

National Summary of the Results for the 2013 Community Mental Health Survey

This national summary provides key findings from the 2013 survey of people who use community mental health services, and highlights statistically significant differences between 2012 (the last time the survey was carried out) and 2013. A 'statistically significant' difference means that the change in the results is very unlikely to have occurred by chance. Where comparisons are not presented, this is because there has not been a statistically significant change.

The 2013 survey involved 58¹ NHS trusts in England (including combined mental health and social care trusts, Foundation Trusts and community healthcare social enterprises that provide mental health services). Responses were received from more than 13,000 service users, a national response rate of 29%.² Service users aged 18 and over were eligible for the survey if they were receiving specialist care or treatment for a mental health condition and had been seen by the trust between 1 July 2012 and 30 September 2012.

The results are primarily intended for use by NHS trusts to help them improve their performance. NHS England will use the results to understand service users' experiences of NHS services and to drive improvements to them. The CQC has included data from this survey in its Quality and Risk Profiles to assess compliance with the essential standards of quality and safety. In the future, questions from the survey will be used in the new CQC surveillance model. For more information on the consultation regarding how CQC is proposing to regulate trusts going forwards please see the further information section. The CQC has published data for all NHS trusts on the CQC website. A set of tables showing the national year on year results for each question is also available on the CQC website which includes information on how the national results were calculated.

At the end of the questionnaire, respondents are also able to write comments about their experiences. They are asked three questions: if there was anything particularly good about their care, if there was anything that could be improved, and if they had any other comments. For the first time, at the end of this document there is a summary analysis of the comments made by a sample of all respondents.

¹ One trust was excluded from the survey as it was unable to follow the sampling instructions as specified in the survey guidance

² At trust level, response rates ranged from 20-40%

The Care Programme Approach

The term 'Care Programme Approach' (CPA) describes the framework that was introduced in 1990 to support and co-ordinate effective mental health care for people using secondary mental health services. Although the policy has been revised over time³, the CPA remains the central approach for co-ordinating the care for people in contact with these services who have more complex mental health needs and who need the support of a multidisciplinary team. The characteristics of those requiring CPA is set out in the policy document, *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance* and trusts should assess individuals' needs in accordance with this.

There are likely to be some differences in the experiences of service users for some questions depending on whether or not they receive community mental health services under the CPA. This is partly due to the different service requirements for people on CPA who, as a result, may have different patterns of care. This document presents findings separately where policy guidance sets out differences between the care pathway of those who are on CPA and those who are not. Forty percent of the service users who responded to the 2013 survey had their care co-ordinated on CPA.

Summary

This section highlights some of the key findings from the survey. The full results are discussed in the subsequent sections.

People generally responded positively to questions asking about staff: this includes the health or social care worker that they had seen most recently and their care coordinator (or lead professional). However, scope for improvement remains in most other areas including information and involvement in: decisions about medication, care planning, care reviews, crisis care and support with day to day living.

Health and Social Care Workers

The majority of service users responded positively to questions about the health or social care worker that they had seen most recently and said that they 'definitely':

- Were listened to carefully (78%)
- Had their taken views into account (72%)
- Had trust and confidence in the person that they had seen (70%) though this was down from 71% in 2012

³ The most recent revision to CPA policy was in 2008 with the publication of *Refocusing the Care Programme Approach*, available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_083649.pdf

- Were treated with respect and dignity (86%)
- Were given enough time to discuss their condition and treatment (70%), though this was down from 72% in 2012.

Medications

The results around medication showed no statistically significant improvements from the 2012 survey suggesting that there remains scope for improving information provision and service user involvement:

- Almost a third (32%) said that their views were only taken into account 'to some extent' when deciding which medication to take and almost one in eight (13%) said that their views were not.
- Of those respondents who were prescribed new medication by an NHS mental health worker in the last 12 months, 69% said that the purposes of the medication were 'definitely' explained to them. Less than half (43%) were 'definitely' told about the possible side effects. Just over half (52%) were 'definitely' given information about the new medication in a way they could understand.
- Almost a quarter (23%) of respondents who had been on prescribed medication for 12 months or longer said that their medication had **not** been reviewed.

Care Coordinators or Lead Professionals

The survey shows that some respondents say they do not know who their care coordinator or lead professional is:

- For respondents **on CPA**, 11% did not know and 5% were unsure
- For respondents **not on CPA**, 33% did not know and 10% were unsure.

Though the majority of respondents who know who their care coordinator is were generally positive about them, results had declined from 2012:

- Seventy two percent said that they could 'always' contact their care coordinator (or lead professional) if they had a problem, down from 74% in 2012.
- Sixty percent said that their care coordinator (or lead professional) organised the care and services they need 'very well' down from 61% in 2012.

Care Plans

The survey shows that some respondents say they either do not have an NHS care plan, or do not fully understand it:

- Fourteen percent of respondents **on CPA** said that they do not have one. Of the remainder, 46% 'definitely' understand their NHS care plan (down from 48% in 2012), 32% do 'to some extent' and 9% said they do not.
- Forty two percent of respondents **not on CPA** said that they do not have one. Of the remainder, 26% said that they 'definitely' understand it, 23% do 'to some extent' and 9% said that they do not understand it.

