



**Development and pilot testing of the questionnaire for
use in NHS Trust-based Mental Health service user
survey**

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1 Executive summary

This report outlines the results of the research undertaken to develop and test the Mental Health Service User questionnaire for use in the NHS patient survey programme. This work on the development of the questionnaire and survey methodology began in April 2002, and a pilot survey was carried out in three mental health NHS trusts in spring 2003. Some very minor alterations were then made to the questionnaire, and 34 mental health NHS trusts carried out a voluntary survey in summer 2003. An advisory committee was then set up by CHI, and further changes were made to the questionnaire. Also, a number of alterations to the survey method were tested, with the aim of improving response rates.

This report describes the methods and results of this research work to date.

1.1 Aims

The aims of the survey development work were:

- To identify key issues important to service users of secondary mental health services to be addressed by the questionnaire
- To identify potential problems that may be encountered when surveying mental health service users
- To draft a questionnaire
- To test the face validity of the questionnaire
- To devise a sampling strategy that would be workable in all mental health NHS trusts
- To pilot test the questionnaire in mailed surveys
- To take advice from the Mental Health Survey Advisory Group organised by CHI on improvements to the questionnaire and methods of enhancing response rates
- To investigate the effects of different methods of survey administration on response rates
- To investigate the characteristics of non-responders compared to responders
- To follow up non-responders to investigate their reasons for not participating in the survey and to examine further any response biases.

1.2 Methods

- Literature search to identify previous survey tools for mental health service users
- Telephone and face-to-face interviews with mental health professionals and individuals working in the mental health voluntary sectors
- Focus groups with people with mental health problems
- Cognitive interviews with people with mental health problems to test the face validity of the questionnaire
- Postal survey in three NHS mental health trusts (spring 2003)
- Consultation with an advisory group including members of Department of Health Mental Health Task Force, and service user group leads
- Voluntary survey in 34 Mental Health trusts (summer 2003)
- Further pilot testing of revised questionnaire and testing of alternative survey methods (autumn 2003)

1.3 Results

The focus groups and interviews highlighted key issues that were important to mental health service users. The draft questionnaire was developed and its face validity was tested in cognitive interviews. Minor alterations to the questionnaire were made based on the findings of these interviews.

For the pilot survey, the questionnaire was sent to service users on Care Programme Approach (CPA) information systems at three Mental Health Trusts (n=400 at each Trust). Response rates in the three trusts were 42%, 46% and 50%. Higher response rates were achieved among service users on standard CPA than for those on enhanced CPA. There were relatively few calls (compared to other surveys of NHS patients) to the FREEPHONE help line, which service users were invited to call if they had any problems, questions or complaints.

The voluntary survey was carried out in summer 2003 by 34 trusts. The mean response rate was approximately 40%. It is likely that it was lower because trusts had a relatively short time to organise the survey and to collate responses.

Further pilot surveys took place in autumn 2003, and a detailed investigation comparing responders and non-responders was carried out in one trust, using additional service user information supplied by that trust. Also, 200 non-responders were sent a “non-response” questionnaire, asking them why they did not respond to the survey.

2 Literature search

The peer-reviewed and grey literatures were searched for examples of patient satisfaction and patient experience research carried out with mental health service users. Where possible, original questionnaires were obtained and reviewed. The following questionnaires were examined:

- CHI Review Client Questionnaire: *Interview schedule for community clients and Interview schedule for inpatients*
- Breakthrough: *Inpatient questionnaire*
- Sainsbury Centre for Mental Health: *Users' voice*
- King's Fund: *Obtaining the views of users of Mental Health Services*
- Quality Health: *Listening to clients*
- Local authorities e.g. Camden & Islington: *Your treatment and care in hospital;* and Hillingdon: *A survey of the community psychiatric nursing services in hospital*
- CUES

Using these questionnaires and the Mental Health National Service Framework as starting points, a list of topics that might be covered in the questionnaire was compiled. This list included: referral, after referral care, information, Care Programme Approach (CPA), treatment, site of treatment, emergency care, health professionals, Patient Rights, family/carers and cultural/ethnicity issues. The evidence in the literature supported the belief that questionnaires should either focus on inpatient care or community care and that these experiences were too different to be covered in a single questionnaire.

3 Interviews with mental health professionals and individuals working in the mental health voluntary sectors

3.1 Introduction

Advice was sought from mental health professionals and individuals working in the mental health voluntary sectors on how best to survey service users. Potential problems in surveying mental health service users were discussed in depth. Table 1 lists the interviews that were held with mental health clinical and policy experts.

Table 1 - Interviews held with mental health experts

Name (Job Title)	Organisation
Richard Brook (Chief Executive) Sophie Corlett (Head of Policy)	MIND
Gary Hogman (Head of Policy and Campaigns)	Rethink
Jon Allen (Director of Nursing) Kate Whitworth-Jones (CPA Lead)	Oxfordshire Mental Health NHS Trust
Ray Davies (CHI Project Manager)	CHI/MIND project: service users who have been trained to be CHI reviewers
John Hyslop	Mental Health Matters
William Finn	Revolving Doors Agency
Liz Skelton	UK Advocacy Network
Richard Jones	Oxford Survivors
Jim Aspdin	Rethink Outreach in Eastbourne
Stuart Lawson	Rethink Outreach in Brighton
Geraldine Mason	Hammersmith and Fulham MIND

3.2 Results

Some interviewees were concerned that using the Care Programme Approach (CPA) information system as a sampling frame would mean that only a subset of all mental health service users would be included. Concerns were also expressed about the potential problems for some mental health service users in responding to a postal survey.

CPA information systems

The main cause for concern was that the CPA information system would not provide a complete sample of mental health service users. Given that CPA is only applicable to users of secondary mental health services, it would exclude all people with mental health needs who are cared for solely at the primary care level. Furthermore, the CPA information system is not an integrated national system and each trust has been free to develop its own information system. Therefore, different trusts have implemented different electronic systems and some trusts have more sophisticated recording systems than others.

The researchers' consultations with trust staff supported this claim. For example, in one trust, the information system is still in its infancy and not all service user details are stored on the electronic information system. Indeed, the most up-to-date files are held by individual practitioners. In another trust, it was reported by professionals working in the voluntary mental health sector that the CPA information system is regarded as just a "paper exercise". Limited resources mean that the extent of CPA implementation varies across the country. However, trusts now face serious financial implications if their CPA information systems are not up and running so the situation is likely to improve.

It was also evident from the interviews that a significant number of people with mental health needs do not engage with the mental health services. The most hard-to-reach groups include people from the ethnic minorities, and those individuals with a dual diagnosis or co-morbidity, such as drug and alcohol abusers. There is also recognition that people with personality disorders need to be managed, but whether they are included on the CPA information system tends to depend on the preferences of the individual Community Mental Health Teams.

Postal questionnaire

The second key area of concern was the use of a postal questionnaire to obtain information from mental health service users. The general view was that the response rate would be low, particularly as mental health problems are often associated with decreased motivation. Moreover, the side effects of medication can make it difficult for people to control a pen, concentrate or even to see clearly. There was also concern that some groups (such as those whose first language is not English, or those who are more severely ill) might find it more difficult to respond to a postal survey than others, so they would be under-represented in the results.

4 Focus groups

4.1 Introduction

Following the literature search and interviews with mental health specialists, the list of topics to be addressed in focus groups was compiled. The topic guide was further refined following consultation with *MIND*, *Rethink* and Department of Health policy leads. The main topics to be included were:

- Referral
- CPA
- Treatment
- Inpatient care
- Community care
- Information
- Health professionals
- Standards
- Family and carers
- Discrimination

4.2 Results

Participants

Five focus groups were conducted in Guildford, Maidstone, Hammersmith, Oxford and Leicester. Participants were recruited from user groups and an advocacy group for ethnic minorities. One group consisted of former service users who were now acting as patient representatives. In total, 11 females and 18 males took part and ages ranged from 20 to 70. The results are presented under the headings of the main topics discussed.

Referral and diagnosis

Most participants had long-term mental health problems and had a poor recollection of their initial contact with mental health services as this was some time ago. However, one exception to this was the ethnic minority focus group in Leicester. Two of these participants had been sectioned in the last year or two and were taken into hospital by the police. They complained about the lack of information provided.

Nothing was explained to me. I wasn't told that I could appeal for a start when I was first sectioned.

I was depressed really and they shoved me in there...I didn't know where I was or anything, no one told me anything.

Misdiagnosis or lack of any clear diagnosis was an issue for many participants.

I am 43 now and they have just realised that they have misdiagnosed me...they have wasted most of my life.

I've been schizophrenic, manic-depressive, catatonic, psychotic and now I'm supposed to be normal so I have to be.

A few participants had a clearer understanding of their condition.

My OCD [Obsessive Compulsive Disorder] was really bad, it was chronic really.

Treatment

Many participants were on medication but sometimes explanations for its purpose appeared very vague.

To help you be yourself, I was told.

For my nerves.

In some cases, treatment had been given forcibly without consent.

I was just injected willy-nilly against my wish.

A few people had been involved in treatment decisions, although this was usually in cases where medication was prescribed at primary care level.

He [GP] discusses and tells me how many to take and if I feel better sometimes, he tries me on one instead of two, that type of thing.

I have a very good, supportive GP and I think if I wanted to change my medication tomorrow...he would let me do it.

I mean basically I made the decision to come off the injections and go onto tablets.

But most people did not feel involved.

No, I have no say.

No, they tell you, they don't discuss it; it's not a two-way thing.

You have to really have a go at them and lose your temper before they decide to try to modify the treatment or change it or whatever.

The fear was also expressed by participants that getting angry might make things worse.

In some cases if you do that, they just give you a larger dose of the injection.

However, not everyone wanted to be involved in their treatment decisions.

They are the professionals, they are supposed to know what they are doing so when they say something, I think right.

Side effects were experienced by virtually everyone to some extent.

They said that it is part of my illness to hallucinate when it was part of the drug they were injecting me with.

You walk around like a zombie.

You are exhausted in the morning, tired, you want to lie down all the time, you get confused, all that business.

I was scratching myself so much I was bleeding.

Very few participants thought they had been adequately warned about side effects or offered help to deal with them.

They say just take it, they don't tell you what it is going to do to you.

Obviously they gave me a piece of paper saying all the side effects but there was nothing to say this could happen if you drink.

Some participants felt strongly that their medication was essential.

It helps me considerably; I would hate to think what would happen if I stopped having it.

When they eventually got the right stuff in the right dose, I have never looked back.

Although most participants were against ECT [Electro-Convulsive Therapy], one participant benefited from ECT and another spoke of the information available about this form of treatment.

I wanted the treatment...I heard voices and they were talking to me and causing trouble so they [ECT sessions] calmed me down.

A friend of mine had been put on ECT...he showed me 2 documents, one locally produced and one produced by the Royal College of Psychiatrists which mentioned the actual process and whatever.

Talking therapies were more readily available to some participants than others and it appeared to be offered more frequently at primary care level.

I have asked from day one for talking treatment or psychological intervention of some kind. Eight years or so have passed now – what is the point of bothering.

Other participants sought this kind of help outside of the mental health services.

The only person who seems to be listening at the moment is X [psychotherapist at the local Survivors' group].

However, not everyone wanted talking therapy or found it helpful.

They kept wanting to go back and I don't want to go back any more.

To me, cognitive behaviour therapy smacks of brain-washing.

A lot of it has screwed me up...the things I needed to say were to people I cared about.

It has always been my experience if you sit there, you talk, you explain it week after week and then you are sitting there saying to yourself, well, what's happening now? Where's the treatment?...You do get the impression that your hour's up, that's it, buzz off.

It was too intense and I didn't speak much about my OCD. I couldn't really talk in a group.

In several cases, it seemed that activities outside the mental health services proved to be the most therapeutic.

It is to do with the human approach...as long as you have got the contact, I find that very helpful.

If I am angry then I paint angrily. I've got a picture going in the art exhibition – it sort of shows all the blows and everyone telling you this, that and the other.

I think a lot of help I have had is from myself and from people I have met.

My sister-in-law...taught me reiki which is the thing that has moved me on.

Inpatient care

This topic was not discussed in two groups as participants had not had recent inpatient experiences. In the other groups, experiences were generally negative.

It was terrible; my hair needed washing and I didn't have my hair washed for how many weeks.

You would come back from a walk and all your stuff had been moved without telling you. Then they would say you were confused.

At midnight, you have this torch shining in your face when you are asleep to see if you are still breathing or something.

Participants reported little confidence in the nursing staff and not enough time with doctors.

Half of them [nurses] aren't worth talking to.

I was a bit worried that some of the night nurses prescribed the wrong drugs on the sheet.

If you pushed your luck, you might see a doctor once every few days, you really had to be playing up.

Participants also complained about the lack of activities, particularly at the weekends.

Oh you just sit there all day, nothing to do.

Unless you've got family that were prepared to take you out on visits...nothing to do at weekends at all.

Furthermore, the general atmosphere was not always conducive to recovery and could sometimes be violent.

Sitting there with a load of people saying I'm going to kill myself, isn't life so terrible, it makes you ten times worse.

One of the big blokes that hurled me down, he actually got into a fight with one of the inmates and broke the pool table.

Two participants felt their freedom was restricted. One of them disagreed with the policy of not letting patients off the ward until they had been assessed and the other was annoyed he could not leave the ward even though he was a voluntary patient.

One of the troubles is that I am extremely claustrophobic...and nobody had a sort of appreciation for that.

I complained to my social worker and the next day they said you can go for 5 or 10 minutes outside and have a cigarette and then come back.

Dietary preferences were not always respected.

It was just English food, there was no Caribbean food put on.

One participant had been a voluntary patient in a therapeutic community but the experience had resulted in even greater mental distress.

It really screwed me up. I met a lot of people who had been sexually and physically abused and stuff and I don't think it was the right place for me.

In contrast, a few participants felt that they benefited from their time as an inpatient and thought the facilities and staff were good.

The new unit is quite nice and everybody has their own room with en-suite facilities.

It was a mother and baby unit where I had severe post natal depression...the care there was very good.

Football, table tennis and I used to run a lot.

CPA (Care Programme Approach)

Only a few participants understood the CPA concept.

It's a system where any client who uses the mental health system can have meetings with their care co-ordinators where your needs are discussed.

One participant thought the system had advantages and disadvantages.

When I signed the thing, I thought this is going to be even worse...because it's something that binds you to the system.

On the other hand, he felt it provided an important safety net.

If you have got some doubt as to your mental health then it is important to keep in contact with the mental health system because if you fall ill, it will cushion the fall.

CPA reviews were sometimes found intimidating or upsetting.

To be honest with you I know I spoke occasionally myself, it's only because I'm frightened you see.

Other participants thought they were a waste of time and their expectations were not high.

I know what CPA meetings are but they don't go anywhere.

They didn't do me any harm anyway.

Participants were able to invite who they wanted to the meetings and a few people found them to be beneficial and empowering.

As a client, I can invite basically who I like to my CPA.

Anybody, you can ask them, please come. My wife comes with me.

I felt very warm, very happy to be there...they were quite nice to me, they were.

However, staff shortages and general pressure of work meant that the system does not always work as it should.

I don't think they've got the staff to do it basically.

GPs are invited and rarely turn up because of their commitments.

Everybody else [except the CPN] was too busy...I can understand it but it makes a bit of a mockery.

Continuity of care was a particular problem highlighted by participants.

But it keeps on chopping and changing...every couple of months there is somebody else.

Care plans are a new thing for me and since it has been drawn up I have nearly killed myself by drinking on medication, there have been cuts in social services, my CPN has changed, the psychiatrist is too busy or he has gone somewhere else and there have been a lot of changes.

One participant had received a written care plan but was not involved in drawing it up and its operation was delayed.

My care broke down...it had to be kick started a few weeks after I got home...all the notes didn't reach the appropriate people and my social worker met me the day before I was being discharged which was a bit late.

Another participant failed to attend a recent CPA review because his mother was away and his brother unsure if he could attend. He was very unhappy with the subsequent report.

They wrote some horrible things about me...he said I was dangerous to myself, I was liable to hurt somebody else.

Another participant said he was discharged from day care a week before his CPA review at which his discharge should have been discussed.

I said to them, why are you coming to this decision when really this should be dealt with at my next CPA meeting?

Contact with key workers and CPNs did not always seem satisfactory.

My key worker sometimes I see and sometimes I don't.

I had a community care nurse who came to see me twice and said she was going to come again but then I never saw her again after that.

Several interesting issues regarding the distinction between standard and enhanced CPA were raised from the perspective of patient representatives rather than direct personal experience.

The way it is all interpreted is, if you don't need social services, it doesn't matter how ill you are, you are on standard. You can't go to a particular level of day centres, it has got implications regarding your carer and a whole load of other things.

