matters worse. Forty per cent of the sample said there were no evening and weekend services or that they were not sure about this.

There are issues about choice which also need to be mentioned. On the whole, people did not feel they could change workers they did not get on with or feel able to complain. 64% said mental health workers only focused on their problems and took no account of their strengths and abilities.

As stated in the results' section, knowledge of what is available is patchy in KCW. In terms of the key elements of the CPA, we know that all the people we interviewed are on record as having a full needs assessment, a care plan, a keyworker and regular reviews. However, the general picture is that the users themselves did not know this. Moreover, the different elements did not form a pattern. For instance, knowing the name of your keyworker was not associated with knowing that you had a care plan.

It has been suggested by people whom we have informed of these results that lack of knowledge of the key elements of the CPA is entirely unsurprising. They

would not expect users to know about this. We believe a basic shared vocabulary would be helpful in clarifying for users how their care is organised and by whom.

Knowledge of the different elements of the CPA is not associated with higher satisfaction levels on services overall. As we have said, this is partly because of gaps in knowledge and may also have to do with the CPA not being fully implemented in some sites. For example, the term 'keyworker' is used to refer to a number of different roles. It may also be that, even when fully implemented, CPA has little impact on users' perception of the quality of their care. CPA may have other purposes, of course, such as keeping in touch with those on the top tier.

We did find one variable that seemed to be associated with perceived quality of care. This variable is 'access to talking therapies'. We cannot make statements about causality. It may be that people who used talking therapies were pleased with their needs assessment because it was conducted by a talking therapist. Nonetheless, the issue came up throughout many interviews and some users definitely thought the answer to their problems lay with psychotherapy or counselling. As we have said, for others it appeared to be a question of having or not having someone to talk to, not formally, but as ordinary human interaction. It can be mentioned, finally, that over half the sample thanked the interviewer for the opportunity to have their say and have a conversation with someone who was clearly interested in them.



# 9 Conclusions

We conclude that users can be successfully interviewed by other users who have been trained to do this. We argue that, in fact, the user interviewers elicit more open and honest responses than professionals do. We conclude, also, that users with severe mental health problems and social difficulties are able to communicate in an open way their opinions about the services they receive. We suggest that the approach developed in KCW can provide a model for user-focused monitoring more generally.

There is a good deal of gratitude and positive attitudes towards mental health services on the part of those interviewed in KCW. But the group were not afraid to say where they thought the gaps were. Talking therapies, someone to talk to, overmedication and lack of information about medication, housing difficulties and lack of choice, all appeared as less than adequate from the point of view of the group. We have an assurance that the findings of this survey will lead to changes in some of the services that are provided to users of the top tier of the CPA in KCW. For instance, it does not take much to inform someone about why they are experiencing side effects from medication, or to take the time to talk to those people who feel abandoned. Certainly many of the people we interviewed said the reason they were willing to participate was because they hoped it would change things for the better.

The Government's recent NHS White Paper makes monitoring and quality improvement a central role for Health Authorities. Consumer involvement in this monitoring is also proposed. Mental health service users have not always been judged to be as competent as consumers of more general medical services. However, we believe this report shows that it is feasible and productive to extend user-focused monitoring to all aspects of mental health services.

## **Dissemination**

In order to make the findings in this report widely available in KCW, feedback meetings have been held with staff at all levels. The feedback meetings take the form of a presentation by the co-ordinator, a contribution from a member of the user group and discussion with those present. The audiences have ranged from the staff and users of a day hospital to senior management and

medical staff in a Trust. A lunch event was also organised for all the keyworkers who had been involved in setting up the interviews and this was very well attended.

The object of these feedback sessions is to strengthen commitment to user involvement and to changing services in line with users' wishes. We have received assurances at the highest level that this is being taken seriously.

Finally, this report is part of a process of disseminating widely the model of user-focused monitoring developed in partnership with KCW HA and the associated Trusts. To this end, The Sainsbury Centre for Mental Health has increased the level of staffing on this work. We have shown that user-focused monitoring is not only feasible, but highly productive. We intend to disseminate this work nationally and will ask for a philosophical and financial commitment from agencies to make sure that user-focused monitoring is taken seriously and will make a real difference to service delivery.



# 10 The View from the Inside - The Interviewers

Below, we print first-hand accounts of the process involved in doing these interviews, from the perspective of those who designed the questionnaire and carried out the interviews. First names only are given because there is still a social problem about being identified as a mental health service user.

## **Hilary:**

'We were contacted through various work projects and day centres, etc., and were assembled in a smart shiny office block in London's City area, spoken to with Peter's American enthusiasm and Diana's quiet, knowing sincerity. We were given a tasty lunch of city sandwiches, fresh fruit and coffee.

'Each month we met, became acquainted with each other, all very different people, all with one thing in common: we had been patients in hospital. Sometimes there was friction, a rush to compete with memories fraught with emotion; at other times we joked sharing private but communal anecdotes.

'We role played; practised interviewing and gradually the questionnaire evolved, was discussed, altered and finally agreed upon. Then we ate sandwiches, fresh fruit and drank coffee.

'Interviewing "proper" began. Could I remember where I was from and why I was asking so many personal questions? Would I be listened to and get answers? Would we both last out?

'I entered various establishments - a posh hospital in Roehampton; a lonely, shabby hostel room; shiny hospital units and a depressing social service complex.

'I was greeted by staff sometimes with genuine warmth but more often with arm's length indifference, politeness or dubious respect.