Of those respondents who had an NHS care plan:

- Some respondents said they have not been given or offered a written or printed copy of their NHS care plan: 24% of those **on CPA** and 44% of those **not on CPA** responded this way.
- Over half (54%) said that their views were ‘definitely’ taken into account when deciding what was in their NHS care plan.
- Less than half (42%) said that their NHS care plan ‘definitely’ set out their goals. Of those respondents whose NHS care plan set out their goals, less than half (44%) said that the NHS mental health services they receive have ‘definitely’ helped them start achieving these goals.
- When asked if their NHS care plan covered what they should do in a crisis 58% of respondents **on CPA** responded ‘yes definitely’ though this is down from 60% in 2012. Less than half of those **not on CPA** (49%) responded ‘yes definitely’.

Care Review

The survey shows that some respondents say they have not had a care review in the last 12 months to discuss their care:⁴

- Twenty six percent of respondents **on CPA** said that they had not had a care review meeting in the last 12 months, up from 24% in 2012.
- Almost half (47%) of respondents **not on CPA** said that they had not had a care review in the last 12 months.

Those respondents who have had a care review in the last 12 months reported that:

- They were told they could bring a friend, relative or advocate to it (79%).
- They had the chance to talk to their care Coordinator before the care review meeting about what would happen (70%).
- They were ‘definitely’ given the chance to express their views at the care review meeting (69%)
- They ‘definitely’ found the meeting helpful (48%).
- They ‘definitely’ discussed whether they needed to continue using NHS mental health services (58%).

Crisis Care

Just over three fifths of respondents (61%, up from 59% in 2012) said that they had the number of someone from their local NHS mental health service that they could phone out of office hours. Of those who called the number, less than half (49%) said that they ‘definitely’ got the help that they wanted.

Day to Day Living

The survey results suggest that some respondents would like more support in getting help with aspects of day to day living asked about in the survey. Of those respondents who needed support:

⁴ Please note that results exclude respondents who have been in contact with services for less than a year.

- Over a third of respondents with physical health needs said that they did not receive support from someone in NHS mental health services in getting help with this but they would have liked it (37%).
- Almost two fifths said that they did not receive support from someone in NHS mental health services in getting help with care responsibilities but they would have liked it (39%).
- Almost a third (32%) of respondents **on CPA** and over half of those **not on CPA** (52%) said they did not receive support from someone in NHS mental health services in getting help with finding or keeping work but would have liked it.
- Over a quarter (28%) of respondents **on CPA**, and over half of respondents **not on CPA** (53%, up from 50% in 2012) said that they did not receive support from someone in NHS mental health services in getting help with finding and / or keeping their accommodation but would have liked it.
- Over a quarter (27%) of respondents **on CPA** and almost half of those **not on CPA** (48%) said that they did not receive support from someone in NHS mental health services in getting help with financial advice or benefits but would have liked it.

Full Results

The survey results are discussed in detail below. Where comparisons are possible, this document highlights notable changes from the 2012 survey.

Health and Social Care Workers

Most respondents (90%) had seen someone from NHS mental health services in the last six months: 56% in the last month and 34% between one and six months.

The health or social care worker seen most recently by service users for their mental health condition was a Community Psychiatric Nurse (32%) followed by: Psychiatrist (23%); Mental Health Support Worker (16%); Social Worker (8%); Psychologist (8%, up from 7% in 2012); Psychotherapist (4%); Occupational Therapist (3%); and 'other' workers (6%).

The majority of service users responded positively to questions about the health or social care worker that they had seen most recently:

- Seventy eight percent felt that they had 'definitely' been listened to carefully and 18% said that they had 'to some extent'.
- Seventy two percent said that this person had 'definitely' taken their views into account and 23% said they had 'to some extent'.
- Seventy percent (down from 71% in 2012) said that they 'definitely' had trust and confidence in the person that they had seen and 23% responded 'to some extent' (up from 22% in 2012).

- Eighty six percent said that they had ‘definitely’ been treated with respect and dignity and 11% said they were ‘to some extent’.
- Seventy percent (down from 72% in 2012) said that they were ‘definitely’ given enough time to discuss their condition and treatment and 21% said that they were ‘to some extent’.

Medications

The majority of respondents (89%) said that in the last twelve months they had taken prescribed medication for their mental health condition. Of these, over half (56%) said that their views were ‘definitely’ taken into account when deciding which medication to take and 32% said they were ‘to some extent’.

Most respondents (87%) had been on prescribed medication for twelve months or longer for their mental health condition. Over three quarters (77%) of these respondents said that an NHS mental health or social care worker had checked how they were getting on with their medication in the last twelve months, leaving 23% who said this had not occurred.