If you are on a standard CPA, the key worker is likely to be your consultant which is an absolute load of rubbish – they can't carry out their duties as laid down in the CPA key worker handbook.

I think there are a lot of people as well who haven't got one that should have one.

This problem was confirmed from the personal experience of a young man diagnosed with schizophrenia who did not think CPA applied to him.

It's for people who can't really cope at all.

Community care

The problem of isolation in the community was very apparent among the groups.

Sometimes I can get so isolated in the house.

People can starve you of attention and they starve you of human contact and that is the worst thing. It is like sensory deprivation and you end up doolally and crazy.

What would I do apart from just sitting in my flat all the time...I would go spare, I would go nuts.

Care in the community seemed to be unpredictable.

I did have a community care nurse. I think she came out a few times and then she just stopped coming.

I used to get care from social services and that was stopped. They didn't think I needed it when I came out of hospital.

I've had so many different social workers and I had different CPNs. The staff turnover is very high in Guildford it seems.

I think support in the community is absolute balderdash – it doesn't happen, you don't get it.

In some cases, it appeared that a supportive family member or friend was regarded as a reason not to be offered more support.

I don't get help from social services because they say you have your wife to look after you.

The GP recommended that my daughter, though she was only about 4 at the time, sort of take care of me.

The simple reason is they said she didn't need somebody to care for her...They said you've got Dave there, Dave is more or less your carer.

The kind of social interaction provided by day centres and voluntary drop in centres was therefore greatly appreciated by many participants and some even used them when they were no longer being treated for mental illness.

You feel safe here, we feel we can talk to members of staff...about our problems.

This place is a God-send.

Oh yes you need somebody to talk to and get out and meet somebody, it helps a lot.

However, one participant thought drop-in centres could also be depressing and their opening hours were limited. Some centres have had to close through lack of funding.

It can make you down again, you know, if you are getting a bit better.

Survivors are sharing the accommodation...so they are there on Friday and Saturday but only from 11am to 4pm.

I live in Chiswick and they had an Oasis there but they stopped it because they had no funds.

Housing is an important issue and several participants had experienced being isolated, living in run-down council estates or in one case, living on the margins of society before he got help.

I told them on the form that I sent to the council that I felt isolated because it is horrible, I didn't know anybody there.

I live like a prisoner at my place, so many break-ins.

Well try living in a van and hearing the rats coming round you.

One participant was concerned that he would not be given enough support if he had his own flat.

But I reckon they just visit you once a week or something...you will be left on your own.

Another participant lived in supported accommodation provided by MIND but he had experienced difficulties with his neighbours.

We've been treated like 3rd rate citizens...by people in the community who have no respect for us.

There was a sense in which people appeared to find their own support in the community from wherever they could: voluntary support teams, other mental health service users and even night shelters for the homeless.

It's a special small team of people who meet people who have great difficulties coping... or life problems, that sort of thing.

We support each other.

I go to Richmond, well it's for the homeless, and get a meal there.

I lived with drunkards and druggies and go down to the night shelter just because whatever you've got to say, you are listened to.

However, one participant was receiving the best care he had ever had as an outpatient.

There is a lot more care and understanding than people I have met in the past.

Information

One participant felt there was almost too much information.

The trouble with mental health is basically that there is too much information...just bombardment of everything – this is your problem, that is your problem, why you can't do that, all that kind of stuff.

However, the majority of participants found it difficult to get information and relied on a variety of sources including social workers, flyers, family and friends, voluntary organisations, GPs and word of mouth.

There was no information about this place or anything – you find out like you say from word of mouth.

We can find out about it here [MIND]. I mean this place has got lots of things to help people.

One participant thought that misinformation was as much a problem as lack of information.

He is supposed to help me with the forms...the CPN he didn't want to know. He told me lies.

Another participant felt that information should be provided on sectioning.

I think once you are sectioned, you should be given a pack of some sort...with all the help that you can get.

One person emphasised that sometimes treatment itself can make it less easy to access information.

If your reading ability has been killed off by ECT, you can have all the literature in the world but it just goes straight in the recycle pile.

It was felt that more information should be available at the GP's surgery but one patient representative was concerned about stigma.

I'm actually toying with the idea of getting out a leaflet which doctors can give to people when they are first diagnosed but you have got the stigma caper. I mean how do you start off...I reckon you're a nutter and here are some places where you can go and get help?

The information people wanted included side effects of medication, housing and support groups. One participant had found it very useful to find out about each professional's role. (This was via the advocacy service.)

Emergency care

Many participants were aware of local help lines but very few people found them helpful in a crisis. Limited availability was frequently mentioned.

They just talk to you – that doesn't make the problem go away.

I've phoned the crisis line loads of times – I did that and they are laid back; don't worry have a cup of hot chocolate or something.

I don't have a telephone so I can't phone up a crisis line.

The only service available is 9-5 Monday to Friday.

Mental health service staff were criticised for only working office hours.

These CPNs...finish work at 4.30/5pm; something happens at 6/7pm at night, you phone the telephone number...sorry nobody is available, please leave your name and message...nobody rings you until the next day, things may be too late then.

One participant, who had a history of self-harm, talked about his difficulties actually trying to see someone in a crisis.

They say psychiatrist is busy – go to see your doctor first...and then I went to my GP and he was closed. Then for a couple of hours I walked around town.

For some people, therefore, the only solution was to go to the emergency department of their nearest hospital or take more extreme measures.

There have been 2 or 3 instances recently where people have been in crisis...they've trashed their flats and houses in order to get themselves arrested and put into hospital.

However, one participant benefited from being in MIND accommodation and another was able to ring his counsellor at home.

Well because I am in their housing, I can phone them [MIND] if there is an emergency.

I do ring her [counsellor] up and we talk for half an hour and let her diffuse it by talking.

Health professionals

There were several complaints about health professionals not being interested or not listening to service users.

I tell you, one meeting he [psychiatrist] was nodding off. I swear he was.

The CPNs that I've been under they don't seem to pay much attention to what you are saying, they just do their thing.

The psychiatrist was rambling on and on and didn't give you time to think ...the best psychiatrists I had hardly ever said a word, just prompted occasionally.

My doctor is not listening.

They don't listen to you and I have to take somebody with me and they talk in front of me.

We changed group therapists half way through...this new woman started...she just didn't listen to me...she said no, no you are not leaving.

One participant felt threatened by his psychiatrist.

If I don't [agree to go into hospital], he might put me in the section.

Another participant had felt very badly treated by the staff at a therapeutic community.

She [the nurse] was really sadistic to me.

Participants felt there were not enough staff, a lack of continuity and poor co-ordination between professionals.

Psychiatrists change every 5 minutes and basically there is just not enough staff for the amount of people that need support.

Health and social services just don't seem to know how to work with each other.

I think there is a fear in psychiatrists that they are losing control...there is a tension going on between the health professionals.

Participants felt that psychiatrists behaved like God and nurses were inadequately trained.

In a way, nobody can argue against a psychiatrist.

A lot of them are not qualified...some of the nursing auxiliaries...should not be there.

Furthermore, participants thought that hospital staff spent too little time with patients and too much time on paper work.

Filling out forms which nobody actions.

Some felt that health professionals did not treat people with respect.

Just treated as a piece of paper and somebody who has got to have an injection and get out.

It is as though you are something dirty.

But there were a few positive comments.

There's a nice sister who helps me.

Now he has got another CPN...and he is as good as gold when he goes to see him, he says how are you? Fine, let's have a sit down and they have a talk...and he is helping him a lot.

I have had an excellent CPN and an excellent GP.

Family and carers

This was not a big issue for many participants and so was not discussed at length.

One participant was largely cared for by his mother. She had had her own CPA and was receiving support from a local carers' group.

She has seen somebody finally...from the National Schizophrenia Society.

The issues of assessments and care plans for carers were raised by one of the patient representatives.

Again it is the eligibility criteria; they have been tending to do it from the enhanced [CPA] point of view whereas the patient who is on standard [CPA], their carer needs more help because they are stuck with the person.

One participant emphasised that some of his problems stemmed from his family, implying that their involvement might not be very helpful.

If they want to get involved they could but they put me through hell and I put them through hell.

Standards

It is not surprising that the group drawn from the advocacy service (in Leicester) were most aware of their rights and had most experience of making complaints. One participant who felt he had been badly treated in a therapeutic community had taken his complaints to the highest level.

I filed loads of complaints and even took it to the Court of Human Rights.

This complaint had resulted in action being taken.

The nurses were investigated by the UKCC, the GMC looked at the doctor's letter and I think the Ombudsman looked at the therapy I was given at the community.

However, most participants thought it was difficult to get redress and would not bother to complain even if things went wrong.

I talked it over with my husband and he said it's not worth it, what are you going to achieve?

It is very hard to sue any hospital or any concern if people think it is your own delusions or your own illness that caused it.

There was even a fear among participants that complaints might jeopardise their treatments.

I think maybe people wouldn't complain because they would be worried that their treatment might be stopped if they were seen as a troublemaker.

In addition, participants felt that the medical profession would always protect its own.

These people have got the backing of the Trust...they kind of cover up what's going on.

Doctors stick together, you know what I mean.

One participant felt his rights had not been respected at all in hospital.

When I was in the [hospital name], I thought I had no rights at all.

Although most participants knew they had a right to change their GP and see their medical records, few participants had any success in exercising their rights

I want to change my doctor...I even asked the medical council...because I heard that down at Luther Street doctors there really listen...and they won't let me go down there.

I have been advised not to look at them [medical records]...they reckon they will upset me.

I tried to see mine and he said exactly what do you want to look at, so they won't let you look at everything.

Discrimination

A few participants felt discriminated against within the health service because of their mental health problem.

I presume he [orthopaedic surgeon] read in my notes that I had a history of self-harm...and his attitude was absolutely horrendous...he made extra snide remarks.

They tend to bring it up. They tend to bring up whether you have got a mental health problem every time.

However, another participant pointed out that GPs needed to know if you were on medication because the side effects could be causing other problems.

One participant, who also had a heart problem, felt his GP had not listened to him because of his mental condition.

I was shouting, I was out of my head and that is why the GP was not sympathetic with me.

Although one participant in the ethnic minority focus group felt she had been discriminated against because she was Afro-Caribbean, most participants felt less strongly towards this issue. Nevertheless, an Asian participant had been unable to explain his problem in his own language when he was unable to stay with his daughter while she had some stitches removed.

I think it was part of being West Indian the way they treated me.

No-one has come to tell me that they have got treated better so I don't feel discriminated at all.

Several people, however, did feel discriminated against by society generally if they had a mental health problem.

You are like stigmatised...no-one thinks that you've got ordinary feelings.

4.3 Conclusions

The tight time schedule for undertaking the focus groups meant the necessary ethical approval to recruit mental health service users via the health service could not be obtained. By relying on user groups, a certain type of participant, was inevitably attracted to participate (some of whom might be described as "professional patients"). Therefore, caution should be exercised before generalising from these results.

Nevertheless, the following important issues were raised which need to be addressed in the mental health survey:

- A diagnosis which users can understand
- Explanation of treatment
- Involvement in treatment decisions
- Warnings of side-effects and strategies for coping with them
- Alternatives to medication
- Quality of nursing staff on acute units
- Access to doctors on acute units
- Activities on acute units
- Violence on acute units
- Food on acute units
- Restrictions on acute units
- Explanation and delivery of CPA
- Continuity of care
- Regularity of contact with key-workers
- Regularity of CPA reviews
- Intimidation at CPA reviews
- Criteria for standard and enhanced CPA
- Isolation in the community
- Support groups
- Housing
- Supported accommodation
- Sources of information
- Types of information needed
- Ability to access information
- Crisis support
- Out of hours support
- Listening skills of all professionals
- Co-ordination between professionals
- Qualifications of nursing staff
- Respectful treatment
- Involvement of family and carers
- Complaints procedures
- Access to medical records
- Discrimination
- Availability of interpreters

5 Draft questionnaire

Following the focus groups, and interviews with health professionals and voluntary workers in the Mental Health Services, a draft questionnaire was compiled. To maximise the acceptability of the questionnaire, it was designed to be understandable for anyone with a reading age of twelve or above. Also, the use of “skips” was kept to a minimum. With all questionnaires, it is usually necessary to include a number of “skips” to guide respondents to miss out sections that do not apply to them. However, these can be confusing if used in excess, so it is important to try to minimise them.

The questionnaire was circulated to members of the Department of Health Mental Health Team, the Steering Group and CHI for comments and was amended.

6 Testing the questionnaire: cognitive interviews

6.1 Introduction

Seven cognitive interviews were conducted over a two week period in October and November 2002. An additional three interviews were then conducted in January 2003. The interviewees were recruited via Oxford MIND, the Leicester Mental Health Shop, and Mental Health Matters in Oxford. The sample of mental health service users consisted of four white females, three white males, two black females and one Asian male. Although awareness of CPA levels was limited, the kind of support participants were receiving suggested that the sample consisted of both standard and enhanced CPA service users. An initial interview was also conducted with the father of a young man with schizophrenia.

6.2 Results

Interview 1: white male, 60s (completed version 8 of the Questionnaire)

The interviewee is an active member of a local Rethink support group and the father of a young man diagnosed with schizophrenia.

General comments

Service users tend to find the term “mental illness” more familiar than “mental health problems” which might suggest something less serious. The definitions for Care Co-ordinator, Care Plan and Care Review could be improved. He suggested that ‘The Care Programme Approach: A Guide for service users and carers’ was consulted. (This is a document provided by Oxfordshire Mental Healthcare NHS Trust.)

Amendments made in light of this interview:

SECTION B

B8/9 Sources of help for alcohol and drug problems: social services were removed and The Drug and Alcohol Team added.

B14 “Did your nurse or doctor do all they could to control the side effects?”

This was deleted as in many cases there is little that they can do.

SECTION C

YOUR CARE PLAN: This was altered to: **YOUR CARE PLAN (CPA)** as some people will know it as CPA.

“A care plan shows how your needs will be met and who will provide services for you” now reads: “A care plan shows your mental health needs and who will provide services for you” based on the Oxfordshire Mental Healthcare leaflet.

Your keyworker: “A keyworker or care co-ordinator is someone who sees you regularly and liaises with the other health professionals involved in your care.”

As care co-ordinator is now the term used in general, this was changed and simplified to:

Your care co-ordinator: “A care co-ordinator (keyworker) is someone who keeps in contact with you and monitors your care”

SECTION D

“Day centres or day hospitals” As day hospitals are now less common, this was deleted.

D2 Social services were deleted from the list of options and “other” added.

Housing As this is a very important issue for many mental health service users, the section relating to housing was extended to include an extra question:

“Do you feel **safe** in the place where you now live?”

D7-D10 There was some discussion about the relative importance of these issues. It was considered that questions on training, employment and benefits might have to be deleted to keep the questionnaire short (see below).

D10 The options were extended to include “The benefits agency”.

D11/12 “advice in support groups” was changed to “information about local support groups”.

SECTION F

The section on Outpatients was deleted as many mental health service users will not see their psychiatrist in a traditional outpatient setting but in the context of a Community Mental Health Team.

F4 “At your appointment were you given enough time to discuss your condition and treatment?” This has now been included in the section on psychiatrists and reads: “When you see your psychiatrist, are you given enough time to discuss your condition and treatment?”

SECTION G

G1 “Do health professionals work well together?” This has now been deleted on the grounds that it would not always be easy for a service user to judge.

G2 “Do you feel you have to repeat your story more often than you should?” This has been deleted on the grounds that it is more appropriate to other health situations.

SECTION H

Standards Complaints were given a separate subheading in this section.

H9 “Were you given a written copy of your rights?” has now been deleted as it was deemed less important.

Interview 2: white female, 50s (completed version 10 of the questionnaire)

This interviewee was diagnosed with bi-polar disorder nearly 20 years ago. She now manages her condition well but requires medication and sees a psychiatrist regularly. She lives in her own home and has a part time job.

General comments

She found the questionnaire covering letter “clear and fine” but wondered if other mental health service users would find it clear. She particularly recommended emphasising the fact that participation in the survey is voluntary and confidential as service users have to fill in so many forms and might be easily deterred from completing another one. Her initial response to the questionnaire was that it was “quite daunting”. This particular draft was 9 pages long and it has been subsequently reduced to 8 pages.

Although she found the wording fairly clear, it could still be quite an ordeal to fill in the questionnaire. She suggested that the covering letter could be “more in your face” so that it is more appealing. She thought the filters were difficult and could be easily missed. She also said that if people in Group Homes [supported accommodation] got the questionnaire, they would just rip it up. She suggested that responsibility should be on those running the homes to make people aware when the survey goes out so that they could offer help. The questions on drink and alcohol abuse were potentially offensive although they did not offend her.

Amendments made in light of this interview:

SECTION A

A1 “Have you ever had mental health problems?” Interviewee response: “Why are you asking this when it’s going out to service users?” This question has now been deleted.

