

# Citizens Advice mental health insights: people's experience of care coordination



## Summary

Mental health care coordination, such as supporting a person to manage their medication, or to arrange for their finances, is essential for people with mental health problems. In response to NHS England's call out for evidence, **this brief presents a feedback summary following two engagement events, with our clients with mental health problems, about their experience of mental health care coordination.** It also forms part of our policy series on mental health.

### **This brief highlights the following findings:**

- 1. Care coordinators:** Clients emphasised the value of the care coordinator's positive attitude and regular communication in order to plan their care more effectively. However, they also highlighted that the eligibility criteria to have access to a care coordinator are very difficult, and out-of-hour care is also very limited. This results in mental health care often being transferred to GPs, who may have insufficient knowledge on how to respond to clients' mental health problems.
- 2. Care plan:** clients do not wish to share their care plan or health records, in advance, with clinicians. They fear that this usually leads clinicians to have a biased or judgmental opinion of how the person would communicate, or how their care should be. There is an emphasis that the care plan should focus on person's needs and skills, rather than risks, and their care plan and records should not be shared without their explicit consent.
- 3. Service transition:** many clients felt not ready to move to another service, but they were made to, with some reporting that they did not know what to expect of the new service. Some clients had a positive experience of service transition when it was made in gradual stages and regular communication between agencies and with the client.
- 4. Community alternatives for support:** there is reluctance to use technology to access mental health support or care records online, due to the lack of training skills, a disability, and the lack of human interaction. However, clients welcome assisted technology by human support to navigate for mental health and community care. There was also a demand to access inclusive community centres, that are open to everyone, and not only for people with mental health problems.
- 5. Choice and decision-making:** client's choice and decision-making were limited. Decisions were often made by clinicians for clients, such as agreeing drinking level, smoking habits, or medication doses. It was reiterated that such decisions should be made in agreement with clients.

**To improve community support for people with mental health problems, and their experience of care coordination, a good practice example may implement the following:**

- To embed meaningful engagement, in service specifications, between service providers and clients. Clients should own decisions about their care and treatment, in agreement with clinicians, and in line with 'No Decision About Me, Without Me'<sup>1</sup>.
- To make inclusive community hubs more widely available and encourage their engagement with clients of mental health problems.
- To provide training to develop clients' digital skills and build their confidence to self-manage their mental health using technology, where applicable. Human support should also be provided alongside technology.
- To ensure that clients' data, health records, and care plan are not shared, without the explicit consent of client. Providers should proactively seek clients' permission to share their data with other services.

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<sup>1</sup> Department of Health, Liberating the NHS: [No decision about me without me](#), government response

## Background

In response to NHS England's call out for evidence, Citizens Advice carried out two focus groups and one interview with people, who used or are using community mental health services. Following a call out for evidence to our network, we held two engagement events in collaboration with a local Citizens Advice in North West England. A group of 15 clients participated, including people with long-term health conditions, aged 30s - 60s, both male and female, and 2 people from ethnic minority backgrounds. All names in this brief have been changed.



**Citizens Advice** support people in 2,700 community locations, including GP and mental health services. Our 23,000 trained volunteers and 7,000 paid staff provide advice to over 2.7 million clients every year. Our advisors have a wealth of knowledge of local needs, ranging from housing, legal issues to health services. In 2017, over 100,000 people, with mental health problems, sought our help.

## What is mental health care coordination

Some people with severe mental health problems will be offered a Care Programme Approach (CPA) package. Under the CPA, they will also get a care coordinator and a care plan. People might be offered a CPA package if they<sup>2</sup>:

- have a severe mental disorder
- are at risk of suicide, self-harm, or harming other people
- tend to neglect yourself and don't take treatment regularly
- are vulnerable – for example, because of financial difficulties
- have misused drugs or alcohol
- have learning disabilities
- rely on a carer, or are a carer yourself
- have recently been sectioned
- have parenting responsibilities
- have a history of violence or self-harm

The care plan would include day-to-day care, and who will give it. It might cover:

- client's medicines
- help with money problems
- help with housing
- support at home
- help to get out and about outside client's home
- any risks
- detail of what should happen in an emergency or crisis

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<sup>2</sup> NHS, [Care Programme Approach](#)

## Why Citizens Advice care about people's mental health in the community

- Most people with mental health problems are supported by community-based services. **90% of people** with severe mental health problems are supported by community mental health services, and **90% of people** with common mental health problems are supported in primary care. However, both mental health services experience a high degree of variation in care quality and availability<sup>3</sup>.
- **45% of NHS clients** surveyed would have liked help or advice in finding financial advice or benefits, but did not get it,
- While **43%** would have liked help or advice in getting support for finding and keeping work but did not get it,
- And a further **43%** would have liked support to take part in an activity locally, but did not get it<sup>4</sup>. Activities can include gardening, walking groups or similar.