Forty five percent of respondents had been prescribed new medication by an NHS mental health worker in the last twelve months. Of these respondents:

- Over two thirds (69%) said that the purpose of the medication was ‘definitely’ explained to them and 23% (down from 25% in 2012) said it was ‘to some extent’.
- Less than half (43%) said that the possible side effects of the medication were ‘definitely’ explained to them with 29% responding ‘to some extent’.
- Just over half (52%) said that they were ‘definitely’ given information about their new medication in a way that was easy to understand and 32% said they were ‘to some extent’.

Talking Therapies

There has been increasing emphasis on the importance of providing access to evidence based psychological treatments as part of personalised care planning and this is set out in *Talking Therapies: a four year plan of action*⁵ which accompanies the cross-government mental health strategy, *No health without mental health*. This plan outlines the government’s commitment to expand and improve access to psychological therapies across a number of groups, including those with severe mental illness. Respondents were asked about their experiences in this area: talking therapies, as defined in the questionnaire, included counselling, cognitive behavioural therapy (CBT), and anxiety management.

⁵ <https://www.gov.uk/government/publications/talking-therapies-a-4-year-plan-of-action>

Just under two fifths (39%) of respondents said that they had received talking therapy from NHS mental health services in the last 12 months. Of these, 52% 'definitely' found it helpful and 37% found it helpful 'to some extent'.

Care Coordinator or Lead Professional

A care Coordinator or lead professional is the main point of contact for service users. For those receiving mental health services on CPA, the role of the care Coordinator is pivotal and involves: keeping in regular contact; co-ordinating and overseeing the service user's care plan and making sure it meets their needs; and liaising with the various professionals and agencies involved in their care and treatment. Service users not on CPA should only require the support of one agency and are allocated a 'lead professional' responsible for facilitating their care.

The majority of respondents on CPA (84%) know who their Care Coordinator is. For those not on CPA, 58% said they know who their lead professional is.

Table 1: Q19 Do you know who your Care Coordinator (or lead professional) is?

(answered by all who saw someone from NHS mental health services)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes	85%	84%	
	No	10%	11%	
	Not sure	5%	5%	
	Number of respondents	5768	5168	
Not on CPA or status unknown*	Yes	59%	58%	
	No	32%	33%	
	Not sure	9%	10%	↑
	Number of respondents	8610	7909	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

Overall, for all respondents who know who their care co-ordinator/lead professional is, the majority were generally positive, though results have declined compared with 2012. People said that:

- They could 'always' contact their care coordinator (or lead professional) if they had a problem (72%, down from 74% in 2012).
- That their care coordinator (or lead professional) organised the care and services they need 'very well' (60%, down from 61% in 2012).

Care Plans

A care plan sets out a service users assessed health and social care needs and how these will be met. In line with national guidance, there are different practice expectations for service users on CPA and those not on CPA. Service users on CPA should have a comprehensive formal written care plan detailing their care and treatment. In the case of those who are not on CPA, there is no formal requirement to have a written care plan or review. However the guidelines recommend that there should be some form of recorded agreement with the service user about how their treatment will be carried out and by whom.

Respondents were asked if they understand what is in their NHS care plan (see table 2 below). Fourteen percent of those **on CPA** said that they do not have an NHS care plan. Of the remainder, 46% 'definitely' understood it (down from 48% in 2012), 32% understood it 'to some extent' with 9% responding that they do not understand their NHS care plan. For those **not on CPA**, 42% said that they do not have a care plan. Of the remainder, 26% 'definitely' understood it, 23% understood it 'to some extent' with 9% responding that they do not understand their NHS care plan.

Table 2: Q22 Do you understand what is in your NHS care plan?

(answered by all who saw someone from NHS mental health services)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, definitely	48%	46%	↓
	Yes, to some extent	31%	32%	
	No, I don't understand it	8%	9%	
	I do not have a care plan	13%	14%	
	<i>Number of respondents</i>	<i>5122</i>	<i>4529</i>	
Not on CPA or status unknown *	Yes, definitely	26%	26%	
	Yes, to some extent	23%	23%	
	No, I don't understand it	9%	9%	
	I do not have a care plan	41%	42%	
	<i>Number of respondents</i>	<i>7459</i>	<i>6872</i>	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

The majority of respondents **on CPA** said that they have been given or offered a written or printed copy of their NHS care plan (see table 3 below), either in the last

year (59%) or more than one year ago (17%, up from 15% in 2012). Just under a quarter (24%) said they were not given or offered a written or printed copy of their NHS care plan.

For those **not on CPA** the majority of respondents said that they have been given or offered a written or printed copy of their NHS care plan, either in the last year (39%) or more than a year ago (17%). Over two fifths (44%) said they were not given or offered a written or printed copy of their NHS care plan.

Table 3: Q27 Have you been given (or offered) a written or printed copy of your NHS care plan?