SECTION B

B6 “In the last 12 months have you been given any talking therapy?” Interviewee response: “Too passive.” This has been changed to “have you had any talking therapy”.

Your care co-ordinator: A care co-ordinator (or keyworker) is someone who keeps in contact with you and monitors your care. Interviewee response: “Need a simpler alternative to monitor.” This was simplified to: “A care co-ordinator (or keyworker) is someone who keeps in contact with you”.

SECTION D

D4 “Do you ever feel lonely?” Interviewee response: “This is a huge issue but it seems funny on its own.” This has now been moved to the Overall section at the end of the questionnaire.

SECTION F

F10 Discrimination “Because of my mental health problems” has now been added to the list.

Interview 3: white male, 30s (completed version 11)

This interviewee was diagnosed with schizophrenia several years ago. He was one of the few interviewees to understand the way CPA works and manages his condition relatively well with the aid of medication. He lives in MIND supported accommodation and does not work.

General comments

He had no problems with the covering letter and managed to complete the questionnaire despite being a little confused from time to time. He found it quite hard work and the filters a bit confusing but thought it was positive, “it makes you think.” He thought that the questionnaire did not really ask about the quality of accommodation and support with day to day living. He also thought that the response rate will depend on what state people are in when they receive the questionnaire because there is a real problem with form-filling. He did not find the questions about alcohol and drug abuse offensive but thought that some people may not want to admit to these sorts of problems.

Amendments made in light of this interview:

SECTION D

D7-D10 Training and Employment and Benefits. Throughout the interviews, it was becoming apparent that the length of the questionnaire might discourage service users from completing it. In light of this, it was decided to delete these 2 sections due to being of less pressing importance (see above).

SECTION H

H1 “Overall, how would you rate the care you receive from mental health services?” Interviewee response: “At the moment?” Now reads: “Overall, how would you rate the care you have received from Mental Health Services in the last 12 months?”

Interview 4: white female, 50s (completed version 12)

The interviewee was diagnosed with paranoid schizophrenia and has been ill for over 10 years. She lives in a Group Home (supported accommodation), sees a CPN regularly and runs a local Survivors Group.

General comments

At first glance, she thought the questionnaire looked manageable and the covering letter sounded straightforward. However, she did think it seemed lengthy as she was going through it. “By the end, I was thinking this is enough already.” She was concerned that mental health service users who find it difficult to concentrate might get fed up half way through and it might be left at the bottom of a pile of paper. She thought education was an important issue that had been omitted from the questionnaire. She was not offended by the drug and alcohol misuse questions.

Amendments made in light of this interview:

SECTION B

It became apparent during this interview that there is a potentially confusing overlap between questions **B1-4** on treatment and **B11-14** on medication as for most people, treatment probably means medication. Therefore, this part of the questionnaire was restructured so that Medications and Talking Therapies are subsumed into a general Section A on Care and Treatment. Section B then becomes Your Care Plan.

B6 “In the last 12 months have you had any talking therapy (e.g....” Interviewee response: “Not within the mental health services but at a voluntary day centre.” Now the options read:

Yes, I have had talking therapy from the Mental Health Services

Yes, I have had talking therapy from somewhere else (e.g. voluntary organisation, private therapist)

No, I have not had any talking therapy in the last 12 months

SECTION D

D4 “In the last 12 months have you received any help with housing?” Interviewee response: “Not sure what it means.” Now reads: “In the last 12 months have you received any help with accommodation?”

D7 “In the last 12 months have you received any information about local support groups?” Interviewee response: “Around mental health issues?” Now reads: “In the last 12 months have you received any information about local support groups for mental health service users?”

Interview 5: white female, 50s. (completed version 12)

This interviewee was referred to a psychiatrist in 1992 with severe depression. In 1998 she took an overdose. She now rents her own flat, takes medication now and again and sees a psychiatrist.

General comments

The interviewee thought the questionnaire seemed fairly clear and thorough. She was quite impressed. However, she noted the individual’s family circumstances were omitted from the questionnaire.

Amendments made in light of this interview:

SECTION B

B1 “Are you taking any medications for your mental health problems at the moment?” Interviewee response: “I’m on and off – I was on them earlier in the year.” Now reads: “In the last 12 months, have you taken any medications for your mental health problems?”

SECTION D

D1 “In the last 12 months, how often have you visited a day centre?”

Most days

About once a week

About once a month

I have not visited a day centre in the last 12 months”

Interviewee response: “Twice a week.” Now reads:

“Most days

Once or twice a week

Once or twice a month

I have not visited a day centre in the last 12 months”

Interview 6: Afro-Caribbean female, 40s (completed version 12a)

Initially, the interviewee was diagnosed with schizophrenia but this was later disputed. She was detained under the Mental Health Act earlier in the year. She still takes medication, sees a psychiatrist regularly and has had support from both a CPN and a social worker in the last few months.

General comments

It took the interviewee an hour to complete the questionnaire but she said she thought it was about the right length and clear. She liked the idea of ticking boxes rather than having to write answers. No questions were missed out and all the questions were relevant and useful. However, she did mention that training and employment was also an important issue. The questionnaire highlighted the fact that she has never been told who is her care co-ordinator, so now she will ask.

Interview 7: Mixed race female, 30s (completed version 12a)

The interviewee is a single mother diagnosed with bi-polar disorder. She had a breakdown a year ago and was hospitalised for four months. She has a psychiatrist, a CPN and a social worker, and takes medication.

General comments

It took the interviewee over an hour to complete the questionnaire although she described it as straightforward. She thought people might worry about confidentiality and whether there would be a backlash, but didn't think it would prevent her from completing it. She misinterpreted the helpline information in the covering letter, thinking that this was a number for help generally.

In general, she felt there was a tendency for her to go for the middle option in response to most questions. She asked for an explanation of psychotherapy, cognitive behaviour therapy and sexual orientation. She was not offended by the questions on drug and alcohol misuse but asked what kinds of drugs were included. She could not think of anything else that should have been included in the questionnaire but felt that there should be more space to comment on some of the questions.

Interview 8: Asian male, 50s. (completed version 12a)

The interviewee appears to suffer from panic attacks and has a tendency to self-harm. He has been in and out of hospital several times this year for short periods as a voluntary patient. He is currently on medication, sees three different psychiatrists, a CPN and a social worker.

This interviewee spoke reasonable English and understood most of the questionnaire. However, he still found it very difficult to complete and probably would not have filled it in at all if he had not agreed to do the interview. It seemed like a lot of questions and he said he was “not good with forms”. Even the covering letter contained too many words – “by the time I’d got to the bottom, I’d forgotten what was at the top”.

He also found psychotherapy, counselling and cognitive behaviour therapy difficult to understand and thought the sort of drugs should be clarified in the question on drug misuse. He was not sure who was his care co-ordinator but thought it might be a volunteer worker at the Mental Health Shop (advocacy service) because he kept in touch with him.

Amendments made in light of the interviews 6, 7 and 8

Mental health services have been changed to Mental Health Services throughout to emphasise the distinction between them and other mental health support.

SECTION A

A6/7 “...(e.g. psychotherapy, counselling or cognitive behaviour therapy)”
Following the confusion over the meaning of some of these terms, this now simply reads: (e.g. counselling)

SECTION C

C8 “A care co-ordinator (or keyworker) is someone who keeps in contact with you.” Interviewees were unsure who this was and an attempt has been made to make this definition clearer. Therefore, this now reads: “A care co-ordinator (or keyworker) is someone from Mental Health Services who keeps in regular contact with you.”

It should be noted that suggestions to include additional questions on education and training, family circumstances, quality of accommodation and support with day to day living were acknowledged. However, there was no unanimous support for their inclusion, and it was felt that adding these topics would only lengthen the questionnaire. The key message from all the interviewees was to keep the questionnaire as short and simple as possible.

It was recognised that some individuals found the filters a little confusing, so they were kept to a minimum. However, they could not be eliminated because many important issues do not necessarily apply to all patients, and there has to be a way of skipping questions or groups of questions that are not applicable.

Interview 9: White male, early 30s. (Completed v. 15)

This man had been experiencing bi-polar and anxiety disorders for the last six years. He was currently taking medication, seeing a psychiatrist, CPN and social worker and lives in MIND housing.

General comments

He experienced a few problems with completing the questionnaire. However, he emphasised that there is much form-filling in mental health so it would be helpful to forewarn people about the survey and to highlight its importance.

He thought the covering letter was clear but then later on he did not realise that it was confidential and anonymous.

Amendments made in light of the interview:

SECTION A

A1 Difficult to quantify. When do you date problems from? When they first develop or when they are diagnosed as mental health problems?

A4 Read about side effects in the drug leaflet.

A5 Found this question confusing and did not know how to answer it. He never felt that he has had any say but did not know if he had been offered it.

A6/7 He answered no to A6 but yes to both options 1 and 2 of A7. He had been made to have talking therapies although he did not want it. The questionnaire does not allow for this possibility.

He thought there might be a lot of denial with the questions on alcohol and drugs.

SECTION B

B8 Slightly confused about the terminology. Keyworker was a more familiar term. He said that many people are between services because if they do not contact their CPN for a while, they are removed from the list and it can take another 12 months to have another CPN. So he would have answered no to B8 because at present, he does not know who is his CPN.

SECTION C

C6 Wanted to add “therapeutic earnings” i.e. a job agreed to be beneficial by a GP or psychiatrist but which would only be part time and for small wage.

C7 His comments were “the only work that people with mental health problems can get is crap so it’s not getting work that’s the problem, but the kind of work”.

In general, he thought the questionnaire covered a lot of ground and could not think of any omitted topics.

Interview 10: White male, early 30s. (Completed v. 15)

This man had long term mental health problems and was currently living in a group home.

General comments

Generally, he thought the questionnaire was good and only had a few problems completing it. He did not find the questions about alcohol or drugs at all offensive and indeed thought they were very important. He missed quite a few skips.

SECTION A

A7 He was not sure if “talking therapies” included counselling offered by CPN or social services.

SECTION C

C9 He was not sure what “support groups” meant.

The “trust and confidence” questions in the health professionals section, he interpreted simply as confidentiality.

Interview 11: White female, mid 30s. (Completed v. 15)

This woman had mental health problems (maybe bi-polar disorder) since adolescence. She lives in supported housing (i.e. own flat with regular support from CPN and social services).

General comments

She thought the questions were good, but there were a number of issues on completing the questionnaire because she failed to read the questions properly and missed skips. In addition, although she now lived on her own, 6 months ago she lived in a rehabilitation centre which is not covered by the accommodation options. Her social worker thought it would be useful to ask if people were helped to make a complaint if they wanted to make one

SECTION A

A6/7 She was a little confused because she has had therapy and was pre-empting Q7 while still answering Q6.

A8-11 Read “If you have had alcohol/drug problems...” and wanted to skip this section entirely as she had not had problems. Said she found the questions slightly offensive.

SECTION B

B8 She did not read the definition of care co-ordinator and so didn't understand what the term meant. She was more familiar with the term, keyworker.

SECTION C

C7 Her response was “Does that refer to paid or voluntary work?”

C9 Her response was “What do we mean by support groups?”

SECTION G

G3 She did not seem to understand that if she was only lonely some of the time, but not at the moment, she could answer “yes, sometimes”

SECTION H

H1 She became confused with all the options.

6.3 Conclusions

The questionnaire was revised and amended in light of the interviews and new drafts of the questionnaire were then tested in subsequent interviews. It was apparent that the questionnaire had to be short and simple if respondents were to be encouraged to complete it. None of the cognitive interviewees raised any objections to the questions and there were very few recommendations for additional questions.

7 Investigation of state of CPA information systems

7.1 Introduction

It was necessary to investigate the current state of CPA information systems used in secondary mental health services to test its use as the sampling frame and to adjust the sampling criteria accordingly.

7.2 Method

A total of 22 Mental Health trusts (including Partnership and Primary Care Trusts) were contacted by telephone and e-mail to investigate the current status of their CPA information systems. In each case, the first contact was with the named survey contact for that trust.

7.3 Results

Highlighted below are the main issues that were reported by trusts.

Systems used to record CPA

CPA information systems are kept on different types of systems. For example, CPA information systems may be recorded on:

- One electronic integrated system for health and social services
- One electronic system – like PIMS + CPA module
- One electronic stand alone system (e.g. Access or Excel database)
- More than one electronic systems
- Part electronic system and part paper based
- Paper only

Inclusion of service users on CPA

Not all people receiving the care of secondary mental health services are listed on the CPA information systems. Below are some examples:

- In one trust, 30% of users are not on the list as they either have a drug or alcohol abuse problem or they are seeing a counsellor or link worker based at their GP.
- Some clinicians do not engage in CPA. For example, in one trust, it was reported that only 45% of users may actually be on CPA list.
- Some trusts are still amalgamating CPA lists from merged trusts and are still updating their systems.
- In most trusts, a very small proportion of people waiting for initial assessment are likely to be on a CPA information system.
- In one trust, 15-20% of those on standard CPA are the list while waiting for assessment.
- One trust reported that 15-20% of standard CPA service users may still be on the information system following discharge
- In most trusts, it was reported that service users' names tend to be removed from CPA information system when discharged.
- In most trusts, it was reported that people who have appointments less frequently than once a year will rarely be on the information system.

Completeness of information on CPA

Completeness of information held on the CPA information system varied a great deal.

- Most information systems contained name, address, date of birth, level of care, gender, and ethnic group. However:
 - In the CPA information system of one PCT, address details were not held for “data protection reasons”
 - In the CPA information system of another PCT, 40% of patients did not have their CPA level recorded due to the back log of inputting information on to the database
- Date of review or date of last of contact tend to be recorded on the most comprehensive CPA lists

Other issues concerning the quality of lists

- Although service users tend to appear once on information systems, some patients have alias names for their different treatments. However, trusts are usually able to link the names together.
- Most lists can identify current inpatients.
- In some cases, inpatients are identified 24 hours following admission.
- In one trust, the names of deceased service users can take up to 6-8 weeks to be removed.

7.4 Conclusions

The above findings suggest that the CPA information system may not be an ideal sampling frame for mental health service users. However, it should be noted that the situation is likely to improve given that Trusts now face serious financial implications if their CPA information systems are not up and running. Also, the Mental Health Minimum Data Set should now be recorded by Trusts which should lead to more uniformity among the CPA information systems. We have explored alternative sampling methods in a separate paper, and concluded that none of the alternatives would provide a better sampling frame.

8 Mailed pilot surveys

8.1 Introduction

The acceptability of the questionnaire, and the sampling method were tested in mailed pilot surveys. Also, the response rates needed to be determined so that estimates for the national survey could be made.

8.2 Methods

Ethical approval was granted for the pilot study by the Multi-Centre Research Ethics Committee (MREC) for Scotland on 30/01/03, following some initial delays. (The application was first submitted on 28/10/02, when the content of the questionnaire had been agreed.)

Three trusts (A, B and C) participated in the pilot. Once a copy of the letter showing ethical approval and the guidance manual had been sent to the trusts, their sampling could be undertaken. Trust B was asked to sample service users receiving enhanced CPA only so that comparisons could be made with the other trusts. Actual sampling was fairly easily executed by trusts. The main delay occurred when waiting for the sample to be checked for deaths by the tracing service. This took between one and four weeks, and none of the service users in these samples was found to be deceased.

A fourth Trust (D) also expressed an interest in being involved in the pilot. However, a Research and Development Project Management form had to be completed for this trust. This, in addition to the trust's own intention to submit the protocol through their own Local Research Ethics Committee, delayed the survey procedure. Furthermore, the process of sending samples to the tracing services to identify any deceased service users took longer for all trusts than the anticipated one or two weeks allocated, and even longer for trust D. Indeed, the other pilot trusts were at the second reminder stage of the survey process by the time Trust D was ready to proceed so the pilot survey at this fourth Trust was not carried out.

The proportion of services users on standard and enhanced CPA varied between trusts as shown in Table 2.

Table 2 - The CPA levels among the samples

CPA level	Trust A (n=400)	Trust B (n=400)	Trust C (n=400)	Total (n=1200)
Standard	57% (227)	-	91% (365)	49% (595)
Enhanced	43% (173)	100% (400)	8% (31)	50% (604)
Assessed prior to CPA system	-	-	1% (4)	0.3% (4)

All three participating trusts agreed to allow Picker staff to organise the mailing of questionnaires to speed up the process. These staff were given honorary contracts with the trusts to comply with the Data Protection Act. The first questionnaires were posted on 24/02/03, followed by first and second reminders (which are sent only to non-responders) to service users at all 3 trusts. The final cut-off date for inclusion was 30/04/03.

8.3 Results

Response rates

The response rates are shown in Table 3.

