



What is in this document?



The purpose of this document is to support the CPA Transformation work, in line with the NHSE CPA Position Statement which was developed to support systems to begin moving away from the CPA in line with the five principles and embed personalised care and support planning for everyone receiving community mental health services.



Click on the links below to be directed to each page

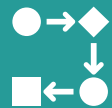
1 [Document development](#)



2 [Summary of the five principles as outlined in the CPA NHS Position Statement](#)



3 [NHSE - Community Mental Health Transformation Roadmap](#)



4 [Case Study examples](#)



5 [Focused resources](#)



6 [Critical Friend Group feedback](#)



7 [Additional resources](#)



8 [Appendix](#)



To read the full NHSE CPA Position Statement, click on the icon >>>>





The following slides provide specific considerations and resources on a number of areas that are central to the CPA Transformation



Click on the links below to be directed to each page

1 [Older Adults](#)

2 [Involving Complex Emotional Needs \(CEN\) Carers as Partners in Care](#)

3 [Personalised Care and Support Planning](#)

4 [Addressing health inequalities in the context of the CPA transition](#)

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Specific considerations for Older Adult services in the transition from CPA to intervention-based care

There are unique needs and factors of the older population in London that must be accounted for in the transition from CPA to intervention-based models of care.



The number of Londoners aged 65 and over is expected to rise by 30 per cent by 2030. This is compared to a rise of 23 per cent across England*. Ensuring that new models of community mental health are fit for supporting both adults and older adults is key to future proofing services.

*Centre for Mental Health, 2020 - <https://www.centreforlondon.org/reader/older-londoners-housing/#introduction>

What do we mean by “Older Adult”?

- Chronological age is an indicator of growing older but differences in ageing are dictated by biological, psychological and social factors. For this reason, mental health services are moving away from age based criteria to focus more on need.
- Some NHS Older Adult Mental Health (OAMH) services have retained a threshold age of over 65, with other sectors including social care and third sector organisations working with people as young as 50.

What is unique for an Older Adult?

The older population in London is extremely diverse – in terms of generation, ethnicity, sexuality, gender and disability. Older adults cannot be treated as a single homogenous group. However, some biopsychosocial factors are more common among this population:

- Common psychological issues affecting older patients may include, but are not limited to, anxiety, depression, delirium, dementia, personality disorders, and substance abuse.
- There may be some physical health needs that are greater in the older adult population such as mobility issues and frailty.
- Common social and emotional issues may involve loss of autonomy, grief, fear and loneliness.

What are the key considerations for care planning with older adults?

As described on page 21, the [PRSB standards](#) require MH providers to base care on ‘what matters’ to an individual and their individual strengths, needs and preferences. Providers therefore need to develop care planning tools and approaches that can be tailored to the needs of older adults. These include:

- Assessments/time for an older person to consider their response can be longer due to cognitive impairment and other reasons.
- Older people living with a serious mental illness are commonly also being supported by social and primary care services. Ensuring effective interfaces and shared responsibilities for care planning with these services needs to be a priority (further details on next page).
- [Age is the biggest indicator of who is digitally excluded](#). This is despite significant increases in older adults getting online. Services can account for this by:
 - Making staff available to support older people to access digital channels (VCSE, lived experience practitioners, peer support workers, digital ambassadors, etc).
 - Developing partnerships with local third, social care and private sector digital inclusion programmes, to enable access to tech hardware, connectivity and training to build skills and confidence.
 - Including offers of non-digital services as standard. [Many older people do not want to access mental health services digitally](#).

Digital – good practice examples:

- [The Age UK](#) network has run a variety of different digital inclusion projects over many years, including one-to-one support; classroom based services; one-off drop-in or larger community awareness sessions; and intergenerational projects.
- Age UK Leeds are offering a new [Digital Wellbeing Service](#) to support anyone over the age of 50 who would like to know how to access health and wellbeing tools online, providing equipment and supporting people through Digital Champions.



Specific considerations for Older Adult services in the transition from CPA to intervention-based care



There are unique features and constraints of OAMH community services that need to be accounted for in the transition from CPA to intervention-based models of care.

1. Scaling

The scale of the transition for OAMH is similar to adult services. However, OA CMHTs are much smaller and fewer in number than core teams, and support patients with particularly complex mental and physical health needs. There are unique constraints to account for when assessing the possible scale and pace of the transition for OAMH services:

- The availability of clinical staff to support service design and transition will be more limited than for the core teams. Care needs to be made to avoid placing unfeasible constraints on existing OAMH services.
- New models of care and care planning will require creative use of non-clinical roles (including through third sector partnerships). These roles will require intensive supervision from the OA CMHTs given the complexity of needs among older people.
- Older Adult CMHTs do not have the resources to align with PCNs. This means that older adult clinicians can be stretched to provide MDT support across areas. Resourcing requirements for the transition need to account for this, including: continuing to increase joint working between adult and older adult teams; upskilling core teams in providing care for older adults; and building MH competencies within physical health teams supporting older adults (e.g. community health teams).