(answered by all who had a care plan)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, in the last year	60%	59%	
	Yes, more than one year ago	15%	17%	↑
	No	24%	24%	
	<i>Number of respondents</i>	<i>4347</i>	<i>3876</i>	
Not on CPA or status unknown *	Yes, in the last year	39%	39%	
	Yes, more than one year ago	16%	17%	
	No	45%	44%	
	<i>Number of respondents</i>	<i>4359</i>	<i>4010</i>	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

Of those respondents who had an NHS care plan, over half (54%) said that their views were 'definitely' taken into account when deciding what was in their NHS care plan and 35% said they were 'to some extent'. Less than half (42%) said that their NHS care plan 'definitely' set out their goals and 40% said it did 'to some extent'. Of those respondents whose NHS care plan set out their goals, less than half (44%) said that the NHS mental health services they receive have helped them to start achieving these goals with 47% responding 'to some extent'.

All service users on CPA should have explicit crisis and contingency plans set out in their NHS care plan which explains what they should do in a crisis (for example, if they are not coping or if they may need to be admitted to a mental health ward). Although there is not the same policy requirement for service users not on CPA, they should be aware of who to contact in the event of a crisis. When asked if their NHS care plan covered what they should do in a crisis (see table 4 below), 58% of

respondents **on CPA** responded 'yes definitely' though this is down from 60% in 2012. Less than half of those **not on CPA** (49%) responded 'yes definitely'.

Table 4: Q26 Does your NHS care plan cover what you should do if you have a crisis (e.g. if you are not coping or if you may need to be admitted to a mental health ward)?

(answered by all who had a care plan and who understood what was in it)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, definitely	60%	58%	↓
	Yes, to some extent	26%	28%	↑
	No	14%	14%	
	<i>Number of respondents</i>	<i>4332</i>	<i>3829</i>	
Not on CPA or status unknown *	Yes, definitely	48%	49%	
	Yes, to some extent	28%	27%	
	No	24%	24%	
	<i>Number of respondents</i>	<i>4215</i>	<i>3859</i>	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

Care Reviews

A care review is a meeting between a service user and those involved with their care to discuss their needs and review their care plan. Policy guidelines suggest that service users receiving care on CPA should receive a formal review at least once a year, although this could be needed more regularly. Those not on CPA should receive on-going reviews as their needs require. However, the survey results (see table 5 below) show that some respondents say that they have not had a care review. Please note that results exclude respondents who have been in contact with services for less than a year:

- For those respondents **on CPA**, the majority had had a care review meeting in the last 12 months with 33% having one and 42% more than one. However, over a quarter (26%) said they had not had a care review meeting, up from 24% in 2012.
- For those respondents **not on CPA**, the majority had had a care review meeting in the last 12 months with 27% having one and 26% more than one. However, just under half (47%) said they had not had a care review meeting.

Table 5: Q28 In the last 12 months have you had a care review meeting to discuss your care?

(answered by all who saw someone from NHS mental health services)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, I have had more than one	43%	42%	
	Yes, I have had one	33%	33%	
	No, I have not had a care review in the last 12 months	24%	26%	↑
	<i>Number of respondents</i>	<i>4647</i>	<i>4175</i>	
Not on CPA or status unknown*	Yes, I have had more than one	26%	26%	
	Yes, I have had one	26%	27%	
	No, I have not had a care review in the last 12 months	48%	47%	
	<i>Number of respondents</i>	<i>6175</i>	<i>5644</i>	

Respondents who have been in touch with mental health services for less than a year have been excluded from this question

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

Those respondents who have had a care review meeting in the last 12 months said that:

- They were told they could bring a friend, relative or advocate to it (79%).
- They had the chance to talk to their care Coordinator before the care review meeting about what would happen (70%).
- They were given the chance to express their views at the care review meeting, either 'definitely' (69%) or 'to some extent' (26%).
- They found the meeting helpful, either 'definitely' (48%) or 'to some extent' (42%).
- They 'definitely' (58%) or 'to some extent' (23%) discussed whether they needed to continue using NHS mental health services.

Crisis Care

Just over three fifths of respondents (61%, up from 59% in 2012) said that they had the number of someone from their local NHS mental health service that they could phone out of office hours. Of these, 37% had called this number in the last 12 months. Of those who called the number, 49% said that they 'definitely' got the help that they wanted, 31% got this 'to some extent', 17% did not get the help they wanted and 3% could not get through to anyone.

Day to Day Living

The survey results suggest that a considerable proportion of respondents would like more support in getting help with some aspects of day to day living.

Over two thirds of respondents (69%) said that someone in NHS mental health services had **ever** asked them about their alcohol intake. Half (50%) said that someone in NHS mental health services had **ever** asked them about their use of non-prescription drugs.

Fifty seven percent said that in the last twelve months, someone in NHS mental health services had asked them about any physical health needs they may have. Of those respondents with physical health needs, almost two thirds said that they received enough support from someone in NHS mental health services in getting help with their physical health needs in the last twelve months either definitely (32%) or 'to some extent' (31%). Over a third (37%) that they did not receive support but they would have liked this.

Of those respondents with caring responsibilities (including looking after children) who needed support with this, three fifths of service users said that they received enough support from someone in NHS mental health services in getting help with this in the last twelve months, either 'definitely' (30%) or 'to some extent' (30%). Almost two fifths of respondents said that they did not receive support but they would have liked this (39%).