Table 3 - Response rates (30/04/03)

	NHS Trust			CPA*		Total
	Trust A (n=400)	Trust B (n=400)	Trust C (n=400)	Standard (n=592)	Enhanced (n=604)	(n=1200)
Completed useable questionnaire	194	163	178	292	239	535
Returned undelivered	14	11	13	15	23	38
Deceased (reported by tracing services)	-	-	-	-	-	-
Too ill	2	-	3	5	-	5
Opt out	18	22	27	37	30	67
Not returned yet	172	204	179	243	312	555
Sum	400	400	400	592	604	1200
Raw Response Rate (%)	48.5	40.8	44.5	49.3	39.6	44.6
Adjusted denominator	386	389	387	577	581	1162
Adjusted Response Rate (%)	50.3	41.9	46.0	50.6	41.1	46.0

* 4 service users were neither recorded as receiving standard or enhanced CPA but all of those returned completed useable questionnaires

These response rates suggest the overall response rates using this method will be approximately 40-50%. Clearly, this falls short of the minimum response rate target of 60% set for other NHS Trust national surveys. However, it is considerably higher than the majority of response rates for surveys of mental health users reported in the published literature.

Response bias

The main concern with low response rates is that respondents might not be representative of all service users on CPA within an NHS trust, so certain groups might be under-represented. For example, it is possible that those for whom English is not their first language will be less likely to respond than service users whose first language is English. Also, service users with more severe illnesses might be less likely to respond than those with less severe illnesses.

Unfortunately, ethnic coding of the samples was very incomplete so it was not possible to make reliable comparisons between the ethnic groups of responders and non responders. However, the proportions of respondents who were White British at Trust A, B and C were 87%, 92% and 97% respectively. These results accord with the ethnic breakdown of the catchment area for Trust B¹, which indicated that 97% of the population were White British (based on the 2001 Census). Furthermore, 92% of all respondents to the pilot surveys who gave their ethnic group said that they were White British. This compares with 91% in the Acute Inpatient surveys 2002, 91.5% for the Acute Outpatient surveys 2003, and 89% for the Acute Emergency surveys 2003.

If the level of CPA is used as a proxy for severity of illness, it is evident that the more severely ill service users are somewhat less likely to respond. The response rate for those service users receiving enhanced CPA was 41.1%, compared to a response rate of 50.6% among respondents receiving standard CPA.

It is also likely that there are other correlates of non-response. This issue is addressed in greater detail later in this document.

FREEPHONE calls

There were 39 calls to the FREEPHONE concerning the mental health pilot surveys which is 3.3% of the service users surveyed. The calls can be categorised as follows:

¹ These data were not examined for Trust A or C.

- There were 11 calls regarding questions about how to fill in the questionnaire (but 3 of these calls were from the same person).
- 9 called to say that they had received the reminder but not first mailing. (These callers were informed that they will receive a second reminder, which will include a duplicate questionnaire in due course.)
- 4 said they were too ill to complete the questionnaire.
- 4 were not at the address.
- 4 opted out (3 were annoyed at having been sent a second reminder).
- 3 reported that they had never had a mental health problem. (This was contrary to medical records, and at least 2 had received some counselling.)
- 2 did not want to receive any more reminders.
- 1 had returned the questionnaire some time ago.
- 1 had been assessed but had not yet started treatment so felt unable to complete the questionnaire.

In comparison, approximately 4% of patients participating in inpatient surveys call the FREEPHONE (i.e. 34 patients from a sample of 850). Therefore, the number of calls from mental health service users is similar to that expected from a survey of acute trust patients.

Respondents

Sample characteristics are shown in Table 4 - .

Table 4 - Basic characteristics of sample

Sample Characteristics	Combined Trust samples (n=535)
Gender	
Male	40.2% (215)
Female	56.1% (300)
Missing data	3.7% (20)
Age (years)	
16-25	3.9 % (21)
26-35	17.9% (96)
36-45	22.8% (122)
46-55	27.9% (149)
56 years or older	25.0% (134)
Missing data	2.4% (13)
Duration of mental health problem	
1 year or less	3.4% (18)
1-5 years	17.6% (94)
More than 5 years	71.8% (384)
Don't know/can't remember	5.6% (30)
Missing data	1.7% (9)

Dimension scores and problem scores

The questionnaire was designed to investigate service users' experiences and to highlight any problem areas within secondary mental health services. The topics have been grouped into the five dimensions of care:

- Access and waiting
- Safe, high quality, coordinated care
- Better information, more choice
- Building relationships
- Quality of life

The questionnaire was designed so that it could be analysed by dichotomous 'problem scores' indicating the presence or absence of a problem (see below). The problem scores on individual questions can then be summed together into five 'dimension scores' representing the above dimensions.

Examples of questions from the Service User Questionnaire showing deviation of problems scores

Black boxes indicate responses coded as a 'problem'.

Do you feel that your psychiatrist listens to you?

- 1 ? Yes, definitely
- 2 | Yes, to some extent
- 3 | No

Have you been told who your Care Co-ordinator is?

- 1 ? Yes
- 2 | No
- 3 ? Not sure/Don't know

Do you agree with what is in your care plan?

- 1 ? Yes, definitely
- 2 | Yes, to some extent
- 3 | No
- 4 ? Don't know

Twenty-three of the questions in this questionnaire could be evaluated and were applicable to most all respondents. Table 5 shows the percentage of service users in each trust who reported problems on this subset of questions. One-way analyses of variance were carried out for each question, comparing problem scores among the three trusts. The questions on which problem scores were significantly different are marked with an asterisk. However, it is important to note that this is an academic exercise only. The pilot trusts are not directly comparable because the distribution of service users receiving standard and enhanced CPA was different in the three trusts.

Table 6 shows the percentages of service users receiving either standard or enhanced CPA who reported problems on these questions. T-tests were carried out for each question to compare problem scores among the CPA levels. As might be expected, those on enhanced CPA tended to report more problems with their care than those on standard CPA.

Table 5 - Problem scores in three pilot trusts

Question	Problem scores for pilot Trusts			
	A (n=194)	B (n=163)	C (n=178)	Total (n=535)
Access and waiting				
Not seen Care Co-ordinator in last 6 months **	6.6%	3.5%	14.7%	7.6%
Unable to contact Care Co-ordinator if you have a problem	29.4%	31.0%	32.7%	30.9%
Do not have the number of someone in Mental Health Services to call out of office hours **	55.4%	34.4%	64.4%	51.8%
Took more than a few hours to get through to someone when calling out of office hours	21.8%	20.8%	18.5%	20.7%
Safe, high quality, co-ordinated care				
Have not had a care review in the last 12 months **	39.5%	11.3%	54.3%	35.4%
Did not find the care reviews helpful	60.9%	57.2%	56.1%	58.3%
Did not have trust and confidence in psychiatrist's professional skills	44.8%	37.4%	34.5%	39.2%
Did not have trust and confidence in CPN's professional skills	19.2%	32.2%	26.2%	30.4%
Have not received any information about local support groups for MH service users in last 12 months **	52.2%	31.3%	57.6%	47.0%
Better information, more choice				
The purposes of the medications have not been explained	44.3%	53.8%	43.2%	46.9%
Possible side effects of the medications were not told	62.5%	63.5%	63.4%	63.1%
Did not have a written or printed copy of the care plan **	48.9%	34.5%	78.2%	54.2%
Did not understand what is in the care plan **	54.4%	42.4%	75.0%	56.8%
Did not agree with what is in the care plan	48.6%	48.8%	49.3%	48.9%
Have not been told who is the Care Co-ordinator **	25.0%	8.6%	39.5%	24.2%
Not enough say in decisions about care and treatment *	62.6%	56.3%	49.7%	56.4%
Building relationships				
Unable to express views at care review meetings	51.1%	52.6%	47.1%	50.8%
Do not feel that psychiatrist listens	42.5%	38.2%	30.8%	37.5%
Not given enough time to discuss condition and treatment with psychiatrist	45.6%	34.4%	35.0%	38.7%
Do not feel that CPN listens	29.5%	25.2%	16.5%	24.9%
Quality of life				
Do not feel psychiatrist treats with respect and dignity	30.2%	26.3%	18.8%	25.4%
Do not feel CPN treats with respect and dignity	19.2%	21.2%	12.9%	18.3%
Feel lonely *	85.1%	71.7%	75.7%	77.9%

* p<0.05, **p<0.005

Table 6 - Problem scores for standard and enhanced CPA levels

Question	Problem scores	
	Standard CPA (n=292)	Enhanced CPA (n=239)
Access and waiting		
Not seen Care Co-ordinator in last 6 months *	11.2%	4.5%
Unable to contact Care Co-ordinator if you have a problem	31.3%	30.7%
Do not have the number of someone in Mental Health Services to call out of office hours **	63.3%	37.9%
Took more than a few hours to get through to someone when calling out of office hours	20.8%	20.7%
Safe, high quality, co-ordinated care		
Have not had a care review in the last 12 months **	51.9%	15.8%
Did not find the care reviews helpful	54.5%	60.8%
Did not have trust and confidence in psychiatrist's professional skills	37.0%	41.6%
Did not have trust and confidence in CPN's professional skills	29.0%	31.9%
Have not received any information about local support groups for MH service users in last 12 months *	54.4%	38.6%
Better information, more choice		
The purposes of the medications have not been explained	43.3%	51.3%
Possible side effects of the medications were not told	60.7%	66.2%
Did not have a written or printed copy of the care plan **	70.8%	33.2%
Did not understand what is in the care plan **	68.3%	44.4%
Did not agree with what is in the care plan	49.2%	48.6%
Have not been told who is the Care Co-ordinator **	35.2%	11.4%
Not enough say in decisions about care and treatment	54.0%	59.8%
Building relationships		
Unable to express views at care review meetings	46.1%	54.1%
Do not feel that psychiatrist listens *	32.9%	42.6%
Not given enough time to discuss condition and treatment with psychiatrist	37.9%	39.1%
Do not feel that CPN listens	22.1%	27.5%
Quality of life		
Do not feel psychiatrist treats with respect and dignity	22.3%	28.7%
Do not feel CPN treats with respect and dignity	15.3%	21.1%
Feel lonely	77.8%	78.0%

* p<0.05, **p<0.005

Questions that were not applicable to the majority of service users

Table 7 shows that less than 20% of service users reported problems in relation to alcohol and drug misuse. For this reason, it was decided to remove those questions from the questionnaire. It was also clear from these data that only 32.0% of the respondents had seen a social worker in the last 12 months. However, given that Social Workers have an important role in some service users' care, the questions pertaining to these health professionals were retained.

Table 7 - Responses to questions relating to alcohol and drug misuse

Question	Combined trusts' responses (n=535)		
	Do not have a problem	Missing data	Total
In the past 12 months, have you received any help for alcohol problems?	81.9% (n=438)	5.6% (n=30)	87.5% (n=468)
Where did most of the help for your alcohol problem come from?	-	89.7% (n=480)	89.7% (n=480)
In the past 12 months, have you received any help for drug misuse?	84.1% (n=450)	6.9% (n=37)	91.0% (n=487)
Where did most of the help for your drug problem come from?	-	92.5% (n=495)	92.5% (n=495)

8.4 Conclusions and recommendations

The response rate to the survey was higher than initially anticipated but in light of the pilot study results, the target response rate was reduced from 60% to 40% for the 2003 voluntary survey.

The face validity of the questionnaire was supported by the quality of the responses received and the small number of calls made to the FREEPHONE. The only additional amendments made to the questionnaire following the pilot survey were:

A1 "How long have you had mental health problems?" This question now reads "How long have you been in contact with mental health services?"

An extra response option has also been included: "I have never been in contact with mental health services".

A8-A11 The questions relating to alcohol and drug misuse have been deleted as these were not applicable to over 80% of service users.

Other Comments Section. Several service users filled the space given for other comments, so this space has now been increased.

9 Consultation with Mental Health Survey Advisory group

In summer 2003, two formal meetings with the Mental Health Survey Advisory Group took place at CHI, and these discussions were followed up in subsequent e-mail correspondence. The purpose of the group was to provide advice on questionnaire content, sampling methods that would facilitate appropriate comparisons between trusts, methods of enhancing response rates, and investigation of response biases in the results, including a follow-up of non-responders.

9.1 Group members

The Advisory Group consisted of:

- Gwyn Bevan, Director, Office for Information on Health Care Performance, CHI
- Sarah Scobie, Assistant Director, Office for Information on Health Care Performance, CHI
- Patten Smith, Survey Advisor to CHI
- Jan Wallcraft, Expert by Experience Fellow, National Institute for Mental Health in England (NIMHE)
- Steve Pilling, Co-Director, National Collaborating Centre for Mental Health
- Stephen Firn, Chief Executive, Oxleas Mental Health Trust and member of the Mental Health Taskforce Board
- Stefan Priebe, Professor, East London and the City Health Authority and member of the Mental Health Taskforce Board
- Glyn Lewis, Professor of Psychiatric Epidemiology, Bristol University, and member of the Outcomes Expert Group, Department of Health Psychiatric Morbidity Survey Follow Up Study
- Tony Grimley
- Rachel Reeves, Manager, NHS Survey Advice Centre, Picker Institute Europe
- Caroline Osborn, Research Officer, NHS Survey Advice Centre, Picker Institute Europe

9.2 Amendments to questionnaire following advisory group consultation

In light of the consultation with the Mental Health Survey Advisory Group, the following amendments were made to the questionnaire.

Questionnaire layout

The **Medications section** was moved to a later section because its being at the very beginning of the questionnaire seemed to reinforce the negative view that mental health care focuses too strongly on medications. It was difficult to find a topic that would be ideally suited to being the first section in the questionnaire, but it was decided that **Health Professionals** should be placed at the beginning.

The questionnaire was divided into a greater number of **sections, rather than having as many sub-headings within sections**. This made twelve sections compared to the previous eight. The main reason for this was to rearrange the order of questions more simply without disrupting the flow of the questionnaire.

Questions removed

- The questions '**Do you feel safe in the place where you live now?**' and '**Do you ever feel lonely?**' have been removed from questionnaire, as it was thought that the findings would not be actionable for the trust.

The questions in sub-sections Complaints, Medical Records and Discrimination were deleted as they were only applicable to a few service users.

Focus on single events

Where possible, throughout the questionnaire, respondents were asked to think about their **most recent** event. This was the case with questions relating to **health professionals, new medications, and care review meetings**.

Where questions have been changed to focus on single events, the answer options have been changed from 'Yes, always; Yes, sometimes; No' to '**Yes, definitely; Yes, to some extent; No**'.

In a number of places respondents are prompted "**Thinking about the LAST time...**"

Health Professionals (now Section B)

The word '**your**' has been replaced with '**the** or '**a**' when referring to the health professional they saw. This allows for the possibility that the last contact might not have been with the person that the service user sees as their usual contact.

The phrase 'Did you **feel** that...' is now replaced with '**Did**...' in a number of questions. For example, '*Did you feel that your psychiatrist listens to you?*' now reads '*Did the psychiatrist listen carefully to you?*' The purpose of this was to make the questionnaire more focused on reports, rather than ratings

The **three different professional groups** were retained, as feedback from patients (in development work for other questionnaires) and service users (for this questionnaire) is consistent in that these professional groups are too heterogeneous to make accurate reports possible if they are grouped together.

A suggested alternative was to ask respondents to tell us the person with whom they had had their last contact, and to ask the set of subsequent questions about that person, regardless of who it was. However, this would have been problematic for the following reasons:

Service users would not have an opportunity to tell us about the different health professionals that might be important to them. If, for example, the last contact had been with the CPN (which would be most likely), the service user would not be able to report on their experience with the psychiatrist.

Patients and service users often state in focus groups that relationships with health care professionals are very important to them, so it would not be sensible to reduce these sections of the questionnaire.

This method might lead to very small numbers of responses for some groups so it might not be possible to make use of those data.

A new question "The last two times you had an appointment with a psychiatrist, was it...? [With the same psychiatrist both times/ With two different psychiatrists]." was added. The purpose of this was to assess continuity of care.

Medications (now Section C)

An additional question: ‘In the last 12 months, have any new medications (e.g. tablets, injections, liquid medicines, etc) been prescribed for you by a psychiatrist?’ was included. This allows the subsequent questions to focus on the most recent experiences of having the purposes and side effects of medicines explained to them, and for those who have not had new medications in the last twelve months to skip these two questions.

Talking therapies (now Section D)

The order of the two questions about talking therapies was changed so that the question about having **had** talking therapy now precedes the one about **wanting** talking therapy, which was simplified to [Yes/No] response options.