2. Ageing population and increasing demand

- As populations age, OAMH services are seeing both, an increase in demand, and changes in how older people present and need to be supported with their mental health. Understanding these demographic changes and their impact on services - including through use of existing service data - will be important to designing services.
- This ongoing increase in demand is putting significant constraints on already-stretched teams. As detailed above, this makes it even more important to ensure that the transition from CPA does not overwhelm the OAMH community workforce.

3. Social care

- Older Adult teams have regular interface with social care given the complexity of needs of older people. Continuing to enhance integration and placing relationship building with local authorities at the heart of community transformation is particularly important for moving to intervention-based care for older adults.
- Finding ways to collaborate more within social care will be key to the transition – e.g. through joint management of services and ensuring participation of social care within MDT structures.
- MH teams could also find ways to build MH competencies within social care teams. This can support a focus on the holistic care needs of a person, rather than over-emphasis on a MH diagnosis.
- Social care are also seeing significant increases in demand to their services, at a time where resources are already severely constrained. Staff turnover, different operating methods and patterns of working within MH and social care teams during COVID have still not recovered and are affecting integration.



Involving Complex Emotional Needs (CEN) Carers as Partners in Care



This guidance has been developed by Jarka Hinksman, a member of the Clinical Reference Group of the 'London Complex Emotional Needs Programme' (June 2022).



This guidance outlines essential knowledge on Complex Emotional Needs (CEN) caring in the context of the current transformation of community mental health services and care in the community policies. It provides evidence-based reasons for carers to be supported in their caring role so they can become confident and effective partners in care.



It is hoped that this guidance will help services to find the right balance when providing support to persons with CEN and their carers.

Its principles are perfectly transferable to other mental health carers.

“A strategic stance to mental health carers is needed as without a systemic and psycho-social approach to treatment, carers cannot feel empowered, or be well enough to provide the quality and amount of caregiving placed upon them by care in the community policies”

Summary of key considerations around involving carers as partners in care

- Including carers as partners in mental health care is essential when the concept of clinic-based practice shifts to a community-based service approach. As such, carers should have access to timely and accurate support and information, which promotes learning, self-monitoring, and accountability.

! Page 11 includes a figure that shows what is required to involve carers as partners in care.

Carers as part of the cared-for person's Care Plan

Carers may often be considered as a protective factor by the person living with a severe mental health condition. Where the cared-for person explicitly agrees, carers should be part of their Care Plan and provided with a copy thereof. However, even if the person would prefer to cope on their own, carers should still be offered support and an assessment of their needs. Whilst in some circumstances there may be reasons for family not to be involved, it is a good practice to keep reviewing this.

! Page 14 includes a Learning Note from a recent serious incident where the patient's carers were not pro-actively included in the patient's care.

Information sharing and confidentiality

- As and when appropriate, professionals should also encourage people with care and support needs to share information about their needs with carers so that they too can participate in care and support planning.
- At times, a person with CEN may not feel comfortable for their relative/carer to access programmes in the same service or Trust they are treated in. As such, there should be a reciprocal arrangement between Trusts to accept carers from different areas, or Trusts should provide carers support regardless of any geographical constraints.
- Services need to have a written consent from the patient regarding information sharing with their family though this should be reviewed periodically. Even if the patient declines to give permission, this should not prevent services from, for example, signposting the carer so they can receive appropriate support elsewhere.

Carers interventions

For carers to become confident partners in care, they have to be provided with the right skills for caring. Once carers feel skilled, they can become an effective resource as well as an essential source of hope for the person they look after.

! Pages 16-23 provide a detailed summary of the recommended Carers Interventions.

Case study – An Innovative example – ‘Together, we can work it out’

Initiated and co-produced by a CEN carer, a psychoeducational, skills-based programme is currently under way at a CNWL CEN pathway. This was in response to a few serious incidents where care delivery problems were identified and it was recognised that carers were not systematically included in the patients' care despite CEN carers having been considered a source of support by the patients.

! Page 24 provides some feedback received on this programme thus far.



To access the full guidance, click on the icon >>>>>





Personalised Care and Support Planning



A key component of [The Community Mental Health Framework for Adults and Older Adults](#) is setting out a method for coordination of care that will replace the CPA and enable high-quality, personalised care and support planning in line with the [NHS England Comprehensive Model of Personalised Care](#).