'Most interviewed were at first cautious, wary of the questions but upon admitting that I too had been a patient and all was confidential, were glad to talk freely, to give accounts of experiences - both good and bad.

'They answered, suggesting improvements and changes; also expressing

gratitude to those who had been good to them. From some rushed a torrent of feeling, emotion and ideas; others were more reserved, cagey and cautious; but all finished the questionnaire.

'The interview over, compensation of £5 paid and for most surprise at how enjoyable it had turned out to be; surprised that they might even have a say in their own futures; and relief too for unloading a big chunk of their life.

'Each month we met, giving accounts of how they went - or not as the case may have been. And some were returned to.

'They had been a challenge, sometimes demanding, always fatiguing; sometimes funny or sad often giving rise to my own forgotten emotional memories. But I always found them rewarding and worthwhile. And again there was the tasty city sandwiches, fresh fruit and coffee.

'Many thanks to the group and especially to Diana and Peter for their insight and encouragement; and let's hope that some good will come out of all the time and effort that went into gaining this information.'

**Pat:**

'I had a breakdown nearly four years ago after depression. I made a full recovery, with the help I received at the Gordon Hospital - for which I will always be grateful.

'I had never interviewed anyone before so, despite the interesting and enjoyable workshops we had at The Sainsbury Centre, I must admit I felt a little apprehensive. I need not have done. I found the work interesting and rewarding. I was surprised at how keen the service users I saw were to help to do something that would improve the mental health service. I did 7 interviews, each person being very different - from a young man in his early 20s who wanted desperately to return to a normal life and the chance to work, to a lady in her middle-50s who, through a breakdown, had lost her occupation, having had it for 20-odd years. Her only ambition was to get a flat where she could be happy.

'The result of doing the interviews is that I feel confident that this survey will provide valuable information and give the service user a better quality of life.'



**Chris:**

'My name is Chris. When I heard about the project, I was delighted.

At last some questions could be answered:

- Why so many patients remain patients for so long?
- How come they are constantly being re-admitted?
- Few drugs actually cure. What does?

Group therapy has worked for me and one-to-one.

Even though I have few living skills, I've succeeded at last in staying out of hospital. So therapy as opposed to drugs seems to be the answer.'

**Susan:**

'When Dr Diana Rose came to SMART to recruit members to take part in The Sainsbury Centre's Survey I was rather unsure about the prospect of interviewing fellow users. I have suffered from a manic depressive illness for many years and was aware of the problems that might arise if the person I was interviewing was high or deluded, but I decided to go along to the first training session and meeting at The Sainsbury Centre in Southwark to see what it was all about. As we went on the group of fellow users became more and more committed to each other and the project in a way that I would not have thought possible at the outset.

'When the time came for me to do my first interview, Diana Rose came with me as the young man had requested to be interviewed at home. I remember feeling very apprehensive as we made our way there and not at all sure of myself or if I would be able to complete much of the questionnaire. I need not have worried, we stepped into a beautifully kept and furnished flat and the young man, although severely obsessional and deluded in some ways made us very welcome and made cups of tea. He was delighted to talk about his illness to a fellow user. It was quite an inspiration for us to meet him as with the help of his CPN he was able to run his flat and his life in a way that would not have been thought possible a few years ago.

'I was very fortunate as my interviewees - though all quite different - were very nice people. All seemed pleased to talk to a fellow user whom they could easily relate to and share experiences with, and where they were able to relax and speak out. This was particularly the case regarding the embarrassing topic of treatment by the police when ill and most complained of unnecessary force being used and rough treatment. This was particularly sad in the cases of three

quite slightly built women, two of whom had been held down and handcuffed when there were several officers present to restrain them, if necessary.

'Most people were very grateful for the support given by their CPNs and keyworkers though there was confusion about the Care Programme Approach and exactly what it meant, and the roles that different workers played, and who they should approach in a crisis.

'I would like to close by relating the case of one man who also impressed me with the way he was coping with his life and illness. He was full of praise for everyone on his multi-disciplinary team. He had suffered from paranoid schizophrenia for many years - often hearing voices which he thought came from space-ships and shutting himself away. But with the help of his psychiatrist and the current medication, he was now able to live a normal life in a flat with the support of his family and ethnic community. He was full of praise for the social service team, for their on-going support, because they were always there to help and advise when he needed them.

'I found that doing the interviews was a worthwhile and confidence building experience for me and I am so glad that I decided to stay with the team and take part in this.'



# 11 Bibliography

Beeforth, M., Conlan, E., Graley, R. (1994) *Have We Got Views For You: User Evaluation of Case Management*. London: The Sainsbury Centre for Mental Health.

Campbell, J. (1989) *The Well-Being Project: Mental Health Clients Speak for Themselves*. California Department of Mental Health.

Cicourel, A. (1964) *Method and Measurement in Sociology*. New York: Free Press.

Department of Health (1996) *Attitudes to Mental Illness: Summary Report*. London: DoH.

Elbeck, M., Fecteau, G. (1990) Improving the validity of measures of patient satisfaction with psychiatric care and treatment. *Hospital and Community Psychiatry*, 41, (9) 999-1002.

Goffman, E. (1963) *Stigma*. Harmondsworth: Penguin.

Johnson et al. (1997) *London's Mental Health*. London: The King's Fund.

Jovchelovitch, S. (1995) *Social Representations and Public Life*. London: Ph.D.

Rose, D. (1996) *Living in the Community*. London: The Sainsbury Centre for Mental Health.

Silverman, D. (1993) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: Sage.