Your care plan (CPA) (now Section E)

- The question “**Do you have** a written or printed copy of your care plan?” has been amended to “**Have you been given** a written or printed copy of your care plan?” This avoids ambiguity around the issue of the service user having been given the care plan but having lost it or discarded it.
- The question ‘**Do you feel able** to express your views at these meetings?’ now reads ‘**Were you given a chance** to express your views at the meeting?’
- The description of Care Co-ordinator has been amended: “A Care Co-ordinator (or keyworker) is someone from Mental Health Services who keeps in regular contact with you. **For example, this person could be a Community Psychiatric Nurse (CPN) or a Social Worker.**”

Support in the community (now Section F)

- The question relating to how often the service user has visited a day centre has been changed from “In the last **12** months” to “In the last **2** months”. This filters out service users who have not had recent experience of a day centre.
- The rating question relating to the activities a day centre provides has been changed to: ‘**Were the activities provided to the centre helpful?**’ The new answer options are “**Yes, definitely; Yes, to some extent; No**”.
- The questions relating to work, benefits and local support groups are now listed under a new sub-section “**Other support in the community**”.
- The question “**Are you currently working?**” has been simplified to make it easier for service users to respond.
- Two questions were added to this section:

- **‘When was the last time you saw someone about your mental health problem?’** The purpose of this question is to provide more concrete evidence of trusts’ performances in combating loneliness and other problems.
- **‘In the last 12 months, have any appointments been cancelled by mental health services?’** Again, this should provide more concrete evidence of trusts’ performances , and it was an issue commented on frequently in the “Other comments” sections of the pilot surveys.

Your background (now Section K)

- The question ‘How old are you?’ has been amended to **‘What was your year of birth?’**, as this will provide more useful information on age, and it can be sub-divided into appropriate categories after the survey is completed.
- Two questions about overall mental state and mood were added in this section to make it possible to standardise results by these variables.

Overall

- A question on diagnosis was added. “Has your diagnosis been discussed with you?”

9.3 Cognitive interviews following Advisory Group consultation

Five cognitive interviews were conducted in July 2003. The interviewees were recruited by visiting the Mill Day Centre, Oxford (a MIND drop-in centre). The purpose of these cognitive interviews was to test the face validity of the new questionnaire (version 8, 25 July 2003).

Sample

The sample characteristics are shown in Table 8 (The mental health state of the interviewee during the interview was provided as part of the questionnaire.)

Table 8 The characteristics of the cognitive interviewees

Gender	Age	Ethnic group	Type of mental health problem	Duration of mental health problem	Mental health state during interview
Male	39	White, British	Schizophrenia	1-5 years	Good
Male	38	White, British/ South African	Schizophrenia/Identity problems	>5 years	Fair
Male	56	White, British	Schizophrenia	>5 years	Very poor
Male	44	White, British	Psychotic depression	>5 years	Very good
Female	39	White, British	Anxiety and depression (maybe Schizophrenia too)	>5 years	Fair

Interview 1: White British male, 39

General comments

The interviewee completed the questionnaire by himself without any problems. He thought the questionnaire was very clear and easy to understand. He did not believe any of the questions were unnecessary or offensive. However, he thought an advance letter prior to the questionnaire may instil fear in the service user depending on the service user's mood at the time of receiving it.

Amendments in light of this interview:

Section D

D1 Service users may be able to tick two answer boxes if they have had talking therapy from the NHS mental health services and from somewhere else (e.g. voluntary organisation, private therapist). Although this point was valid, there had not been any problems with service users from the pilot survey who answered this question, so rather than allow more than one box to be ticked, the question remained unchanged.

Section E

E2 “Do you understand what is in your care plan?”

The interviewee felt quite worried about his care plan when it was initially given to him. He thought it should have been explained more clearly. However, now he has had the plan for over a year, he is happy with it and understands it well.

Section F

F4 Some people are unable to work due to their mental health problems.

An answer option: “I am unable to work because of my mental health problems” has now been added.

F5 “Are you currently in paid work?”

He suggested including an answer category of “No, but I am a part-time student”. However, this suggestion was not added to the questionnaire because the answer option “No, but I work on a casual or voluntary basis” would be applicable for part-time students who may also be working.

Interview 2: White British/South African male, 39

General comments

The interviewee completed the questionnaire with very few problems. He thought the questionnaire was easy to follow and not offensive.

Amendments made in light of this interview:

Section C

C1 and **C3** The skips provided next to the answer options were corrected from D2 to D1.

Section F

F3 In response to this question about receiving help with accommodation, the interviewee’s answer was yes, although he did not necessarily want the help. The answer options were not amended because it was very much a personal experience he was discussing compared to an issue that would reflect other service users’ experiences.

Interview 3: White British male, 56

General comments

This man said the questionnaire was clear, easy to understand and not threatening. He also said that receiving an advance letter prior to the questionnaire would be good as it would be something to look forward to.

Amendments made in light of this interview:

(Although not an amendment, he was particularly pleased that question D2 "...did you want talking therapy?" was included as he believed that some talking therapies are not appropriate to all service users.)

Section F

F9 "In the last 12 months, have any appointments been cancelled by mental health services?"

He asked whether this included appointments that were rescheduled by the mental health services. The question now reads: "In the last 12 months, have any appointments been cancelled or changed by the mental health services?" The answer options have been amended to include the words "cancelled or changed" e.g. "Yes, 1 appointment was cancelled or changed".

Interview 4: White British male, 44

General comments

Although he thought the questionnaire was very straightforward, he did miss a couple of skips. He also felt that receiving an advance letter prior to the questionnaire would be fine.

No amendments were made in light of this interview. However, he did query question K3: he lived in a group home but was unsure if living with people other than family members was the right box to tick.

Interview 5: White British female, 39

General comments

She found the questionnaire relatively straightforward to complete.

Amendments made in light of this interview:

Section E

E1 As the interviewee answered “no” to the question “Have you been given a written or printed copy of your care plan?” she wondered whether questions E2 and E3 were applicable and perhaps should be a skipped. However, as some care plans are verbal, skips are not included in this question.

Section F

F4 The same issue about being unable to work due to mental health problems was raised (as by interviewee 1). This issue has now been added as an additional answer option.

Conclusions

It was apparent from the five interviews that the questionnaire was in a format that was easy to follow by respondents. Problems with missing skips or not reading the questions properly were slightly evident. No major problems were highlighted and no further cognitive interviews were arranged. The questionnaire was amended as appropriate (version 9, 1 August 2003).

9.4 Amendments to sampling following advisory group consultation

There was concern to ensure that trusts used the same inclusion criteria when sampling for the survey, and that those included in the sample would have had sufficient and recent enough experiences of mental health services to ensure that the questionnaire would be relevant to them. One suggestion was that only enhanced CPA service users (rather than both standard and enhanced CPA service users) should be included in the sample. The enhanced group tend to have a greater number of contacts with a wider range of services provided by the secondary mental health services. Therefore, they may have a broader experience of the services compared to someone receiving standard CPA.

However, it was noted that the definitions of standard and enhanced CPA vary greatly between trusts. ²It was agreed that all people on CPA (standard or enhanced) should be included in the sample, but that the inclusion criterion for date of last contact with the service should be reduced from six months to three months. The purpose of this was to reduce the number of people in the sample who had only occasional contact with mental health services.

This was the only alteration to the sampling frame. The other inclusion criterion remained unchanged.

² This is supported by the evidence of the recent Voluntary Survey in mental health trusts. Trusts were asked to supply data on the CPA level of the service users in their samples and the percentage of service users in each trust on enhanced CPA ranged from 4% to 94%.

10 Randomised trial to test methods of enhancing response rates

10.1 Methods considered for enhancing response rates

The peer-reviewed literature on response rates to postal surveys was reviewed. The advisory group considered the following methods, all of which had been reported in the literature to enhance response rates under some circumstances.

Methods of maximising the response rates of the survey were also examined. Proposed methods included:

1. Enclosing a pen with the first mailing
2. Using personalised letters
3. Putting stamps on the reply envelopes
4. Posting the questionnaire by special delivery
5. Sending an advance letter prior to the questionnaire to inform service users of the survey
6. Sending a third reminder
7. Enclosing a monetary incentive with the first questionnaires

It was noted that there was some fairly weak evidence to support the use of non-monetary incentives. Personalised letters and putting stamps on envelopes have both been found to be effective, but it was decided that they would be impractical for these surveys as they would be time consuming for trusts, and these interventions tend to have small effects on response rates. Sending the questionnaire by special delivery raised concern among group members. Although this method has been reported to increase response rates, it could be perceived as threatening by some service users.

10.2 Agreed approaches

Advance letter

It was agreed by all group members that sending an advance letter would be a low-risk, low cost intervention that could enhance response rates.

Third reminder

It was agreed that sending a third reminder was a feasible option for trusts to undertake. However, caution was expressed by some group members, who thought that service users might become distressed by receiving a third reminder, given that the survey is voluntary. This view is supported by the experience with other surveys carried out under the NHS patient survey programme. When second reminders are posted, there is always a surge of telephone calls to the survey helpline by service users not wishing to participate in the survey and not wanting to receive any further correspondence. Occasionally, recipients are upset or irritated by receiving a second reminder, so the third reminder might increase the incidence of this type of reaction.

Cash incentives

The reviewed literature indicates that cash incentives can enhance response rates if they are sent with the questionnaires, but this is generally not the case if they are offered on condition that the questionnaire is returned, or if entry into a prize draw is offered.

It was agreed that the minimum cash incentive would have to be £5, as it would be impractical to send coins in the post. However, if this option had been used the extra cost per trust carrying out a survey in the main survey programme would have been £4250 (£5 x 850). Therefore, a £2 Co-op gift voucher was used as the closest alternative to cash that could be posted. Co-op shops are nationwide and are generally accessible by most people, and the Co-op is perceived to be an ethical organization.

10.3 Method

Ethical approval was granted for the pilot study by the Multi-Centre Research Ethics Committee for Scotland on 3/09/03.

Two trusts (A and B) participated in the pilot. Once a copy of the letter showing ethical approval and the guidance manual had been sent to the trusts, they could start sampling could be undertaken.

A third Trust (C) also expressed an interest in being involved in the pilot. However, once their sample had been drawn from their CPA information system and the inclusion and exclusion criteria had been applied, their sample consisted of only 315 service users. Therefore, it was advised that this trust should not participate in the pilot survey because it would compromise their sample for the compulsory survey in 2004.

The pilot postal survey was carried out using 781 service users across the two mental health NHS trusts. The same version of the newly-revised questionnaire was used for all service users. In each trust, service users were divided into 3 different groups. The **Standard Method** (initial questionnaire with 2 reminders sent to non-responders) was used in each group, with different additional interventions for each group. This 3-group design allows comparison of 6 different methods, since responses to the standard method alone can be assessed in each group before the third reminder is posted.

1. **Group 1.** The standard method: No advance letter, no gift voucher, two reminders (a total of three mailings).
2. **Group 2.** The standard method, with an advance letter (a total of four mailings).
3. **Group 3.** The standard method, with an advance letter and a gift voucher with the first questionnaire (a total of four mailings)
4. **Group 4.** The standard method with an additional third reminder (a total of four mailings)
5. **Group 5.** The standard method, with an advance letter and an additional third reminder (a total of five mailings)
6. **Group 6.** The standard method, with an advance letter, a gift voucher with the first questionnaire and a third reminder (a total of five mailings)

The rationale for testing some interventions individually, and some together was to ensure that there would be enough service users in each group to detect a significant increase in response rate. A significant increase may only be possible by including all interventions together. Testing each intervention individually and also testing each combination separately would have been preferable, but this would not have been possible without a larger sample.

10.4 Results

After the third reminder had been sent to half of the sample in each of the three groups, a total of 414 useable questionnaires were returned, representing a 55% response rate overall, once adjustments were made.³ Response rates for the six experimental groups are shown in Table 9.

Table 9 – Response rates for 6 experimental groups in Autumn 2003 pilot

Method	Advance letter	Gift voucher	Third reminder	Response rate
Group 1				50.8%
Group 2	Yes			52.5%
Group 3	Yes	Yes		58.5%
Group 4			Yes	52.0%
Group 5	Yes		Yes	54.9%
Group 6	Yes	Yes	Yes	59.3%

It can be seen that the highest response rates were achieved for Group 6, which included all of the three interventions. Overall, the intervention that had the strongest single effect was the gift voucher. The addition of the gift voucher raised response rate by 4.4-6%. The advance letter raised response rates by 1.7-2.9%, and the third reminder raised response rates by 0.8-2.5%.

10.5 Amendments to questionnaire following autumn pilot

Some minor amendments were made to the questionnaire following the second pilot survey. Ethical approval was granted for these amendments to the questionnaire (version 10) by the Multi-Centre Research Ethics Committee for Scotland on 7 December 2003. The following changes were made to the questionnaire:

³Thirty-three service users were excluded from the sample because their questionnaires were returned undelivered by the post office. There were no reports that any service users had died.

Health Professionals (Section B)

The section on social workers was altered to 'other health professionals' as the pilot work showed only a small percentage of respondents had seen a social worker in the previous 12 months. Furthermore, some trusts felt that other health professionals, such as occupational therapists, should be included in the questionnaire. Question B12 was added to allow respondents to report which 'other' health professional, if any, they had seen within the last 12 months.

Talking Therapies (Section D)

Question D1 was shortened so that the response option, 'Yes I have had talking therapy from somewhere else' was removed. The pilot work showed that this question had not worked in the previous format. By focusing the question solely on talking therapies provided by NHS Mental Health Services, the results would also be more actionable by trusts.

Description of a care plan (Section E)

Some concern was expressed by trusts that service users on standard CPA would not know or realise that they had been given a 'care plan'. Therefore, at the start of section E, the description of a care plan has been extended to clarify to service users what may actually constitute a 'care plan'. Additional text reads, 'It might be a document given to you by one of the mental health team, or it might be a letter, explaining how your care has been planned.'

Comments section

Some prompt questions have been added to the optional comments section at the end of the questionnaire to help structure respondents' comments, which will aid the subsequent analysis.

11 Non-response investigation

Part of this research was carried out on the full data set for the 37 trusts that took part in the spring pilots and the summer voluntary survey. Trusts had been asked to supply information about the service users they sampled. This included age, gender, level of CPA (standard or enhanced), ethnic group and date of last contact. This information was not supplied by all trusts nor was it complete for all the trusts that supply it, so the following results should be interpreted with caution.

11.1 Age

The mean age of responders was 44.7, compared to a mean age of 42.1 in non-responders. An independent samples t-test showed that this difference was significant ($t=15.7$, $df=25601$, $p<.001$).

This finding is consistent with the Emergency Department, Outpatient and Primary Care Trust Surveys 2002/3, where the average age of responders was higher than that of the non-responders ($p<.001$ in all cases).

11.2 Gender

The response rate for women was 42% compared to 37% for men. This difference was statistically significant ($X^2=90.4$, $df=1$, $p<.001$).

This finding is consistent with the response rates by gender for the Emergency Department, Outpatient and Primary Care Trust Surveys. The response rates for women were significantly higher than for men in all surveys ($p<.001$ in all cases).

11.3 Ethnic group

Prior to the survey it was suggested that non-white ethnic groups would be less likely to respond. For other trust-based surveys (Emergency Department, Outpatients and Primary Care Trust), the response rate for white service users was also statistically higher than the response rate of non-white groups ($p<.001$).

Analysis of response rates by ethnic group supported this assumption as the difference in response rates between white (40.9%) and non-white groups (36.1%) was statistically significant ($X^2=20.2$, $df=1$, $p<.001$).

11.4 Level of CPA

It was hypothesised that service users on enhanced CPA would be less likely to respond to the surveys than those on standard CPA due to the greater severity of their illnesses. In the spring pilots, the response rate for those service users receiving enhanced CPA was 41.1%, compared to a response rate of 50.6% among respondents receiving standard CPA.

However, for the Voluntary Survey, analysis of response rates by level of CPA showed no statistically significant differences between responders and non-responders ($X^2=1.9$, $df=1$, n.s.). When the analysis was undertaken at trust level, only three trusts showed a statistically significant difference between responders and non-responders with regard to the level of CPA. At one trust the response rate was higher for service users on standard CPA than for those on enhanced CPA (39% compared to 31%). At the other two trusts, contrary to expectation, the response rate for services users on enhanced CPA was significantly higher than the response rate for those on standard CPA (36% to 25% in one trust and 42% to 28% in the other trust).

The most likely explanation for these inconsistent findings is that the definitions of standard and enhanced CPA vary greatly between trusts. As noted above, the percentage of service users in each trust on enhanced CPA ranged from 4% to 94% in the Voluntary Survey, even though all trusts were asked to sample randomly, regardless of CPA level.

11.5 Date of last contact

It was suggested that the length of time since a service user had last been in contact with mental health services may influence the response rate to the survey. A two-way hypothesis was proposed; firstly it was possible that service users who had more recently been in contact with mental health services would find the questionnaire more salient and would therefore be more likely to respond. On the other hand, those who had been in contact more recently might also be in contact more frequently, and this might be indicative a more severe illness, which could lower response rates.