National guidance states that service users receiving care on CPA should receive support with employment, housing and finance from mental health services, if they need it. These needs should be identified in an initial assessment which should cover all needs and risks to the service user. For those respondents not on CPA, the focus is more on clinical needs rather than providing support for a wider range of needs, nevertheless policy guidelines state that they should receive a full assessment 'including risk assessment' to identify if they have these needs. The survey shows some quite large differences between the two groups in the results for these questions.

The majority of respondents **on CPA** said that they had received support from someone in NHS mental health in getting help with finding or keeping work in the last twelve months (see table 6 below), either 'definitely' (34%) or 'to some extent' (33%). Almost a third (32%) said that they would have liked support but did not receive any. For those **not on CPA**, over half (52%) said that they would have liked support but did not receive any.

Table 6: Q42 In the last 12 months, have you received support from anyone in NHS mental health services in getting help with finding or keeping work (e.g. being referred to an employment scheme)?

(answered by all who saw someone from NHS mental health services. Respondents who said that they do not need any help, or that they are unable to work because of their mental health problems have been excluded)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, definitely	34%	34%	
	Yes, to some extent	32%	33%	
	No, but I would have liked support	34%	32%	
	<i>Number of respondents</i>	<i>1503</i>	<i>1344</i>	
Not on CPA or status unknown*	Yes, definitely	23%	21%	
	Yes, to some extent	26%	27%	
	No, but I would have liked support	52%	52%	
	<i>Number of respondents</i>	<i>1599</i>	<i>1435</i>	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

The majority of respondents **on CPA** had received support from someone in NHS mental health services in getting help with finding and/or keeping their accommodation in the last twelve months (see table 7 below), either 'definitely' (43%) or 'to some extent' (29%). This leaves over a quarter (28%) who would have liked this support but did not receive it. For those **not on CPA**, over half (53%) would have liked this support but did not receive it, up from 50% in 2012.

Table 7: Q43. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with finding and/or keeping your accommodation?

(answered by all who saw someone from NHS mental health services. Respondents who said that they do not need any help have been excluded)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, definitely	45%	43%	
	Yes, to some extent	28%	29%	
	No, but I would have liked support	27%	28%	

	<i>Number of respondents</i>	1943	1822	
Not on CPA or status unknown*	Yes, definitely	28%	25%	
	Yes, to some extent	22%	21%	
	No, but I would have liked support	50%	53%	↑
	<i>Number of respondents</i>	1676	1669	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

The majority of respondents **on CPA** said that they had received support from someone in NHS mental health services in getting help with financial advice or benefits (such as Housing Benefit, Income Support or Disability Living Allowance) in the last twelve months (see table 8 below), either 'definitely' (46%) or 'to some extent' (27%). This leaves over a quarter (27%) who said that they had not received any support but would have liked some. For those **not on CPA**, almost half (48%) would have liked this support but did not receive it.

Table 8: Q44. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with financial advice or benefits?
(answered by all who saw someone from NHS mental health services. Respondents who said that they do not need any help have been excluded)

CPA Status	Response	Percentage		Significant change 2012-2013
		2012	2013	
On CPA	Yes, definitely	47%	46%	
	Yes, to some extent	28%	27%	
	No, but I would have liked support	25%	27%	
	<i>Number of respondents</i>	3327	3103	
Not on CPA or status unknown	Yes, definitely	28%	29%	
	Yes, to some extent	24%	23%	
	No, but I would have liked support	47%	48%	
	<i>Number of respondents</i>	3774	3643	

(note not all percentage add up to 100 due to rounding)

↓ indicates a statistically significant decrease

↑ indicates a statistically significant increase

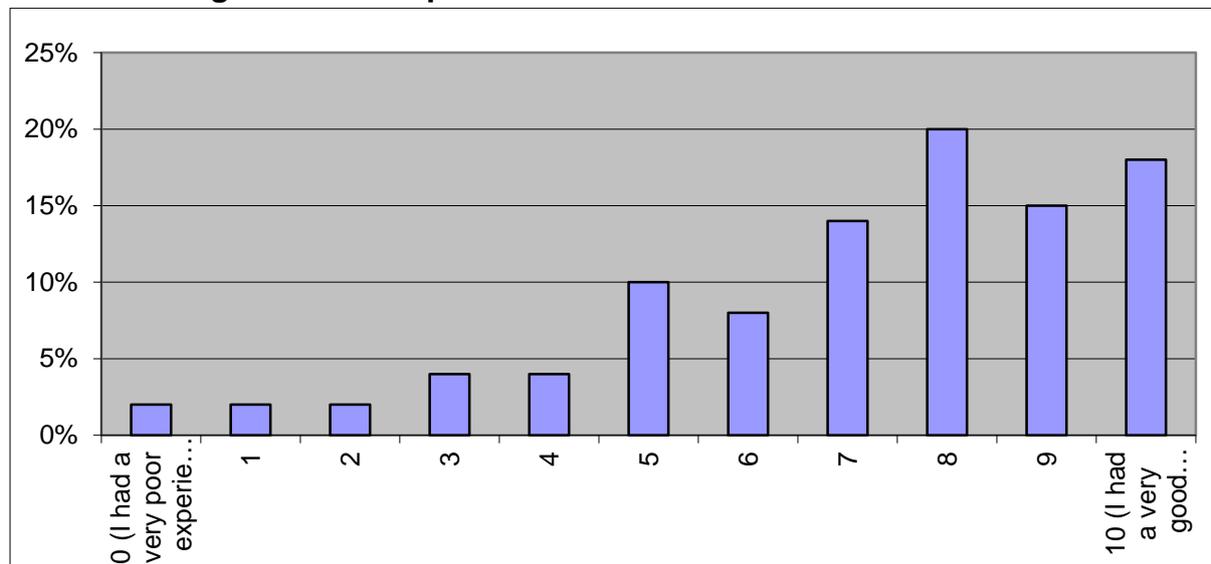
No arrow means that any difference is not statistically significant