As outlined in the NHSE CPA Position statement: *while the type of plan and the level of support needed will depend on the person and their individual needs, ensuring that all care and support plans are genuinely co-produced, **personalised** – and Care Act-compliant and integrated with Mental Health Act section 117 plans where necessary – should be a key aim of all new models*

As outlined by the NHSE Personalised Care and Support Planning (PCSP) Programme

The 5 areas below are the key criteria for counting PCSPs:

- People are central in developing and agreeing their personalised care and support plan including deciding who is involved in the process
- People have proactive, personalised conversations which focus on what matters to them, paying attention to their needs and wider health and wellbeing
- People agree the health and wellbeing outcomes they want to achieve, in partnership with the relevant professionals
- Each person has a sharable, personalised care and support plan which records what matters to them, their outcomes and how they will be achieved
- People are able to formally and informally review their personalised care and support plan

In Personalised Care and Support planning you start the conversation from a different point, by finding out what matters or is important to the person in their life before discussing, in any detail, their health.

One tool that can help show this balance in the plan is the 'important to and important for' tool, [click here >>](#) 



NHSE commissioned The Professional Records Standard Body (PRSB) to develop care plan standards. As outlined in the CMHT Roadmap draft published by NHSE (August 22): *Ensure new local planning guidance is congruent with the [PRSB standards](#) and develop local guidance to ensure a consistent approach to logging and storing information within personalised care plans.*

The personalised care and support plan (PCSP) standard has now achieved ISN status following rigorous quality assurance by the NHS Data Alliance Partnership Board.

See [here](#) for more details about the information standard.



The PRSB has developed and published an [information standard for Shared Decision Making](#). The standard provides a framework for clinicians to record the decision-making process between themselves and their patients. The standard also allows the shared decision information to be shared between professionals and their different record systems.

For more info and resources on 'Shared Decision Making', [click on the icon >>>>](#) 



Find out about the value of Personalised Care and Person centred conversations

Greater Manchester Combined Authority developed a video for people wanting to understand more about person centred conversations and the positive difference this makes to people's lives.

Click on the link to see the video (7:54mins) >>>> 



Free training opportunities on Personalised Care for staff

The [Personalised Care Institute](#) has collaboratively developed the first curriculum for personalised care. The curriculum articulates the values, behaviours and capabilities required by a multi-professional workforce to deliver personalised care. It sets out an educational framework for learning the essential elements to this approach and supports ongoing professional development.

Click on the icon for more information >>>> 



For a range of resources on Personalised Care, you can join the [Personalised Care Collaborative Network](#) in the FutureNHS platform, [click on the icon >>>>](#)





Addressing health inequalities in the context of the CPA transition

Mental health inequalities are varied and contextual and local health systems are ideally positioned to co-produce local solutions with communities experiencing mental health inequalities.

Systems need to ensure that the CPA Transformation is used as another opportunity to address inequalities in access, experience and outcomes of mental healthcare and to advance equalities within MH service delivery, as part of the wider Community Mental Health Transformation work.



In line with the 'NHSE Community Mental Health Roadmap for Transformation' (August 22):

- Principles for advancing equalities have to be embedded in care provision.
- Ensure new local planning guidance is congruent with the **PRSB standards** and develop local guidance to ensure a consistent approach to logging and storing information within personalised care plans. (A section named 'About me' aims to include a description of what is most important to service users including: values, spirituality/religion, ethnicity, goals, aspirations, etc).

➤ As outlined in the NHSE **'2021/22 priorities and operational planning guidance: Implementation guidance'**, to address the urgent need to prevent and manage ill health in groups that experience health inequalities, systems are now asked to focus on five priority areas:

1. Restore NHS services inclusively
2. Mitigate against digital exclusion
3. Ensure datasets are complete and timely
4. Accelerate preventative programmes that proactively engage those at greatest risk of poor health outcomes
5. Strengthen leadership and accountability

➤ ICSs are asked to take a lead role in tackling health inequalities, building on the **Core20PLUS5** approach, a National NHSE approach to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort – the 'Core20PLUS' and identifies '5' focus clinical areas requiring accelerated improvement.

➤ The **2022/23 priorities and operational planning guidance** outlines that systems are asked to focus on a number of priorities for 2022/23 and across all these priority areas, systems are asked to maintain their focus on preventing ill-health and tackling health inequalities by redoubling their efforts on the five priority areas for tackling health inequalities, set out in guidance in March 2021.

➤ Pages 17-20 of the **'Advancing mental health equalities strategy'** provide a summary in terms of differential access, experience and outcomes of some of the most pervasive and apparent mental health inequalities in England highlighted in the available literature and best available evidence: **age, ethnicity, gender, sexual orientation, disability, deprivation and other**.

➤ As outlined in the 'Advancing Mental Health Equalities Strategy', collecting and using data to inform intelligent insights and decision-making is critical in advancing mental health equalities. Taking these inequalities into consideration when undertaking population-level service planning and provision has its benefits, though system leaders must also recognise smaller population groups can face significant inequalities in the round but are often 'swallowed up' at a population-level, or not recognised in the first place.

➤ **The Healthcare Inequalities Improvement Dashboard** measures, monitors, and informs actionable insight to make improvements to narrow health inequalities. It covers the five priority areas for narrowing healthcare inequalities in the 2021-22 planning guidance and data relating to the five clinical areas in the **Core20PLUS5** approach. The process for dashboard access is through the **Equality and Health Inequalities Network – FutureNHS Collaboration Platform**.