The number of months since a service user had last been in contact with mental health services was calculated. (If the last date of contact was prior to 2002 then the service users were excluded from this analysis). The mean number of months since the last date of contact was 4.0 for responders and 4.1 for non-responders. An independent samples t-test showed that this difference was significant ($t=3.39$, $df=19545$, $p<.001$).

11.6 Further analysis of non-response in one trust

One trust was able to provide the researchers with more information about the service users in their sample, so it was possible to test for other response biases in this subset of service users.

Of the total sample of 850 service users, 357 responded (40.3%) and 478 did not respond (54.0%). The remaining 15 (1.7%) service users were excluded from the following analysis because they were either reported deceased or their questionnaire was returned undelivered by the mail service. It was hypothesized that response rates might be affected by employment status, socio-economic status, severity of illness, frequency of contact with the secondary mental health services.

Employment status

The employment information provided by the trust was not complete for all service users. (The employment status for 56% of the sample was 'not specified'.) The response rate for 'employed' services users (including those in full time education, housewife/persons, voluntary work and retired persons) was 49%, compared to 44% of service users 'unemployed'. However, the Chi-Square test showed that this difference was not statistically significant ($X^2= 0.71$, $df=1$, n.s.).

Area of residence

It was suggested that service users of lower socio-economic status might be under-represented in the sample. A useful proxy for this is to examine the level of deprivation within their area of residence. The Index of Multiple Deprivation (IMD), produced by the Department for Transport, Local Government and the Regions in 2000, was used to compare the responders and non-responders in terms of the socio-economic status of their area of residence (i.e. ward).

The full postcode information provided by the trust for each service user in the sample was matched to the correct ward code. (Only 8 postcodes could not be matched to a particular ward due to incorrect or incomplete data). The overall IMD 2000 has two strands of data. The first is the Index of Multiple Deprivation Score and the second is the Rank of the Index of Multiple Deprivation. The ward with a rank of 1 is the most deprived, and 8414 the least deprived, on this overall measure. The IMD 2000 was constructed by combining six domain scores, including: income; employment; health deprivation and disability; education skills and training; housing and geographical access to services.

The wards in this trust cover a fairly large geographical area and there is a wide range in the IMD ward ranks, from 212 (the most deprived) to 8394 (the least deprived). The mean ward rank of the service users in the sample was 3815. Given the wide range of ward 'types' (i.e. in terms of socio-economic status), this trust was therefore a good example from which to undertake this analysis.

In this survey, the mean ward rank of where the responders live was 3967, compared to a mean ward rank of 3718 (i.e. slightly more deprived) for the non-responders. However, an independent samples t-test showed that this difference was not significant ($t=1.28$, $df= 825$, n.s.).

Severity of illness

Whilst the level of CPA has already been used for analysing severity of illness, further data on the number of admissions and outpatient appointments was supplied by this trust. Such information can be regarded as alternative measures of severity of illness, given that information on diagnosis could not be provided. Service users with a greater number of inpatient admissions and outpatient appointments could indicate a more severe mental health problem. As discussed previously, service users with more severe illnesses might be less likely to respond than those with less severe illnesses.

Conversely, it can also be suggested that service users who have had more contacts with mental health services are more likely to respond to the survey due to a greater level of experience of mental health services and professionals. Furthermore, service users who are more likely to attend outpatient and other appointments may also be more inclined to complete a questionnaire. Non-response to the survey may correlate with non-attendance at appointments with mental health services.

Inpatient admissions

The mean number of inpatient admissions for responders was 0.56 compared to 0.53 for non-responders. An independent samples t-test showed that this difference was not significant ($t=.397$, $df=832$, n.s.).

Outpatient appointments

Responders to the voluntary survey had a slightly higher mean number of outpatient appointments (14.5) since January 2002, when compared to the non-responders (13.2). However, independent samples t-tests showed that this difference was not statistically significant ($t=1.99$, $df=832$, n.s.).

12 Follow-up of non-responders

A short non-response form was sent to a random sample of 200 of the non-responders to the Voluntary Survey in one trust to try to identify possible biases in the respondent sample.

A total of 26 questionnaires were returned and 3 service users phoned the free helpline number giving their reasons for not participating in the survey (one questionnaire was also returned undelivered). This represents a 15% response rate.

12.1 Reasons for non-response

Table 10 shows the reasons that services users gave for not responding to the survey (The follow-up form allowed respondents to tick as many reasons as they felt were applicable.).

Table 10 The reasons for non-response to the survey

Reason for not responding	Frequency
Other reason (not listed on form)	7
I did not receive a survey	6
I was too ill/frail to complete the survey	5
I do not have a mental health problem	4
I have not been in contact with the Mental Health Services in the last 3 months	4
I was too busy to complete it	2
I did not see the point as it would not improve my care	2
The instructions of the survey were unclear	2
The person to whom this survey was sent no longer lives at this address	1

The 'other' reasons respondents wrote on the form for not participating in the survey included:

- *I'm not very good in filling in forms and I did not want to fill it in.*
- *I was going through a very depressed moment and wasn't living a normal life so everything that I would have written would have been biased.*
- *It felt intimidating and was voluntary – an invasion into private things.*
- *I did not complete the survey because it reminds me of last year when I was in hospital, which is also the reason I stopped attending 3 times a week psychotherapy group sessions. It brings back too many bad memories.*

Three service users choose to telephone the helpline number to say why they had not responded to the survey. One of the services users said that they had just been too lazy to complete the questionnaire. Another service user reported they had been sent too many different types of questionnaires and the third service user who phoned said that she had completed the questionnaire and had returned it.

Whilst only a small proportion of service users responded to the follow-up questionnaire, this investigation did show that the reasons for non response were varied. Interestingly, four respondents reported that they had not participated in the survey because they do not have a mental health problem and/or they have not been in contact with mental health services.

13 Appendix 1 - Topic Guide for Mental Health Focus Groups

Welcome from facilitator (5 mins)

Introduction (5 mins)

Explain that the aim of the discussion group is to find out about mental health services within the NHS from the point of view of people who've experienced a mental illness.

Emphasise that participants should feel free to talk about their personal stories but they are not obliged to do so.

The discussion will focus on several topics related to users' experiences.

The group will last for approximately 2 hours.

Explain that the discussion will be tape-recorded to ease later analysis. Reassure participants that nobody will be identified individually and personal details will be removed from the transcripts. All comments will be anonymised which means that none of the comments made in the discussion will be attributable to any individual participant.

Themed discussion (90 mins)

Participants will then be asked to talk of their own experiences using the following discussion prompts:

Referral

How did you get in touch with the Mental Health services?

- Self-referral
- Family/carer referral
- GP
- Hospital/A&E
- Court/police
- Social services
- Other

Was this at crisis point? How long was it before you were contacted by MH services? How long did it take to be seen by MH services? Were you given the opportunity and enough time to explain your problem(s)?

CPA

Have you heard of CPA? What do you think it's all about? What is your experience of it? Does this approach work well for you? What are the good things about it? What are the bad things about it?

- Do you know what a care plan is – and do you know if you have one?
- Do you have a written copy of your care plan?
- Are you involved in drawing up your care plan?
- Do you think your needs have been properly assessed?
- Do you know when your next CPA review is?
- Do you have a say in who attends your CPA meetings? (probe: carer, advocate)
- Who attends your CPA meetings?
- Do you know if you have a key worker?
- Has his/her role been explained to you?
- Does he/she keep your GP informed of your progress and help with any additional support you may need?
- Does your care plan address your cultural and spiritual needs?
- Is your care plan available to you in a language of your choice?
- Is your key worker responsive to your race, culture and gender?
- Has your CPA mentioned employment?
- Has your CPA been put into practice satisfactorily?

Treatment

Have you had any say in the kind of treatment you receive? Were you offered talking therapies or medication or both? Were you told about different options?

If you are receiving medication:

- Were you told what it was for and what the prognosis may be with or without it?
- Were you told you have a right to refuse it?
- What would happen if you didn't take your drugs?
- Has this been discussed with those around you? With your consent?
- Were you told about any possible side-effects?
- Does the health professional who prescribes your medication ask if you've experienced side-effects?
- Have you experienced any side-effects?
- Have you been offered treatment for these?
- Were you told about any possible withdrawal effects?

- How is your medicine administered? If by injection, is this given with respect for you and your timetable?
- Can you negotiate your dosage?
- Could others discuss your views and needs with you in your own language?
- If you've wanted to withdraw from your medicine, have you been offered any support?
- Does help exist to collect/request prescriptions?

What does therapy mean to you? Have you had therapy?

- Is this group or individual or both?
- How long did you have to wait?
- How often do you attend sessions?
- Is there any limit to the number of sessions in your course of therapy?

What other aspects are there to your treatment? (Probe: ECT, occupational therapy, social activities, alternative therapies).

Has the treatment made you feel better? Have some aspects of your treatment been more successful than others? Are there other treatments you feel would assist you? Have you discussed with anyone what would happen if you become unwell again?

Inpatient care

Have you been admitted to hospital within the last 5 years? What were your general impressions of that experience? Is hospital where you'd want to be in order to get better? Why or why not? In more detail:

- Was this an emergency admission?
- If not, how long did you have to wait to be admitted?
- Were you given any information about what to expect, about the ward routine and facilities?
- Were you frightened at any time during your admission? Did any member of staff offer reassurance?
- Were you able to talk to someone about your home situation e.g. child care, housing and benefits, if you needed to?
- Did you have enough opportunity to talk to your doctor? In private? Was he/she open with you? Did you get clear answers to your questions?
- Did the nurses have enough time to talk to you when you wanted them to?

- Did you have confidence and trust in the staff treating you?
- Were you on a single sex ward? Were there separate toilet and bathroom facilities for men and women?
- Could you get away to somewhere quiet when you wanted to or when you wanted to speak to your visitors in private?
- Did you think that the ward, toilet and bathroom facilities were clean?
- Did you like the food served? (probe: special dietary requirements) Did you have access to hot and cold drinks during the day?
- Was there enough to do on the ward?
- Were you subjected to any harassment on the ward? (probe security of property, violence etc)
- When you left hospital, was this well managed?
- Were you involved in decisions about your discharge?
- Are there any particular comments you want to make about your inpatient experience or suggestions about how it could have been improved?
- What do you think are the things that matter most when you are an inpatient? Why?

Community care

If you are receiving or have received care in the community, have you:

- Attended a day centre? (Probe: access, involvement in running of centre, activities, other comments)
- Attended a clinic? (Probe: access, waiting times, appointments system)
- Lived in supported accommodation? (Probe: say in the running of the house, facilities, privacy, social contact, independence, other comments)
- Received support at home? (Probe: say in the service received, independence, social contact, emotional support, other comments)

Have you received any help with training and employment? Have you received any help with benefits? Were you told about support groups? Do you attend any groups?

Are there any community care services you would like that you do not have access to?

Information

What kind of information were you given about your mental health problem and possible treatment? Were you given information about medication and side-effects? Was the information clear and easy to understand?

Were you given any information about:

- Support groups
- Housing
- Benefits
- Employment, education and training
- Advocacy services
- Who to contact in an emergency
- Help-lines
- Non- medical treatment options
- User and carer involvement in the health services

What sort of information would you have liked to be given?

Emergency care

How easy is it for you to contact someone when you need help? Does your MH service offer an on-call service for people who need urgent help? Have you ever used it? How long did it take for someone to respond?

What type of help would you like if you needed urgent help in the future:

- face to face contact with a professional or voluntary worker?
- telephone contact with a professional?
- voluntary helplines
- advice about medication?
- non-medical intervention e.g. crisis house?
- GP back-up?

Health professionals

What type of people are involved in your care? (Probe: GP, Psychiatrist, psychologist, psychotherapist, CPN, social worker, OT, outreach worker, support worker, other). What is your key worker?

Do the different professionals co-operate well? Is your care well co-ordinated?

Do you find that some professionals contradict each other sometimes?

For each professional involved in your care:

- Do they listen to you and understand your problems?
- Do you feel they have a good knowledge of your medical history?

- Do they have an understanding of your social support networks and economic situation?
- Do you have trust and confidence in them?
- Do they offer help with emotional and practical problems?
- Are they easily available when you need them?
- Do they keep you informed about your progress?
- Does what you say to them remain confidential?
- Do they treat you with respect?
- Would you like the choice of seeing male or female professionals?
- Do you feel they are helping you to overcome your problem?
- Do they often cancel appointments?
- Would they check you were okay if you missed an appointment?
- Do you feel you have enough time with them?
- Is there general agreement or disagreement over your treatment goals?
- What qualities do you think are important in a good professional?

Standards

What would you do if you had a problem with any of the services? Have you ever had to make a complaint about your MH services or would you know how to do so if necessary? Would you feel comfortable about making a complaint? What do you think it would achieve?

Do you know that you have the right to see your medical records?

Do you know you could change your key worker? Have you ever had to do so?

Do you know you can change your GP? Have you ever had to do so?

If you have ever been detained under the Mental Health Act, were given a copy of your rights and were they explained to you?

Do you know what an advocate is? Have you ever used one?

Family and carers

Do you feel that your family/carer has been given enough information and support? Have they been involved in their own care plan? Have they ever been offered respite care? Have they been involved when you didn't want them to be?

Discrimination

Do you feel you've ever been discriminated against in the health service because of your mental health problem?

Do you feel you've ever been discriminated against for another reason? (Probe: race, religion, physical disability, gender, sexuality).

Is information available in other languages if you need it? Are interpreting/sign language services available if you need them?

Are your particular cultural/religious practices respected? Are your dietary requirements respected?

Is disabled access available in your clinic, day centre etc?

Close

Ask participants if they have any questions or additional comments. Thank them all for taking part. Explain how the information will be used and how feedback can be provided. If appropriate, explore the possibility of further involvement i.e. testing questionnaire.

14 **Appendix 2 Service User Questionnaire used in Spring Pilot Survey**

Service User Questionnaire

What is the survey about?

This survey is about the health services you receive from the National Health Service.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Who is carrying out the survey?

The survey is being carried out by an independent research organisation, Picker Institute Europe, on behalf of your local health service trust.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the Picker Institute Europe FREEPHONE helpline number: 0800 197 5273.

Please Return to:

Picker Institute Europe
FREEPOST (SCE10829)
OXFORD
OX1 1YE

NNNNN

Your participation in this survey is voluntary.

If you choose to take part, your answers will be treated in confidence.

A. YOUR CARE AND TREATMENT

A1. How long have you had mental health problems?

- 1 1 year or less
- 2 1 to 5 years
- 3 More than 5 years
- 4 Don't know/ Can't remember

Medications

A2. In the last 12 months have you taken any medications for your mental health problems?

- 1 Yes → **Go to A3**
- 2 No → **Go to A6**

A3. Have the purposes of the medications been explained to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

A4. Were you told about possible side effects of the medications?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

A5. Do you have a say in decisions about the medication you take?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Talking therapies

A6. In the last 12 months would you have **liked** any talking therapy (e.g. counselling)?

- 1 Yes
- 2 No

A7. In the last 12 months have you **had** any talking therapy (e.g. counselling)?

- 1 Yes, I have had talking therapy from Mental Health Services
- 2 Yes, I have had talking therapy from somewhere else (e.g. voluntary organisation, private therapist)
- 3 No, I have not had any talking therapy in the last 12 months

Alcohol problems

If you have had alcohol problems:

A8. In the past 12 months have you received any help for alcohol problems?

- 1 Yes, definitely → **Go to A9**
- 2 Yes, to some extent → **Go to A9**
- 3 No, but I would have liked help → **Go to A10**
- 4 I have not had alcohol problems → **Go to A10**

A9. Where did **most** of the help for your alcohol problem come from? (**Tick ONE only**)

- 1 The Drug and Alcohol Team (DAT)
- 2 Mental Health Services
- 3 Voluntary organisation (e.g. Alcoholics Anon)
- 4 Friend or family member
- 5 Someone else
- 6 Don't know

Drug misuse problems

If you have had drug misuse problems:

A10. In the past 12 months have you received any help for drug misuse?

- 1 Yes, definitely → Go to A11
- 2 Yes, to some extent → Go to A11
- 3 No, but I would have liked help → Go to B1
- 4 I have not had drug misuse problems → Go to B1

A11. Where did **most** of the help for your drug problem come from? (Tick **ONE** only)

- 1 The Drug and Alcohol Team (DAT)
- 2 Mental Health Services
- 3 Voluntary organisation (e.g. Drugscope)
- 4 Friend or family member
- 5 Someone else
- 6 Don't know

B. YOUR CARE PLAN (CPA)

A care plan shows your mental health needs and who will provide services for you.

B1. Do you have a written or printed copy of your care plan?

- 1 Yes
- 2 No
- 3 Don't know

B2. Do you **understand** what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

B3. Do you **agree** with what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

Your care review

A care review is a meeting with you and the people involved in your care in which you discuss how your care plan is working.

B4. In the last 12 months have you had a care review?