*for some respondents trusts' records did not show if they were on CPA or not

Overall Impression

In a new question, respondents were asked to rate their overall experiences on a scale of 0-10. Most people (67%) responded positively (see Chart 1 below) rating their overall experiences as “7” or above.

Chart 1 Rating of overall experience



Over half (53%, up from 51% in 2012%) said that NHS mental health services ‘definitely’ involved a member of their family or someone else close to them as much as they would like. There had been a corresponding decrease in the proportion to respond ‘to some extent’ from 27% in 2012 to 25% in 2013.

Service User Comments

The final part of the community mental health survey gives respondents the opportunity to describe in their own words what was good about their care and what could have been improved. Nearly 8,000 of the 13,655 respondents of the survey made at least one comment and these have been fed back to NHS trusts.

Due to the very large volume of comments, a random sample of 976 comments from 500 service users across 43 NHS trusts have been analysed for the purposes of this briefing. It is important to note that these are only a sample of the total comments provided and are not necessarily representative of the views of all respondents.

Having continuity of staff and the care provided were aspects frequently raised by the service users, as well as the communication between professionals. One respondent felt that seeing the same CPN every week ‘boosted their confidence’ and another said that ‘seeing the same faces’ helped them. When continuity of care or carer is not achieved it can have a negative impact on the experience of service users and this was very much the case for some. Issues included a lack of communication and coordination between healthcare professionals and providers:

“All the services don't seem to be working together, each provider gives me information on my care (but they have) not carried anything out, so far.”

Involvement in care and treatment was raised by some service users, who wanted the opportunity to have their opinions taken into account and to have a discussion both about on-going care and discharge from community mental health services: *“My CPN was helpful unfortunately she had to discharge me and since then I have had a really bad spell which I had to battle with on my own as I can't get to see a psychiatric GP”*.

Some carers and family members requested more involvement in care and treatment provided. Those who filled out the questionnaire on behalf of their relative felt that they should be better involved in decisions made.

A number of service users felt that care was sometimes difficult to access. Some comments requested earlier /quicker access, and shorter waits. Another source of frustration in relation to access to care was the change of appointments, or health professionals being late for, or not turning up for, arranged appointments: *“Yes I often find a lot of my appointments get changed or cancelled in fact my CPN has forgotten to come twice when she was supposed to, and when I did need to talk to her those times.”*

Many were concerned about the reduction or closure of mental health services or support groups. One perception was that services were being cut back and some seem concerned about the effect closures or cut backs have had, or might have in the future: *“When you need professional help, the places to escape are a life line for the patient and their families around them. These mental hospitals need to stay open to control the population with mental health illnesses.”*

Others felt that the care and treatment provided was just not long enough and this led to individuals feeling alone or abandoned: *“Would have liked a slightly longer programme. Six months didn't feel long enough.”*

Additionally some of the individuals that commented on their care and treatment felt that follow up was poor or lacking. Issues included a lack of follow up appointments and a lack of further contact after being discharged from discharged from an inpatient hospital stay or from community mental health services.

Support both while receiving treatment and afterwards seems to be incredibly important to those who commented and a lack of support can be detrimental. Many would have liked a say about the frequency or type of support provided, and some felt that professionals needed to listen more. Service users wanted support that was individual to their particular situation, for example with regard to finding jobs, help in finding support groups or support based on their personal circumstances. While some suggested improvements with regard to the support provided, many felt that support was not provided at all or that support had been offered but had not materialised.

With regard to treatment itself, complaints focused upon it not being helpful or not being forthcoming: *“The treatment for anorexia needs to be addressed. My treatment*

(I have seen this with others) is simply not effective. In fact I have gotten worse. Everyone was lovely and worked hard but the treatment is flawed."