Good practice example: At the beginning of their CPA Transition journey, The Midlands Partnership NHS Foundation Trust spent a lot of time on engagement, collaboration and understanding their population health needs, data and outcomes before they started to design what they wanted their services to look like. They used the **Health Equity Assessment Toolkit** (HEAT) developed by PHE to identify their wider determinants of health, gaps in provision and priorities. They also identified their under-represented groups through the HEAT analysis and commissioned **The Community Foundation for Staffordshire** to administer grant provision to hyper-local organisations who are very good at engaging with under-represented groups. Their population health data has influenced the services that they have commissioned and they have configured their teams around their data. They created data packs for every PCN and they consulted on those data packs with the public, their staff, local authorities, voluntary sector partners, as well as service users - they identified a number of priorities that they were going to work on, so they co-produced and co-identified the priorities in each area.



As outlined in the NHSE CPA position statement, carers often face specific inequalities and are protected from discrimination under the Equality Act. NHS England's development of a **Patient and Carer Race Equality Framework** for use in mental health services is a response to the need to address racial disparities and is part of the wider Advancing Mental Health Equalities Strategy.



VCSE Partnership working to address Health Inequalities

The next two pages provide a summary of the work of 'Coffee Afrik', a Community Interest Company established in East London, and how they are working in partnership with East London NHS Foundation Trust to address health inequalities.

i **For context:** as outlined in the [CMHT Roadmap draft published by NHSE \(August 22\)](#) in relation to 'Commissioning and partnership working with a range of VCSE services'. Development of a VCSE alliance which brings together the breadth of provision in a local area – facilitating collaboration between organisations and ensuring smaller grassroots, local community/faith and user-led organisations are supported.



About Coffee Afrik

Our focus is to reduce health inequalities whilst creating good noise and good trouble to magnify intersectional issues and harnessing joint third sector support: by having co-production as a core function. We apply our unique referral pathway model pioneered through our experts by experience to amplify all of our multiple projects. We have built an innovative approach that empowers our community and delivers the support they need when they need it, with a focused no referral pathway approach. Access for all, with love at our core.



Understanding their Community needs

Coffee Afrik commissioned a research paper - to access the paper, click [here](#)



About Coffee Afrik Projects

Somali Digital Peer to Peer Support Group

We launched the UK's first-ever Somali digital peer-to-peer support pathway for women. We launched this project to help heal a community with existing undiagnosed mental health conditions.

The success of our pilot project has been captured in an impact report and has been received positively by funders, local authorities, public health directors. If you want to find out more about the project including data, their Referral-Pathway Model and future plans, click [here](#)



Rooted Advocacy support

The aim behind our project was to coordinate an advocacy support programme for the largely Black, Asian and minority ethnic (BAME) community in Hackney who are currently facing many intersectional issues, a model rooted in divesting from whiteness, using trauma informed language and rooted advocacy.

Our Advocacy Support Officer played a huge role in assisting many clients in the borough with a wide range of issues. Facilitated at our safe space, clients from many diverse backgrounds would often reach out to us, due to our culturally competent support, which is our ability to cater and consider their cultural needs.

If you want to find out more about the project including case studies, data and their Signposting-Referral Pathway Model, click [here](#)



To find out more about 'Coffee Afrik' and their work, click on the icon >>>





Insight into the principles through the lens of a Health Equalities Expert

We have discussed the five principles with Abdi Hassan, founder of Coffee Afrik, a Community Interest Company based in East London, and we have captured some of the main messages, particularly in relation to personalised care and support planning.

Insightful recommendations to progress the principles to advance equality and equity:

- *Interventions and services that are culturally competent – principles and initiatives that are designed with local communities.*
- *Commissioning local community grassroots organisations to address anti-racism practices.*
- *ICs/ICBs working with grassroots organisations to transform and develop clear pathways for marginalised and under-represented groups.*
- *Looking at the disproportionate use of the Mental Health Act particularly on black men and other marginalised groups in the NHS, up and down the country. What can we do differently and how we can use lived experience to influence change? For example: lived experience statements, lived experience practitioners, experts by lived experience in ICS/ICB boards, lived experience in leadership, etc.*
- *From health perspective, what do marginalised communities need? We need to empower service users to define their own care. It is about service users saying “this is who I am”, “this is my culture”, “this is what I want in relation to my care plan”.*

In practice.....



Case study - Community hubs in Hackney

‘We have set up five Community hubs in Hackney that are run by service users for other service users, people with severe mental illness who have come together with our infrastructure support and have co-designed a space that is culturally competent. We have advocacy healing practices, a community garden, a crisis café with hot food everyday, cooked by our own service users. There are individual and group mental health sessions, that use ‘tree of life’ - a South-African healing methodology, which looks at trauma and how to reframe trauma and how the use of African principles of healing can allow communities to come together and provide a holistic be-friended support. We also help people improve their English and help them find work, by providing rooted advocacy - when you triage a client, you cannot just triage their mental health, they might also have debts, substance use and we look at their needs and the person as a whole’.