- 1 Yes, I've had more than one → Go to B5
- 2 Yes, I've had one → Go to B5
- 3 No, I have not had a care review in the last 12 months → Go to B8

B5. Were you told that you could bring a friend or relative to your care review meetings?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember
- 4 I did not want to invite a friend or relative

B6. Do you feel able to express your views at these meetings?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B7. Do you find care reviews helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Your Care Co-ordinator

A Care Co-ordinator (or keyworker) is someone from Mental Health Services who keeps in regular contact with you.

B8. Have you been told who your Care Co-ordinator is?

- 1 Yes → Go to B9
2 No → Go to C1
3 Not sure/ Don't know → Go to C1

B9. How long is it since you **last saw** your Care Co-ordinator?

- 1 Less than one month
2 1-3 months
3 3-6 months
4 More than 6 months

B10. Can you contact your Care Co-ordinator if you have a problem?

- 1 Yes, always
2 Yes, sometimes
3 No

C. SUPPORT IN THE COMMUNITY

Day centres

Some mental health service users go to a day centre where staff are available to help with problems, and activities are arranged.

C1. In the last 12 months, how often have you visited a day centre?

- 1 Most days → Go to C2
2 Once or twice a week → Go to C2
3 Once or twice a month → Go to C2
4 I have not visited a day centre in the last 12 months → Go to C3

C2. How would you rate the activities the centre provides?

- 1 Excellent
2 Very good
3 Good
4 Fair
5 Poor

Where you live

C3. In the last 12 months, have you received any help with accommodation?

- 1 Yes
2 No, but I would have liked help
3 I didn't need any help

C4. Do you feel **safe** in the place where you live now?

- 1 Yes, completely
2 Yes, to some extent
3 No

Work

C5. Are you currently working? (**Tick ONE only**)

- 1 Yes, I am in full-time paid work
2 Yes, I am in part-time paid work
3 Yes, I am self-employed
4 I work on a casual basis
5 I work on a voluntary basis
6 I am not employed
7 I am a full-time student
8 I am retired

C6. In the last 12 months have you received help with finding work?

- 1 Yes
- 2 No, but I would have liked help
- 3 I didn't need any help

Benefits

C7. In the last 12 months have you received help with getting benefits?

- 1 Yes
- 2 No, but I would have liked help
- 3 I didn't need any help

Local support groups

C8. In the last 12 months have you received any information about local support groups for mental health service users?

- 1 Yes
- 2 No, but I would have liked information
- 3 I didn't need any information

D. CRISIS CARE

D1. Do you have the number of someone in Mental Health Services that you can call out of office hours?

- 1 Yes → Go to D2
- 2 No → Go to E1
- 3 Not sure/ Don't know → Go to E1

D2. In the last 12 months, have you called this number?

- 1 Yes → Go to D3
- 2 No → Go to E1

D3. The last time you called the number, how long did it take you to get through to someone?

- 1 I got through immediately
- 2 I got through in one hour or less
- 3 A few hours
- 4 A day or more
- 5 I couldn't get through to anyone

E. HEALTH PROFESSIONALS

Psychiatrists

E1. Have you seen a psychiatrist in the last 12 months?

- 1 Yes → Go to E2
- 2 No → Go to E6

E2. Do you feel that your psychiatrist listens to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E3. Do you have trust and confidence in your psychiatrist's professional skills?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E4. Do you feel your psychiatrist treats you with respect and dignity?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

E5. When you see your psychiatrist, are you given enough time to discuss your condition and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Community Psychiatric Nurse (CPN)

E6. Have you seen a CPN in the last 12 months?

- 1 Yes → Go to E7
- 2 No → Go to E10

E7. Do you feel that your CPN listens to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E8. Do you have trust and confidence in your CPN's professional skills?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E9. Do you feel your CPN treats you with respect and dignity?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

Social workers

E10. Have you seen a social worker in the last 12 months?

- 1 Yes → Go to E11
- 2 No → Go to F1

E11. Do you feel that your social worker listens to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E12. Do you have trust and confidence in your social worker's professional skills?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E13. Do you feel your social worker treats you with respect and dignity?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

F. STANDARDS

Complaints

F1. In the last 12 months, have you made a complaint about Mental Health Services?

- 1 Yes → Go to F3
- 2 No → Go to F2

F2. If you **did not** make a complaint, why didn't you? **(Please tick all that apply)**

- 1 I was satisfied with the service
- 2 No point, no-one would listen
- 3 It might upset the staff who care for me
- 4 My care might be affected
- 5 I tried but was prevented
- 6 I was too frightened
- 7 I did not know how to make a complaint

Medical Records

F3. In the last 12 months, have you asked to see your medical records?

- 1 Yes → Go to F4
- 2 No, I did not want to see them → Go to F5
- 3 No, I did not know I could see them → Go to F5

F4. Did you get to see your medical records?

- 1 Yes, I saw all that I wanted to see
- 2 I saw some but they held some back
- 3 No, I was not able to see them

Mental Health Act

F5. In the last 12 months, have you been detained under the Mental Health Act?

- 1 Yes → Go to F6
- 2 No → Go to F7

F6. Were your rights explained to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No

Discrimination

F7. Do you feel you are discriminated against by mental health professionals?
(Please tick all that apply)

- 1 Yes, because of my **race**
- 2 Yes, because of my **religion**
- 3 Yes, because of my **sex**
- 4 Yes, because of my **sexual orientation**
- 5 Yes, because of a **physical disability**
- 6 Yes, because of my **mental health problems**
- 7 No, I have not been discriminated against

G. OVERALL

G1. Overall, how would you rate the care you have received from Mental Health Services in the last 12 months?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

G2. Do you feel you have enough say in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

G3. Do you ever feel lonely?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

G4. Have you been admitted to a hospital as a mental health patient in the last 12 months?

- 1 No
- 2 Yes, once
- 3 Yes, 2 or 3 times
- 4 Yes, more than 3 times

H. YOUR BACKGROUND

H1. To which of these ethnic groups would you say you belong? (Tick **ONE** only)

a. WHITE

- 1 British
2 Irish
3 Any other White background
(Please write in box)

b. MIXED

- 4 White and Black Caribbean
5 White and Black African
6 White and Asian
7 Any other Mixed background
(Please write in box)

c. ASIAN OR ASIAN BRITISH

- 8 Indian
9 Pakistani
10 Bangladeshi
11 Any other Asian background
(Please write in box)

d. BLACK OR BLACK BRITISH

- 12 Caribbean
13 African
14 Any other Black background
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

- 15 Chinese
16 Any other ethnic group
(Please write in box)

H2. Are you male or female?

- 1 Male
2 Female

H3. How old are you?

- 1 18-25 years
2 26-35 years
3 36-45 years
4 46-55 years
5 56 years or older

I. OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

No stamp is needed.

Picker Institute Europe
FREEPOST (SCE10829),
OXFORD, OX1 1YE

15 Appendix 3 Service User Questionnaire used in Voluntary Survey

Service User Questionnaire

What is the survey about?

This survey is about the health services you receive from the National Health Service.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire.

Your participation in this survey is voluntary.

If you choose to take part, your answers will be treated **in confidence**.

A. YOUR CARE AND TREATMENT

A1. How long have you been in contact with mental health services?

- 1 1 year or less → Go to A2
- 2 1 to 5 years → Go to A2
- 3 More than 5 years → Go to A2
- 4 Don't know/ Can't remember → Go to A2
- 5 I have never been in contact with mental health services → Go to Section H on Page 7

Medications

A2. In the last 12 months have you taken any medications for your mental health problems?

- 1 Yes → Go to A3
- 2 No → Go to A6

A3. Have the purposes of the medications been explained to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

A4. Were you told about possible side effects of the medications?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

A5. Do you have a say in decisions about the medication you take?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Talking therapies

A6. In the last 12 months would you have liked any talking therapy (e.g. counselling)?

- 1 Yes
- 2 No

A7. In the last 12 months have you had any talking therapy (e.g. counselling)?

- 1 Yes, I have had talking therapy from Mental Health Services
- 2 Yes, I have had talking therapy from somewhere else (e.g. voluntary organisation, private therapist)
- 3 No, I have not had any talking therapy in the last 12 months

B. YOUR CARE PLAN (CPA)

A care plan shows your mental health needs and who will provide services for you.

B1. Do you have a **written or printed** copy of your care plan?

- 1 Yes
- 2 No
- 3 Don't know

B2. Do you **understand** what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know
- 5 I don't have a care plan

B3. Do you **agree** with what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

Your care review

A care review is a meeting with you and the people involved in your care in which you discuss how your care plan is working.

B4. In the last 12 months have you had a care review?

- 1 Yes, I've had more than one → **Go to B5**
- 2 Yes, I've had one → **Go to B5**
- 3 No, I have not had a care review in the last 12 months → **Go to B8**

B5. Were you told that you could bring a friend or relative to your care review meetings?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember
- 4 I did not want to invite a friend or relative

B6. Do you feel able to express your views at these meetings?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B7. Do you find the care reviews helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Your Care Co-ordinator

A Care Co-ordinator (or keyworker) is someone from Mental Health Services who keeps in regular contact with you.

B8. Have you been told who your Care Co-ordinator is?

- 1 Yes → **Go to B9**
- 2 No → **Go to C1**
- 3 Not sure/ Don't know → **Go to C1**

B9. How long is it since you **last saw** your Care Co-ordinator?

- 1 Less than one month
- 2 1-3 months
- 3 3-6 months
- 4 More than 6 months

B10. Can you contact your Care Co-ordinator if you have a problem?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

C. SUPPORT IN THE COMMUNITY

Day centres

Some mental health service users go to a day centre where staff are available to help with problems, and activities are arranged.

C1. In the last 2 months, how often have you visited a day centre?

- 1 Most days → Go to C2
- 2 Once or twice a week → Go to C2
- 3 Once or twice a month → Go to C2
- 4 I have not visited a day centre in the last 2 months → Go to C3

C2. How would you rate the activities the centre provides?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

Where you live

C3. In the last 12 months, have you received any help with accommodation?

- 1 Yes
- 2 No, but I would have liked help
- 3 I didn't need any help

C4. Do you feel **safe** in the place where you live now?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No

Work

C5. Are you currently working? (Tick **ONE** only)

- 1 Yes, I am in full-time paid work
- 2 Yes, I am in part-time paid work
- 3 Yes, I am self-employed
- 4 I work on a casual basis
- 5 I work on a voluntary basis
- 6 I am not employed
- 7 I am a full-time student
- 8 I am retired
- 9 I am unable to work due to my illness

C6. In the last 12 months have you received help with finding work?

- 1 Yes
- 2 No, but I would have liked help
- 3 I didn't need any help

Benefits

C7. In the last 12 months have you received help with getting benefits?

- 1 Yes
- 2 No, but I would have liked help
- 3 I didn't need any help

Local support groups

C8. In the last 12 months have you received any information about local support groups for mental health service users?

- 1 Yes
- 2 No, but I would have liked information
- 3 I didn't need any information

D. CRISIS CARE

D1. Do you have the number of someone in Mental Health Services that you can call out of office hours?

- 1 Yes → Go to D2
2 No → Go to E1
3 Not sure/ Don't know → Go to E1

D2. In the last 12 months, have you called this number?

- 1 Yes → Go to D3
2 No → Go to E1

D3. The last time you called the number, how long did it take you to get through to someone?

- 1 I got through immediately
2 I got through in one hour or less
3 A few hours
4 A day or more
5 I couldn't get through to anyone

E. HEALTH PROFESSIONALS

Psychiatrists

E1. Have you seen a psychiatrist in the last 12 months?

- 1 Yes → Go to E2
2 No → Go to E6

E2. Do you feel that your psychiatrist listens to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

E3. Do you have trust and confidence in your psychiatrist's professional skills?

- 1 Yes, definitely
2 Yes, to some extent
3 No

E4. Do you feel your psychiatrist treats you with respect and dignity?

- 1 Yes, always
2 Yes, sometimes
3 No

E5. When you see your psychiatrist, are you given enough time to discuss your condition and treatment?

- 1 Yes, definitely
2 Yes, to some extent
3 No

Community Psychiatric Nurse (CPN)

E6. Have you seen a CPN in the last 12 months?

- 1 Yes → Go to E7
2 No → Go to E10

E7. Do you feel that your CPN listens to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

E8. Do you have trust and confidence in your CPN's professional skills?

- 1 Yes, definitely
2 Yes, to some extent
3 No

E9. Do you feel your CPN treats you with respect and dignity?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

Social workers

E10. Have you seen a social worker in the last 12 months?

- 1 Yes → **Go to E11**
- 2 No → **Go to F1**

E11. Do you feel that your social worker listens to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E12. Do you have trust and confidence in your social worker's professional skills?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E13. Do you feel your social worker treats you with respect and dignity?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

F. STANDARDS

Complaints

F1. In the last 12 months, have you made a complaint about Mental Health Services?

- 1 Yes → **Go to F3**
- 2 No → **Go to F2**

F2. If you **did not** make a complaint, why didn't you? (**Please tick all that apply**)

- 1 I was satisfied with the service
- 2 No point, no-one would listen
- 3 It might upset the staff who care for me
- 4 My care might be affected
- 5 I tried but was prevented
- 6 I was too frightened
- 7 I did not know how to make a complaint

Medical Records

F3. In the last 12 months, have you asked to see your medical records?

- 1 Yes → **Go to F4**
- 2 No, I did not want to see them → **Go to F5**
- 3 No, I did not know I could see them → **Go to F5**

F4. Did you get to see your medical records?

- 1 Yes, I saw all that I wanted to see
- 2 I saw some but they held some back
- 3 No, I was not able to see them

Mental Health Act

F5. In the last 12 months, have you been detained under the Mental Health Act?

- 1 Yes → Go to F6
2 No → Go to F7

F6. Were your rights explained to you?

- 1 Yes, completely
2 Yes, to some extent
3 No

Discrimination

F7. Do you feel you are discriminated against by mental health professionals?
(Please tick all that apply)

- 1 Yes, because of my **race**
2 Yes, because of my **religion**
3 Yes, because of my **sex**
4 Yes, because of my **sexual orientation**
5 Yes, because of a **physical disability**
6 Yes, because of my **mental health problems**
7 Yes, for **another reason**
8 No, I have not been discriminated against

G. OVERALL

G1. Overall, how would you rate the care you have received from Mental Health Services in the last 12 months?

- 1 Excellent
2 Very good
3 Good
4 Fair
5 Poor
6 Very poor

G2. Do you feel you have enough say in decisions about your care and treatment?

- 1 Yes, definitely
2 Yes, to some extent
3 No

G3. Do you ever feel lonely?

- 1 Yes, often
2 Yes, sometimes
3 No

G4. Have you been admitted to a hospital as a mental health patient in the last 12 months?

- 1 No
2 Yes, once
3 Yes, 2 or 3 times
4 Yes, more than 3 times

H. YOUR BACKGROUND

H1. Are you male or female?

- 1 Male
2 Female

H2. How old are you?

- 1 16-25 years
2 26-35 years
3 36-45 years
4 46-55 years
5 56 years or older

H3. To which of these ethnic groups would you say you belong? (Tick ONE only)

a. WHITE

- 1 British
- 2 Irish
- 3 Any other White background
(Please write in box)

b. MIXED

- 4 White and Black Caribbean
- 5 White and Black African
- 6 White and Asian
- 7 Any other Mixed background
(Please write in box)

c. ASIAN OR ASIAN BRITISH

- 8 Indian
- 9 Pakistani
- 10 Bangladeshi
- 11 Any other Asian background
(Please write in box)

d. BLACK OR BLACK BRITISH

- 12 Caribbean
- 13 African
- 14 Any other Black background
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

- 15 Chinese
- 16 Any other ethnic group
(Please write in box)

I. OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

No stamp is needed.

16 Appendix 4 Service User Questionnaire used in Autumn Pilot Survey

Service User Questionnaire

What is the survey about?

This survey is about the health services you receive from the National Health Service.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the Picker Institute Europe FREEPHONE helpline number: 0800 197 5273.

Please Return to:
Picker Institute Europe FREEPOST (SCE10829) OXFORD OX1 1YE NNNNN

Your participation in this survey is voluntary.

If you choose to take part, your answers will be treated **in confidence**.

A. YOUR CARE AND TREATMENT

A1. How long have you been in contact with mental health services?

- 1 1 year or less → Go to B1
- 2 1 to 5 years → Go to B1
- 3 More than 5 years → Go to B1
- 4 Don't know/ Can't remember
→ Go to B1
- 5 I have never been in contact with mental health services
→ Go to Section K on Page 7

B. HEALTH PROFESSIONALS

Psychiatrists

B1. Have you seen a psychiatrist in the last 12 months?

- 1 Yes → Go to B2
- 2 No → Go to B7

The LAST time you saw a psychiatrist...