Some felt that they waited a long time for a diagnosis or that they were misdiagnosed: *"Not enough was done to reach a proper diagnosis early on so that the right treatment could be provided."*

Quite a few comments were provided about talking therapies. Some of the respondents found talking therapies helpful but getting access appears to be a problem. Long waits were reported: *"Yes that I see a CBT Therapist once a week now, but it took over 12 months to see him. Way too long."*

Others felt that the duration of some forms of therapy were not long enough: *"Not enough resources for additional CBT once sessions have come to an end."*

While some of the service users felt that the care and treatment provided to them made them feel safe, for example: *"My care team have been amazing. I firmly believe if it wasn't for them I would have taken my own life. They are always there and make me feel secure and safe."*

It was felt by some that care provided should consider their personal preferences and beliefs to gain the best out of the experience. A couple of service users felt that talking therapy was not the right treatment for them and had not taken into account their personal traits or beliefs.

There were a few comments about the location of the treatment provided and the facilities, most of which were negative. Hospitals or clinics were described as poor, in need of a 'revamp' or were not accessible, while some felt unhappy about the environment that they were receiving their treatment in because they were too cold or too loud and distracting, for example: *"Yes the staff in 'the clinic' are in general exquisite but they are let down because we have to share a building now and it's so loud during my group that I don't get the best out of it because I can't hear or focus. I know there are cuts but you can't just shove us into a room, because we will be back in a few years if you do."*

Problems reported with regard to crisis teams and crisis lines focussed on a lack of responsiveness, for example: *"Crisis line is total joke. I phoned completely suicidal asking to speak to doctor, 3 times same person answered phone, twice she put phone down on me, I was cutting myself, never done that before."*

Some respondents felt that the service did not provide the help they felt they needed when a crisis occurs, and it is clear that this is a real source of frustration: *"I've had three crisis points in the past 36 months with urgent referral back to 'the hospital' for help. I got appointments to see someone for these crisis's 6, 8 sometimes 12 weeks after the events when I was asked if I had recovered."*

In some cases service users perceived staff as dismissive or unhelpful. One patient felt nervous about the idea of having to use the team in the future due to how using the service in the past had made them feel: *"I don't need the Crisis Team, but have had a bad experience in the past, not finding them very friendly or helpful at all."*

Always bothers me in care I will need them in the future. ..I feel a little anxious about contacting the crisis team ...”

It was clear that service users can feel alone during a crisis and that support at such a difficult time is needed. Some felt it would be helpful to have home visits when in crisis as it can be very difficult to travel. Others also did not want to have to go to A&E to access crisis care; they felt that this added to the distress of the situation.

Positive comments about medication focused upon the medication being reviewed, monitored and changed if necessary. However, close review and monitoring has not been experienced by all service users. Some service users felt that their medication was not monitored and in some cases not fully explained. Others felt that side effects could have been explained and perhaps advice given on how to deal with them. Some of the service users who have been prescribed medication did not want it and some felt that they wanted or would have benefited from therapy instead. Others reported that their medication was not effective and that they have not benefitted from taking medication.

A number of service users mentioned having no care plan at all and had never been offered one, in one case seeing a mention of it in the questionnaire was the first time they had heard of them. Others knew what a plan was and wanted more input into their own plan.

In some cases there appears to be a lack of understanding or clarity about care plans, either because service users did not see how it would fit in their future plans or because the plan itself was not clear. A feeling expressed by one service user was that people do not fit neatly into "care plan boxes".

Both positive and negative comments were provided about staff involved with the care of service users. There were many examples provided of responsive staff and responsive services, both in terms of getting back to service users and in reacting to service users' needs. Having someone available to talk to seemed important to many of the service users that commented, in terms of knowing that someone is available to provide help if they need it, and preventing isolation and loneliness: *“I felt I was always listened to and still am. I have never felt as though I am on my own, and that all the people I have come into contact with have been brilliant.”*

Some of the service users felt that staff members were available to offer help if they needed it. Unfortunately this was not experienced by all and some struggled to get the help needed. Some felt that there was a real lack of availability of staff and this impacted upon their care both in hospital and in the community, despite staff doing their best: *“...There's not enough staff to give the standard of care needed out in the community there too many clients and they really don't care.”*

“The service certainly shows signs of being overstretched, with the staff doing their best but being overworked.”

In some cases service users felt that family or carers had to fill the gap left by the perceived shortage of staff. Others complained about staff providing care but inconsistently, and either not turning up for appointments or turning up late, the

consequence of this can be anxiety and frustration: *“Social worker says he will ring and he never does. This causes anxiety and frustration.”*

Inconsistent care can hinder the trust in staff. Many respondents stated how trusting the health professional has been very important to them: *“Yes my CPN knew me better than I did myself! She was perfect.”*

“I have received care twice from CPN . She is the one person I trust more than my mum to give me Advice and care and help I need.”

There were examples provided of how a lack of trust can have a negative impact the experience of service users: *“Was getting help with how I feel about life and being around people, over all I started to trust people again. But saying that they pushed me out of my group for being ill and in hospital I Feel they have pushed me back into my depression and it’s not help my PTSD at all. Trust is a big thing for me I feel that I’ve lost that trust with the mental health for being pushed away.”*

Being listened to is a key part of building a trusting relationship and respondents reported both negative and positive experiences of this. Staff were praised in many cases for listening and engaging with service users: *“I think the last two people I say listened to me very well and I could talk to them very easily. I think I have been helped superbly.”*

“For the time I have been a patient with the care quality service they have been most helpful and kind - it was such a help to have someone who listens to you. I thank you very much.”