It is about practices that look at creating care plans with the person and are culturally competent. Service users need to design their own health plan, it puts the ownership in the person, they are responsible for their own care, but we give them autonomy to seek what services are suitable for them. If you come to Coffee Afrik, in Hackney or Tower Hamlets, we use the language that is appropriate for service users.

How did we start? – *‘We identified the neighbourhood, we identified the hub, and with local people we designed the space, the governance and the health programme. We piloted the work of the programme and created autonomy and empowered local people to become service users, to design what they want, how they want it, who manages the space, what language will be used in the space, what principles of engagement will apply in that space and through the experimentation we ended up forming the hub. We have now created five hubs using the same approach.*

We look at models that empower local communities but fundamentally about tackling the historic roots of health inequalities.

Partnership working - ELFT Community connector

‘We have a Community connector who works within an embedded ELFT MDT, based in a PCN, and provides ELFT with our knowledge of community grassroots navigation and signposting. The Community connector is able to refer back into community, for example to the community garden, health projects, etc. If there is a need to refer to secondary care, they have daily MDT huddles with clinicians. This model works well for ELFT as service users will get the community navigation support as well as the clinical support.



Practical step by step guides

Rethink Mental Illness

This page includes a recap of the practical guides that were developed by [Rethink Mental Illness](#) in October 2020 and February 2021 outlining the steps needed to deliver real transformation of community mental health services.

i To read the full '[Thinking differently](#)' guide, click on the icon >>>



Summary: this is a 'first steps' short, practical guide to the first five steps needed to begin to redesign a community mental health model that was published ahead of the transformation funding entering the system in April 2021.

The first five steps:

- 1. Leadership and governance** - A leaders group of experts by experience and staff who can sign off decisions.
- 2. Co-production** - A co-production project group of people with lived experience and staff gaining local insights, co-producing a new model and feeding back to the community.
- 3. Mapping community assets** - An understanding of who is currently delivering support for people severely affected by mental illness and their clinical, practical, social, financial and physical health needs.
- 4. Alliance building** - An alliance of voluntary and community organisations coming together, ready for procurement.
- 5. Workforce** - A new model of community mental health care forming (but not necessarily finalised) and a workforce plan and recruitment starting with role adverts published.

i To read the full '[Keep thinking differently](#)' guide, click on the icon >>



Summary: This guide builds on the first guide summarised above 'Thinking differently' and moves on to commissioning, evaluating and recruiting, with a particular focus on peer working supported by a range of examples and initiatives.

The next five steps:

- 6. Addressing and overcoming barriers** - Work to overcome hurdles in completing the first five steps before moving ahead to finalise your model of community care.
- 7. Measurement and evaluation** - Co-produce a person-centred model of evaluation with experts by experience to measure the efficacy of your model.
- 8. Commissioning and contracting** - Use new and innovative models of commissioning and long-term contracting to jointly create a new, alliance-focused system of community mental health care.
- 9. Recruitment and skills development** - Ensure that the right roles are in place and that new and existing staff are equipped with the right knowledge and behaviours to deliver your new community model.
- 10. Co-delivery of your new model** - Spread the word about your new model of support and begin co-produced delivery of services. Continue to meet as a partnership to build and evolve your model.

Critical Friend Group Feedback



We have established a 'Critical Friend Group' of people with lived experience including service users and carers to check and challenge the content of our work. The following slides provide their feedback, experiences and feelings.

How was the feedback collected?

1

Questionnaire



In March 2022, we asked four service users to complete a questionnaire, including a few questions around each of the five principles of the NHSE CPA Position Statement.

We have included a summary of the answers and feedback received.

2

Workshop



In July 2022, we held a workshop with our 'Critical Friend Group' formed by four service users and four carers to explore their views and feelings around the five principles (including older adults) and how they think the CPA transition will impact them and the people they are caring for.



1 A shift from generic care co-ordination to meaningful interventions

“ **Treatment of people with complex emotional needs, particularly associated with the diagnosis of a personality disorder, regardless of having a diagnosis, should be long-term as the latest evidence re-confirms.** Of course, if a person wishes to step away, that is OK, but the evidence is that people with complex emotional needs require long-term engagement. This does not mean that they need to be in intensive treatment for years. Often, after the evidence-based length of treatment, they may just need occasional sessions / groups for maintenance, but this needs to be offered on a long-term, flexible basis. It takes time to rewire one’s brain, especially if the difficulties are of developmental nature or if they even happened in-utero or are subject to intergenerational trauma. ”