Source: Citizens Advice, [Advice Trends](#), April 2018

## 1. Care coordinators

### Staff attitude and person-centred approach

- Care coordinators' attitude plays a major role in supporting people. Many clients cited that their care coordinator's support has made a major difference to their mental health.
- Clients look for the following qualities in a care coordinator: validation, empathy, encouraging independence, encouraging choice and ownership.
- Many clients felt their individual needs on how they would like to be

<sup>3</sup> [The Five Year Forward View for Mental Health](#), 2016

<sup>4</sup> Care Quality Commission, [Community Mental Health Survey](#), 2017

supported, were not understood by care coordinators. They felt that a 'one size fits all' approach does not work, while the support approach should be made more personable.

- There was a consensus that the relationship between the care coordinator and client, should shift away from the clinical model to a person-centred approach. Clients emphasised the importance of being treated as a 'person', as opposed to a 'clinical file'. The care coordinator should have the ability to build rapport and trust with the client, and make them feel as 'friends' and not as 'patients'. Care coordinator should ask the right questions:
  - 'What is important to me?'
  - 'What would I like to get out of my plan?'
  - 'How would I like to stay in contact with my family?'

### **Contact frequency**

- There was a mixed experience of the communication between care coordinator and clients.
  - Some clients reported that they had no regular contact with their care coordinators.
  - Some clients had experience of their care coordinator rushing through the appointment, having their appointments cancelled at the last minute, or their care coordinator showing up late. Not knowing what is going on often leads to worsening client anxiety. Some clients said that when care coordinators cancelled last minute, it was to attend to a more urgent case, which left them feeling unimportant.
  - However, one client said that when their care coordinator was late, they stayed for another hour to compensate for the time lost, which was appreciated.
- Clients found it very helpful for their mental health to know that there is someone from the community mental health team who checks in with them 2 or 3 times a week. They also stressed that the frequency of contact should be agreed as well as when and how, that is, by phone or home visits.

### **Place of meeting**

- All clients preferred to meet with their care coordinators on a face-to-face basis, somewhere that is private and confidential. This could be the person's home, or a private room in a public place, where it is agreed in advance with the client.

## Access to crisis care

- While access to a care coordinator is often between 9am - 5pm, there is limited community mental health and out-of-hour care. This sometimes leads to crisis care provided by non-mental health services, such as the police.

### **Community mental health support is replaced by police support**



*"...to be honest, the services don't really exist. Due to the lack of resources on the ground, teams are discharging people to inappropriate services. Now people are relying on the police... the police are the only real service there is for people with mental health problems. They're good. They are... compassionate, and [the police] are equipped to deal with mental health. We get better care from [the] police than anyone else".*

## 2. Care plan

### Approach

The role of a care coordinator is crucial in care planning. It is more important for the care coordinator to understand the person's needs first, than to treat the care plan as 'another paperwork', or a 'checklist'.

### Content

A care plan should focus on areas that are important to the individual, and not on the 'risks' in the person's life:

- A structured plan on daily and weekly activities
- Mechanisms that encourage independence and choice
- An agreement how frequent communication should be between care coordinator and client, and emergency and non-emergency contacts
- Medication agreement between client and clinicians, where self-management and choice are supported
- Family and relationships
- Faith and spirituality
- Education and training opportunities
- A person's skills, strengths and community activities to pursue

### Data sharing and care records

- Clients see their care plan as a private and confidential document, that should not be shared with clinicians or others, without their explicit consent. Decision on whom to involve, in the care plan, should be owned and made by clients.
- Sharing a care plan or care records, in advance with clinicians, was raised as

a concern. As a result of sharing records, clients felt that clinicians develop a biased or judgmental opinion of how they are going to behave or respond, or how their care should be delivered based on their history. Clients emphasised that clinicians should build rapport with clients before they read their care plan or health records.

### **Who to involve**

- There were mixed views on whom to involve in care planning and decision-making about the care plan. Having rapport and trust in a particular clinician or a family member is key to involving them in a client's care plan.
- However, there was a consensus that explicit permission should be sought from clients, prior to involving any clinician, GP, a family member or any other in care planning.

### **3. Service transition**

While moving between services, transition should be gradual to help clients feel ready, and a progress report and regular communication are in place between services, as well as with clients.

There was a consensus that clients wanted to have more access to mental health support, during transition, specifically:

- To have a designated care coordinator or key worker, to refer to for questions or support while in transition
- Transition to a new service should be gradual, and made at the right time, to avoid relapse and anxiety. For example, staff from service A can reduce their contact with client from once a week to every 2 weeks, while new staff from the new service B starts to see them once every 2 weeks.
- During transition between services, care records must share progress and individual's needs between the 2 services, while keeping the client up to date.
- GPs should be kept informed about transitions, but only with the client's explicit permission.