Listening is a key part of building a relationship and should involve getting to know the service user, some felt that this happened but not all. One respondent reported the positive effect of health professionals getting to know their service users: *“I think the home visits from my CPN and now Social worker have been an absolute lifeline to me. They interact and really learn about you. I would not be here if it was not for them.”*

However, not all respondents felt listened to, some felt ‘brushed off’ or let down: *“My Care Coordinator did not listen to me, did not do the things she said she would and failed to support me through a very difficult time. Having made a complaint, I have been allocated a new Care Co-Ordinator. I hope she will be better.”*

Many just wanted a chance to be heard: *“All I was asking for was someone I could talk my problems out with one to one and know that it’s confidential. Have not heard a thing back.”*

It is important that service users feel listened to and supported, and many of the respondents described the positive impact that supportive staff can have on their care and recovery. This support can be in many forms, including sometimes challenging the service users, for their own good. Feeling that the support from staff members is there if they need it is very important: *“If it wasn’t for my social worker I would not be here today I’d be dead she helps support me with my mum, son, having teeth fixed, benefits, prompts, supports me.”*

The different staff groups were described as caring, friendly, understanding, helpful and professional by many respondents, for example: *“Everyone I have had contact with seems to have a vocation for the work and genuinely care for us.”*
“The understanding and sympathy showed towards the problems you are experiencing is praiseworthy.”

Many felt that they have been treated with dignity and respect: *“I found myself to be in a safe atmosphere where I could talk freely, and felt I was respected and treated well.”*

Staff members’ professionalism was also praised but some were felt to lack key traits such as compassion: *“I had a student psych nurse initially who was fantastic, she was responsive and proactive. Much better than the full trained staff who seemed to have lost their compassion.”*
“There is no care, compassion or interest in mentally ill people by ‘the hospital’, it’s all about the pay check at the end of the month, they should really be looked into very seriously and carefully, people are dying.”

Mental health classes and groups were felt to be very important and had been beneficial. Some service users identified a need for more support groups or day centres in the community, they clearly saw the value in such facilities and appeared very disappointed in the current provision. In a few cases this was particularly the case in relation to dementia, for example: *“More day centres for patients with early dementia. We travel to take my husband to attend the activity club which is excellent once a week. 68 miles there and back twice! There is nothing suitable in the area.”*

This was not just reported by service users with dementia or their carers, as others reported that local groups had been ‘cut’ and which appears to have had a negative impact on their day to day lives: *“My local Mind group was cut last year due to funding that used to assist me with CV, letters, job hunting, etc. I was made redundant in October 2012 since then no work!”*
“A club which I attended and organised trips and activities which had a positive effect on my mental health has been cut this has had a negative effect on my quality of life.”

Many respondents commented that they would be grateful for help and advice on benefits and accommodation, getting back to work or finding a job, and many were happy with having received such advice. One service user felt that their day to day life has changed for the better due to the help they had received: *“I was not going out very much and I had no real structured life. All that has changed now. Thanks to my CPN and mental health support workers!”*

It was felt by some that more support and assistance was needed and some service users felt that it should not just cover mental health needs but also should encompass physical health problems, as they felt that the two come hand in hand.

There was a sense of fear of treatment and support ending, some expressed worry about what will happen when their care ends and about regaining access if they relapse, for example:

“Therapy is supposed to be finished in July but I don’t feel ready for help to be taken away and nor so the rest of the group - all of us are getting extremely anxious about what happens next but none of us are being told - we are just being left worrying and wondering what happens next is all help just going to be taken away? will we be just left to try and cope alone?”

Many felt that it was important to see health care professionals in the community and after they have been discharged:

“As a long term user of MH support and past hospital spells I would still like to have appointments with my CPN after discharge even if 6 monthly as I don’t see a psychiatrist any more (NHS procedure change).”

Further information

The full national results for the 2013 survey are on the CQC website, together with an A to Z list to view the results for each trust (alongside the technical document outlining the methodology and the scoring applied to each question):

www.cqc.org.uk/PatientSurveyMentalHealth2013

The results for the 2010, 2011 and 2012 community mental health surveys can be found on the NHS surveys website at:

www.nhssurveys.org/surveys/290

Full details of the methodology for the survey can be found at:

<http://www.nhssurveys.org/surveys/675>

More information on the programme of NHS patient surveys is available at:

www.cqc.org.uk/public/reports-surveys-and-reviews/surveys

More information on Quality and Risk Profiles (QRP) can be found at:

www.cqc.org.uk/organisations-we-regulate/registered-services/quality-and-risk-profiles-qrps

More information about CQC’s consultation on changes to the way we inspect, regulate and monitor care services can be found here:

<http://www.cqc.org.uk/public/sharing-your-experience/consultations/consultation-changes-way-we-inspect-regulate-and-monitor>