“ Attitude needs to change, healthcare professionals have to be trained very early on, even before they become professionals, **trauma informed care needs to be part of education and mental health care**....we need more psychologists, more people who are trauma informed who can do mentalising, psychological interventions, open dialogue, etc, **Like in Scotland, the whole NHS needs to be trauma-informed.** ”

“ The problem is the medical model of mental health is currently not equitable and **the system needs to adopt a completely different attitude to treating mental health difficulties. People want things like open dialogue, mentalising. People need to understand and have knowledge of the mental health difficulties, rather than most people getting medicated,** then addicted to the medication, overprescribed and then dying decades earlier; whereas if a person starts understanding what happened to them in their childhood or if there is an intergenerational trauma in their family, things can move on and progress and people can get insight and they do not have to get stuck in services. ”

“ As service users and carers, for years now, **we have been advocating and campaigning for more talking therapies and interventions that are not medical.** In the long run, the medical model is financially not sustainable because it does not treat the underlying condition..... It does not have to be delivered by consultants, it can be delivered by trained peer workers and it would revolutionise this medical model approach to psychiatric illness. I am not saying ‘no’ to medication, but it has to be used as a precision instrument and not as a blunt tool. ”

“ **Antipsychotic medications are not the only pathway to treating mental ill health and other alternatives such as talking therapies should be given equal consideration.** People’s lives and the quality of their lives are shortened when they are taking these medications. ”



Feedback - questionnaire

1 A shift from generic care co-ordination to meaningful interventions

Please explain your experience of the CPA

“ My overall experience of CPA has been good. Regular contact from coordinator and doctor’s appointments to monitor mental health, but since using DIALOG+ as part of my care plan, I feel this has helped structured the meetings and I have a say in my care. In these meetings, I share decision making, it is person centred and not just about the medications review. Through the DIALOG scale you can talk through other barriers that are affecting your mental health, like your financial situation and housing, etc ”

“ I have experienced CPA as a document that I have done with my care worker and also as a follow up from consultants appointments in the form of the MH4. This was always an information based document with very standard approach (e.g. medication...risks...follow up...presentation) and more for the professional; even with the care worker there was little time to explore my perspective and was often rushed and felt a burden for the care worker. ”

In your experience, how helpful has the role of the care coordinator been to yours / another’s recovery?

“ The role of the care worker is I would say imperative in the recovery and support process. Having a point of reference and feedback for myself and for the carer is absolutely vital in ensuring wellness and identifying early trigger warnings and for discussing any anxieties and coming up with joint solutions. Also a vital bridge for consultant appointments, medication review and medication reminders. ”

What would you say are the most important factors in making your care meaningful and supporting sustainable recovery?

“ A strong connection with the care worker and an open dialogue between the service user, carer and care worker. A good line of communication decided by the service user that defines how often and in which way. A focus on reassurance and support and also encouragement for any positive steps the service user makes...also the rapid response is very important in times of crisis and fast turnaround for increasing meds or hospital admission. A good administrative skill from the care worker who is able to fight for their service user to get emergency care and reassure the family at crucial times. ”

“ Building of relationships, having a say in my care, being able to ask for other alternative treatments with confidence, being heard, being given choice in my care and not always being seen as having a mental health difficulty and being seen as the person I am. ”



2 A named key worker for all service users with a clearer MDT approach

“

*In the time I have been treated in my CMHT, I have only had two care coordinators and they have been absolutely super, each one lasting for many years and their role has always been to bring in interventions when they are needed. Because of the nature of my disorder, I am up and down, I need this and I need that. I have been having problems with my sleep recently, and my care coordinator has referred me to a sleep clinic. If I need an appointment with my psychiatrist, she will arrange it for me, but the benefit is because she has been with me for so many years and she knows me really well. I think **my anxiety is about any change in the system, is about breaking up that relationship and getting to know somebody new. I really benefited from a very deep relationship with my care coordinator.***

The new CMHT hubs should not be breaking these relationships. Continuity of care in professional relationships and treatment should be prioritised and it is essential to maintain good mental health and prevent illness.

”

“

*A key worker, or any professional coming into contact with patients, needs to efficiently mentalise = to be compassionate, nurturing, empathetic, respectful, reflective and be able to role-model a healthy way of being and connecting with others. They need to be relational and understanding in a way that gently steers the person to gain a different perspective and insight into their struggles. For that, **the key worker needs to be trauma-informed.** They need to be systemic and able to work therapeutically with the family / carers in an equal measure.*

”

“

***The key worker has to be able to understand attachment, how relationships work, family dynamic** and able to provide an intervention to a family member if required.*

”

“

*The main thing for me is trust and connect, to have somebody who you can build trust and a relationship with. In between my long term care coordinators, I had someone who was quite judgemental and seemed to fire questions at me that made me a lot more ill than I was before. **It is really important to have somebody who can listen, can respond, and can be non-judgemental within the role and the personality of the key workers needs to fit the role.***

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“

*In the past **my partner has had experience with a peer support worker and they were a real help but he has quite severe personality disorder and he needed the care coordination as well** – this person helped him to go to the gym, got him physically active and that was great for improving his wellbeing aside from needing appropriate psychiatric support that he got at the CMHT. I do not think it was a substitute but it was certainly a good **supplementary support.***

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*Healthcare professionals are always in a rush and they do not have time to spend with you or your partner. **I just feel that they just do not have time and it is all about time and rush.** Everyone is talking fast and when they leave, you are like ‘oh we should have spoken about this and that’.*

”



Feedback - questionnaire

2 A named key worker for all service users with a clearer MDT approach

Please describe which stakeholders you have encountered as a service user? What are the key strengths and weaknesses of the teams you have come across as a service user?