**An example of service transition that worked in the past for some clients:**

Week 1-3	Care coordinator from service A (existing), makes contact with clients once a week, as agreed
Week 4	Care coordinator from service A (existing): <ul style="list-style-type: none"> <li>- makes contact with clients once a week,</li> <li>- agrees with them about a new plan of service transition, what to expect, and how frequent communication with existing and new service is going to be</li> <li>- Introduces key worker from service B (new)</li> </ul>
Week 5	Care coordinator, from service A (existing), makes contact with client once a week
Week 6	Key worker, from service B (new), makes contact with client once a week
Week 7	Care coordinator, from service A (existing), alternates and makes contact with client once a week
Week 8	Key worker, from from service B (new), alternates and makes contact with client once a week
Staff from service A and B should be in regular contact with one another about client's progress, while also keeping client up to date about their communication. They alternate being in contact with client until a client's care is transferred to the new service.	



**Gradual transition between services is reassuring**

*“Now I have John and Pardeep. John is from [service A, and Pardeep is from service B], checking in on me alternately every other week. They thought I might want to be discharged now because I’m doing so well, but I didn’t feel ready yet so they are chatting together and making sure I’m still seeing them for as long as I need them”.*

## 4. Community alternatives for support

### Technology

There were mixed views about the use of technology for mental health support:

- **Viewing own care records online** raises concerns about data security, person's privacy and confidentiality. It is also considered impersonable to be able to view one's records online without discussing it with a care coordinator or the person whom the client would like to involve.
- **Accessing online support for mental health** varies based on individual circumstances. Generally, reluctance to use technology was either due to the lack of digital skills, a disability, or the lack of human interaction.
- **Assisted technology with human interaction** is welcomed and seen as important, to offer reassurance and support.



#### Use of technology is impersonable

*"[accessing records online or using technology] sounds like another way to feel like a number. They're [im]personal and should be face to face. You should be able to share them if you want to, but also not if you don't want to. If you do want to, you should be able to do this with ease, and [not made feel guilty]" --*

a male client, aged 30-40s

#### Use of technology is difficult without human interaction

*"I am dyslexic, so I prefer one-to-one support and conversations. Using online support is difficult for me",* a male client, aged 40-50s

- **Sharing care records online with clinicians is a NO!** there was consensus that a care plan or health records should *not* be shared with clinicians, in fear of being judged or facing bias in how individuals are going to be treated by mental health services.



#### Health records and care plans are owned by clients

*"...we'd like to be in control with whom we share our records. Some clinicians are very judgemental. They see my plan or records, and they don't both [even] have a chat with me about my health. Specially at hospital, there is pre-judgment. They just don't want to agree with [me]".*

*"...security is a real concern. You know a load of patients' records were leaked to insurance companies. People worry about things going online".*

- **Sharing care records online with the voluntary sector is a YES!** on the other hand, there was a consensus that care records should be shared with the community and voluntary-sector services, in order to facilitate or to tailor support for the individual's needs, "definitely, the more, the merrier".

### Community engagement

- **Access to inclusive community hubs:** there was a consensus that there should be more access to community hubs that are not mental health-related, more inclusive and open to everyone from the community. However, mental health peer support should also remain available to help manage one's mental health in the community.
- **Working with a key worker to encourage gradual independence and self-confidence:** positive experiences were shared by some clients about how they were able to develop their confidence to self-manage their mental health, and be independent in the community. This is often with the assistance of a care coordinator or a key worker, who provides a clear step-by-step guide to achieve a certain task, agreed with client.



#### Building self-confidence

*"[it was] first step by step. Someone accompanied me to collect my meds, [from chemist]. The next time I go in to collect meds but the worker stays in the car. The time after that I go on my own to collect them. I then have to return home to take the meds".*

## 5. Choice and decision-making

There was a consensus that clients had poor experience of decision-making when decision is not often shared with them:

- Clients feel that decisions by clinicians about medication are sometimes made to help clinicians manage clients' behaviour more easily, and not in response to clients' needs.
- When there are no care coordinators available, care is often transferred to GPs. However, GPs do not always know how to respond to clients' mental health needs.
- Decisions around smoking habits, levels of drinking alcohol, or medication doses are often made by clinicians, and not in agreement with clients.
- In case of limited capacity to consent or to make an informed decision, it should be agreed with clients in advance how they like decision to be made. Decisions should be made by or in agreement with clients. Choice should be offered.

# We help people find a way forward

Citizens Advice provides free,  
confidential and independent advice  
to help people overcome their problems.

We advocate for our clients and consumers  
on the issues that matter to them.

We value diversity, champion equality  
and challenge discrimination.

We're here for everyone.



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