B2. Did the psychiatrist listen carefully to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B3. Did you have trust and confidence in the psychiatrist you saw?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B4. Did the psychiatrist treat you with respect and dignity?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Still thinking about the LAST time you saw a psychiatrist...

B5. Were you given enough time to discuss your condition and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B6. The last 2 times you had an appointment with a psychiatrist, was it...?

- 1 With the **same** psychiatrist both times
- 2 With two **different** psychiatrists

Community Psychiatric Nurse (CPN)

B7. Have you seen a CPN in the last 12 months?

- 1 Yes → Go to B8
- 2 No → Go to B11

The LAST time you saw a CPN...

B8. Did the CPN listen carefully to you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B9. Did you have trust and confidence in the CPN?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

B10. Did the CPN treat you with respect and dignity?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Social workers

B11. Have you seen a social worker in the last 12 months?

- 1 Yes → Go to B12
2 No → Go to C1

The LAST time you saw a social worker...

B12. Did the social worker listen carefully to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

B13. Did you have trust and confidence in the social worker?

- 1 Yes, definitely
2 Yes, to some extent
3 No

B14. Did the social worker treat you with respect and dignity?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C. MEDICATIONS

C1. In the last 12 months have you taken any medications for your mental health problems?

- 1 Yes → Go to C2
2 No → Go to D1

C2. Do you have a say in decisions about the medication you take?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C3. In the last 12 months, have any **new** medications (e.g. tablets, injections, liquid medicines, etc.) been prescribed for you by a psychiatrist?

- 1 Yes → Go to C4
2 No → Go to D1
3 Can't remember → Go to D1

The LAST time you had a new medication prescribed for you...

C4. Were the **purposes** of the medications explained to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C5. Were you told about possible **side effects** of the medications?

- 1 Yes, definitely
2 Yes, to some extent
3 No

D. TALKING THERAPIES

D1. In the last 12 months have you had any talking therapy (e.g. counselling)?

- 1 Yes, I have had talking therapy from NHS Mental Health Services
2 Yes, I have had talking therapy from somewhere else (e.g. voluntary organisation, private therapist)
3 No, I have not had any talking therapy in the last 12 months

D2. In the last 12 months, **did you want** talking therapy?

- 1 Yes
2 No

E. YOUR CARE PLAN (CPA)

A **care plan** shows your mental health needs and who will provide services for you.

E1. Have you been given a **written or printed** copy of your care plan?

- 1 Yes
- 2 No
- 3 Don't know

E2. Do you **understand** what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know
- 5 I don't have a care plan

E3. Do you **agree** with what is in your care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

Your care review

A **care review** is a meeting with you and the people involved in your care in which you discuss how your care plan is working.

E4. In the last 12 months have you had a care review?

- 1 Yes, I've had more than one → Go to E5
- 2 Yes, I've had one → Go to E5
- 3 No, I have not had a care review in the last 12 months → Go to E8

E5. Were you told that you could bring a friend or relative to your care review meetings?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember
- 4 I did not want to invite a friend or relative

The LAST time you had a care review meeting...

E6. Were you given a chance to express your views at the meeting?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

E7. Did you find the care review helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Your Care Co-ordinator

A **Care Co-ordinator (or keyworker)** is someone from Mental Health Services who keeps in regular contact with you. For example, this person could be a Community Psychiatric Nurse (CPN) or a Social Worker.

E8. Have you been told who your Care Co-ordinator is?

- 1 Yes → Go to E9
- 2 No → Go to F1
- 3 Not sure/ Don't know → Go to F1

E9. How long is it since you **last saw** your Care Co-ordinator?

- 1 Less than one month
- 2 1-3 months
- 3 3-6 months
- 4 More than 6 months

E10. Can you contact your Care Co-ordinator if you have a problem?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

F. SUPPORT IN THE COMMUNITY

Day centres or day hospitals

Some mental health service users go to a day centre where staff are available to help with problems, and activities are arranged.

F1. In the last 2 months, how often have you visited a day centre?

- 1 Most days → Go to F2
- 2 Once or twice a week → Go to F2
- 3 Once or twice a month → Go to F2
- 4 I have not visited a day centre in the last 2 months → Go to F3

F2. Were the activities provided by the centre helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Where you live

F3. In the last 12 months, have you received any help with accommodation?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help

Other support in the community

F4. In the last 12 months have you received help with **finding work**?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help
- 4 I am unable to work because of my mental health problems

F5. Are you currently in paid work? (Tick **ONE** only)

- 1 Yes
- 2 No
- 3 No, but I work on a casual or voluntary basis
- 4 No, but I am a full-time student

F6. In the last 12 months have you received help with **getting benefits**?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help

F7. In the last 12 months have you received any information about **local support groups** for mental health service users?

- 1 Yes
- 2 No, but I would have liked information
- 3 I did not need any information

F8. When was the **last time** you saw someone about your mental health problem?

- 1 Less than one month ago
- 2 1-3 months ago
- 3 3-6 months ago
- 4 More than 6 months ago

F9. In the last 12 months, have any appointments been cancelled or changed by mental health services?

- 1 No
- 2 Yes, 1 appointment was cancelled or changed
- 3 Yes, 2 or 3 appointments have been cancelled or changed
- 4 Yes, 4 or more appointments have been cancelled or changed

G. CRISIS CARE

G1. Do you have the number of someone in Mental Health Services that you can call out of office hours?

- 1 Yes → Go to G2
- 2 No → Go to H1
- 3 Not sure/ Don't know → Go to H1

G2. In the last 12 months, have you called this number?

- 1 Yes → Go to G3
- 2 No → Go to H1

G3. The last time you called the number, how long did it take you to get through to someone?

- 1 I got through immediately
- 2 I got through in one hour or less
- 3 A few hours
- 4 A day or more
- 5 I couldn't get through to anyone

H. STANDARDS

Mental Health Act

H1. Have you been admitted to a hospital as a mental health patient in the last 12 months?

- 1 No
- 2 Yes, once
- 3 Yes, 2 or 3 times
- 4 Yes, more than 3 times

H2. In the last 12 months, have you been detained (sectioned) under the Mental Health Act?

- 1 Yes → Go to H3
- 2 No → Go to J1

H3. When you were sectioned, were your rights explained to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No

J. OVERALL

J1. Overall, how would you rate the care you have received from Mental Health Services in the last 12 months?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

J2. Do you have enough say in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

J3. Has your diagnosis been discussed with you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

K. ABOUT YOU

K1. Are you male or female?

- 1 Male
- 2 Female

K2. What was your **year of birth**?

(Please write in) e.g.

1	9	3	4
---	---	---	---

--	--	--	--

K3. Who else, if anybody do you live with?
(Tick all that apply)

- 1 No-one, I live alone
- 2 Partner
- 3 Child/children under 18
- 4 Child/children over 18
- 5 A parent or guardian
- 6 With other family members
- 7 With people other than family members

K4. During the past 4 weeks how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?

- 1 Not at all
- 2 Slightly
- 3 Moderately
- 4 Quite a lot
- 5 Extremely

K5. In general, how is your mental health right now?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

K6. To which of these ethnic groups would you say you belong? (Tick ONE only)

a. WHITE

- 1 British
- 2 Irish
- 3 Any other White background
(Please write in box)

b. MIXED

- 4 White and Black Caribbean
- 5 White and Black African
- 6 White and Asian
- 7 Any other Mixed background
(Please write in box)

c. ASIAN OR ASIAN BRITISH

- 8 Indian
- 9 Pakistani
- 10 Bangladeshi
- 11 Any other Asian background
(Please write in box)

d. BLACK OR BLACK BRITISH

- 12 Caribbean
- 13 African
- 14 Any other Black background
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

- 15 Chinese
- 16 Any other ethnic group
(Please write in box)

L. OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

No stamp is needed.

Picker Institute Europe
FREEPOST (SCE10829),
OXFORD, OX1 1YE

17 Appendix 5 Service User Questionnaire used in main 2004 Survey

Service User Questionnaire

What is the survey about?

This survey is about the health services you receive from the National Health Service.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

Your participation in this survey is voluntary.

If you choose to take part, your answers will be treated **in confidence**.

A. YOUR CARE AND TREATMENT

- A1. How long have you been in contact with mental health services?
- 1 1 year or less → Go to B1
 - 2 1 to 5 years → Go to B1
 - 3 More than 5 years → Go to B1
 - 4 Don't know/ Can't remember → Go to B1
 - 5 I have never been in contact with mental health services → Go to Section K on Page 7

B. HEALTH PROFESSIONALS

Psychiatrists

- B1. Have you seen a psychiatrist in the last 12 months?
- 1 Yes → Go to B2
 - 2 No → Go to B7

The LAST time you saw a psychiatrist...

- B2. Did the psychiatrist listen carefully to you?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
- B3. Did you have trust and confidence in the psychiatrist you saw?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
- B4. Did the psychiatrist treat you with respect and dignity?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No

Still thinking about the LAST time you saw a psychiatrist...

- B5. Were you given enough time to discuss your condition and treatment?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
- B6. The last 2 times you had an appointment with a psychiatrist, was it...?
- 1 With the **same** psychiatrist both times
 - 2 With two **different** psychiatrists

Community Psychiatric Nurse (CPN)

- B7. Have you seen a CPN in the last 12 months?
- 1 Yes → Go to B8
 - 2 No → Go to B11

The LAST time you saw a CPN...

- B8. Did the CPN listen carefully to you?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
- B9. Did you have trust and confidence in the CPN?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
- B10. Did the CPN treat you with respect and dignity?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No

Other health professionals

B11. Have you seen anyone else in mental health services in the last 12 months?

- 1 Yes → Go to B12
2 No → Go to C1

B12. The **last time** you saw someone, other than a psychiatrist or CPN, who did you see?
(Tick **ONE** only)

- 1 A social worker
2 An occupational therapist
3 A psychologist
4 Someone else

The LAST time you saw this person...

B13. Did they listen carefully to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

B14. Did you have trust and confidence in the person that you saw?

- 1 Yes, definitely
2 Yes, to some extent
3 No

B15. Did the person treat you with respect and dignity?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C. MEDICATIONS

C1. In the last 12 months have you taken any medications for your mental health problems?

- 1 Yes → Go to C2
2 No → Go to D1

C2. Do you have a say in decisions about the medication you take?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C3. In the last 12 months, have any **new** medications (e.g. tablets, injections, liquid medicines, etc.) been prescribed for you by a psychiatrist?

- 1 Yes → Go to C4
2 No → Go to D1
3 Can't remember → Go to D1

The LAST time you had a new medication prescribed for you...

C4. Were the **purposes** of the medications explained to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

C5. Were you told about possible **side effects** of the medications?

- 1 Yes, definitely
2 Yes, to some extent
3 No

D. TALKING THERAPIES

D1. In the last 12 months have you had any talking therapy (e.g. counselling) from NHS Mental Health Services?

1 Yes

2 No

D2. In the last 12 months, **did you want** talking therapy?

1 Yes

2 No

E. YOUR CARE PLAN (CPA)

A **care plan** shows your mental health needs and who will provide services for you. It might be a document given to you by one of the mental health team, or it might be a letter, explaining how your care has been planned.

E1. Have you been given (or offered) a **written or printed** copy of your care plan?

1 Yes

2 No

3 Don't know/ Not sure

E2. Do you **understand** what is in your care plan?

1 Yes, definitely

2 Yes, to some extent

3 No

4 Don't know

5 I do not have a care plan

E3. Do you **agree** with what is in your care plan?

1 Yes, definitely

2 Yes, to some extent

3 No

4 Don't know

Your care review

A **care review** is a meeting with you and the people involved in your care in which you discuss how your care plan is working.

E4. In the last 12 months have you had a care review?

1 Yes, I have had more than one

→ Go to E5

2 Yes, I have had one

→ Go to E5

3 No, I have not had a care review in the last 12 months

→ Go to E8

E5. Were you told that you could bring a friend or relative to your care review meetings?

1 Yes

2 No

3 Don't know / Can't remember

4 I did not want to invite a friend or relative

The LAST time you had a care review meeting...

E6. Were you given a chance to express your views at the meeting?

1 Yes, definitely

2 Yes, to some extent

3 No

E7. Did you find the care review helpful?

1 Yes, definitely

2 Yes, to some extent

3 No

Your Care Co-ordinator

A Care Co-ordinator (or keyworker) is someone from Mental Health Services who keeps in regular contact with you. For example, this person could be a Community Psychiatric Nurse (CPN) or a Social Worker.

E8. Have you been told who your Care Co-ordinator is?

- 1 Yes → Go to E9
- 2 No → Go to F1
- 3 Not sure/ Don't know → Go to F1

E9. How long is it since you **last saw** your Care Co-ordinator?

- 1 Less than one month
- 2 1-3 months
- 3 3-6 months
- 4 More than 6 months

E10. Can you contact your Care Co-ordinator if you have a problem?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

F. SUPPORT IN THE COMMUNITY

Day centres or day hospitals

Some mental health service users go to a day centre where staff are available to help with problems, and activities are arranged.

F1. In the last 2 months, how often have you visited a day centre?

- 1 Most days → Go to F2
- 2 Once or twice a week → Go to F2
- 3 Once or twice a month → Go to F2
- 4 I have not visited a day centre in the last 2 months → Go to F3

F2. Were the activities provided by the centre helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Where you live

F3. In the last 12 months, have you received any help with accommodation?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help

Other support in the community

F4. In the last 12 months have you received help with **finding work**?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help
- 4 I am unable to work because of my mental health problems

F5. Are you currently in paid work? (Tick **ONE** only)

- 1 Yes
- 2 No
- 3 No, but I work on a casual or voluntary basis
- 4 No, but I am a full-time student

F6. In the last 12 months have you received help with **getting benefits**?

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help

F7. In the last 12 months have you received any information about **local support groups** for mental health service users?

- 1 Yes
- 2 No, but I would have liked information
- 3 I did not need any information

F8. When was the **last time** you saw someone about your mental health problem?

- 1 Less than one month ago
- 2 1-3 months ago
- 3 3-6 months ago
- 4 More than 6 months ago

F9. In the last 12 months, have any appointments been cancelled or changed by mental health services?

- 1 No
- 2 Yes, 1 appointment was cancelled or changed
- 3 Yes, 2 or 3 appointments have been cancelled or changed
- 4 Yes, 4 or more appointments have been cancelled or changed

G. CRISIS CARE

G1. Do you have the number of someone in Mental Health Services that you can call out of office hours?

- 1 Yes → **Go to G2**
- 2 No → **Go to H1**
- 3 Not sure/ Don't know → **Go to H1**

G2. In the last 12 months, have you called this number?

- 1 Yes → **Go to G3**
- 2 No → **Go to H1**

G3. The **last time** you called the number, how long did it take you to get through to someone?

- 1 I got through immediately
- 2 I got through in one hour or less
- 3 A few hours
- 4 A day or more
- 5 I could not get through to anyone

H. STANDARDS

Mental Health Act

H1. Have you been admitted to a hospital as a mental health patient in the last 12 months?

- 1 No
- 2 Yes, once
- 3 Yes, 2 or 3 times
- 4 Yes, more than 3 times

H2. In the last 12 months, have you been detained (sectioned) under the Mental Health Act?

- 1 Yes → **Go to H3**
- 2 No → **Go to J1**

H3. When you were sectioned, were your rights explained to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No

J. OVERALL

J1. Overall, how would you rate the care you have received from Mental Health Services in the last 12 months?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

J2. Do you have enough say in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

J3. Has your diagnosis been discussed with you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

K. ABOUT YOU

K1. Are you male or female?

- 1 Male
- 2 Female

K2. What was your **year of birth**?

(Please write in) e.g.

1	9	3	4
---	---	---	---

1	9		
---	---	--	--

K3. Who else, if anybody do you live with?
(Tick all that apply)

- 1 No-one, I live alone
- 2 Partner
- 3 Child/children under 18
- 4 Child/children over 18
- 5 A parent or guardian
- 6 With other family members
- 7 With people other than family members

K4. During the past 4 weeks how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?

- 1 Not at all
- 2 Slightly
- 3 Moderately
- 4 Quite a lot
- 5 Extremely

K5. In general, how is your mental health right now?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

K6. To which of these ethnic groups would you say you belong? (Tick ONE only)

a. WHITE

- 1 British
- 2 Irish
- 3 Any other White background
(Please write in box)

b. MIXED

- 4 White and Black Caribbean
- 5 White and Black African
- 6 White and Asian
- 7 Any other Mixed background
(Please write in box)

c. ASIAN OR ASIAN BRITISH

- 8 Indian
- 9 Pakistani
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d. BLACK OR BLACK BRITISH

- 12 Caribbean
- 13 African
- 14 Any other Black background
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

- 15 Chinese
- 16 Any other ethnic group
(Please write in box)

L. OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

Is there anything particularly good about your care?

Is there anything that could be improved?

Any other comments?

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

No stamp is needed.