“ I have had a community connector calling me instead of the normal coordinator. I find her helpful and she signposted me quicker than a coordinator. Using DIALOG and DIALOG+ with my consultant has enabled me to establish and promote my independency and my recovery. ”

“ In terms of strength, my consultant psychiatrist is first, clinical psychologist is second, mental health nurse is third and social worker is fourth. The weakest member is the GP. ”

What other improvements are needed to the way care providers work with other organisations / stakeholders (e.g. friends and family, carers, voluntary care sector, local authority)?

“ Communication between other involved in the care. This communication has to be clear and consistent and keeping the family informed. ”

“ The local authority needs more integration with the NHS, especially in relation to Care Act Funding and Personal Health Budgets. ”

“ Always good signposting and not allowing someone to just be okay with medication and nothing else going on in their daily lives. Loneliness and isolation do not aid wellness. Healthcare professionals could encourage socialising by volunteering, getting involved with a hobby or factoring in some physical activity to help a person stay stable and make them feel part of life, as opposed to being stuck in an eternal haze of medication and just getting through. I have built up exercise and I have a social drop in once a week at a community where I can socialise and benefit from social activities. I also do art and poetry and I have a part time work that suits my condition and schedule. I also work on all my family relationships and have trusted friendships. I also have a care worker and I am supported by a consultant. All of these areas must begin somewhere and services should be helping people to find what their motivation is and listening to service users and carers who want to get back to living and being happy. ”



3 High-quality co-produced, holistic, personalised care and support planning

“ A lot of the things that we really need like access to talking therapies and things like that, we never really get them from the CPA so I do not know if we will get them from DIALOG+, but just calling it by a different name is not going to make the services available. **I have been through these things for decades now and it just seems like we are going round in circles giving the same thing a different name. I am hoping that DIALOG+ is going to be better.** The only feedback I have had from someone who has done it, is that it was very good and I am hoping that it does not become a tick box exercise and remains meaningful to the service user and their loved ones. ”

“ What you have to do is to make sure that this does not become a tick box exercise – I was talking to a lady and her son has had the **DIALOG+ assessment and she said that it was really good and it was the first time that she felt involved in years.** In principle, it should work very well, but you have to remember that it is only as good as the people delivering the service. ”

“ I have not had any experience of DIALOG+ in my personal care but I know it is rolling out because I am busy training on it to train staff to actually use it. It kind of gives service users a personalised approach to how they feel about and how they are. **As part of the care plan, it could really help in terms of giving the service user a sense of that they are driving this and it is about the areas of their life that concerns them, so that is where it differs from traditional care planning.** I really hope it is going to work. It is in the training stages now and I know it is being used. I personally, as a service user think it is a really useful tool. It is a facilitated conversation that is meaningful to the service user which is different to having tick box exercises. ”

“ **Implementing a holistic approach with a service user about different aspects of their care and lives to be able to assess and identify what is important for them and central to co-produced care planning, something that is done collaboratively and together and it is the basis to build upon.** My worry is that it becomes a tick box exercise because it is recorded the way it is, because data is needed into the systems. ”



3 High-quality co-produced, holistic, personalised care and support planning

Any thoughts on how care planning might be improved going forward, in terms of co-production, and holistic personalised approaches

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Service user led co-production, training workshops for services to understand the benefits of the care plan DIALOG+ and how it improves the quality of life. Also services could develop leaflets and information sheets explaining why it is important for service users and also for staff members so service users can get the best outcome by using DIALOG+.

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Consultant psychiatrists are best placed to coordinate care for those with severe mental illnesses. They are aware of all the support available in the local community of the patient. Patients with Section SS17 aftercare need to have prompt Care Act Assessments for support services to pay for their care. They also need prompt Personal Health Budget assessments to pay for services to keep themselves healthy physically and in the community.

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Service users and carers voices must be at the heart of any changes. Improving approaches and making cultural change requires a buy in from the executives as well as those on the front line. The rewards for service users and staff seeing and getting to know service users, listening and having the DIALOG tool can only work if the right kind of person has it at their disposal.

Trauma informed approaches would help healthcare professionals to see service users as who they are with a full spectrum of goals and dreams rather than discharging people into community to an empty room with no links into their community. There should be interests and actions that are put in place before that happens. DIALOG is a chance for service users and carers to really be at the centre of their worlds. We need a guiding hand to find new solutions and new pathways. We will not be the same after a mental health crisis but with DIALOG service users can get back on track or find new ways of being part of the world and happy again.

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4 Better support for and involvement of carers

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What I think is missing is confidentiality as that is often used to shut carers up and it is used inappropriately. I do not think staff members always understand what they can and cannot say to carers very often. One of the things that usually tends to happen, because the carer is the person that is most involved with the service user, very often service users will turn on the carer as they become very unwell. Generally when you are a carer for someone with mental health problems, you do not chose to do this, this just happens to you. It is usually the person that you love the most in the world that becomes unwell, so you just cannot walk away and leave, you are involved and it is your life as much as their life unfortunately. Very often if the person is unwell they might ask staff to not to talk to their carer. **The carer can provide very valuable information about the person (e.g. what has happened to them in the last days, what their triggers are) and it can take staff days to find out these things or they may not even find them out. Carers talking to healthcare professionals about the person they care for is not a breach of patients confidentiality.**

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“

The whole system needs to be systemic through and include families, friends, partners and carers in the treatment from the very start, not as an afterthought when it is too late. Families, on commencement of treatment, have to be informed that their relative cannot make a successful recovery without their input and thorough understanding of the mental health difficulties. Mental health difficulties largely lie in the person's social environment and there is no magic pill that will cure the person's difficulties. **Carers need to be provided with skills and knowledge for caring from the very start. They become experts by experience through the years of looking after somebody with complex mental health issues.**

”

“

When I get psychotic, I do not trust my family yet they are doing the best for me. There have been situations when my carers have been trying to speak to the professionals and the professionals would only speak to me when I am not making any sense. **There is real case for advanced directives. Now I have written in my care plans that when I get ill and I am psychotic, my carers will know because they will have seen that build up and the signs before anybody else does. They should be able at that point to talk to appropriate healthcare professionals and have their concerns taken seriously.** This is to protect carers as well when things really do get bad as they need protection from the services and support as much as the service user does. Relationships can be terribly destroyed during a really horrible episode.

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Very often, when someone has died, carers and family have not been involved or they have been ignored and families know what is going on. **As carers, our number one priority is the safety of our loved ones.** Talking to carers, family members or significant others is so important - it has to be joined up care.

”



4 Better support for and involvement of carers

How can the system better support carers?

“ *Understanding the needs of individual carers and barriers in accessing services for the service user and carer. This will help the service user understand the process that has been used and why and how both can benefit from the process alongside the team.* ”

“ *Give them all the information you can about resources in the community and legislation to obtain financial support through the Care Act 2014.* ”

“ *Ensure carers and families are listened to and that they are given the respect and importance they deserve....they do know a lot about the person they are caring for. Their concerns over safety and over medication and care have to be taken seriously. Communication needs to be clear and consistent so that carers know that they have access to a professional. They should feel that they can ask anything about their loved ones' care and that they are listened to when it comes to their needs.* ”

“ *Regular meet ups between the healthcare professionals and the carers, so they can discuss any matters arising to better support the service user.* ”

“ *Carers need a resource pack providing them with information of all the support in the community or a special carers app with all the resources and rights they are entitled to under the Care Act 2014.* ”

From the perspective of the service user, how can carers play a better role in the provision of care and support planning?

“ *To be better informed of the support out there for them as carers, like support groups, online groups, etc and to be better informed by the service user's team on how to get the best support plan in place.* ”

“ *Best for their views to be heard as part of DIALOG+.* ”

“ *Always being involved and asked for their views on the situation. Routinely being invited to appointments, being copied into care plans or professional decisions. Where they have advocacy, being the first point of contact in decisions' sharing and information. Being recognised and given a welcome onto wards and by the community as a vital resource and part of a service users support circle.* ”



5 Developing a culture of safety

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*What is safety? because many patients even carers, do not feel safe in a mental health setting. It is one of those basic needs, we need to be safe around people, especially in the mental health system and that is not largely happening. The course I conducted was based on a number of situations where patients died by suicide and families were not involved in the crisis and care planning at all, despite the patient considering their loved ones and significant others as a protective factor. The family and loved ones were asking for help or some skills from the professionals. So again **this comes down to professionals and how they have the skills and knowledge to help families to help their loved ones. Much more knowledge around safety is needed and what it means as a basic need,** and again skilling up carers as well as professionals, knowing how to talk about suicide and what it is. For many people it is an escape mechanism, it is actually release and relief, because they might have been traumatised and this is the belief that was left with them as children and then adults.*

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*It is essential that family and carers are involved in safety planning. **If carers understand the mental health difficulties of the person and have the skills on how to deal with mental health distress, they can prevent their loved ones' distress from escalating.** As part of safety planning, treatment should include lots of learning as a whole family so they all understand trauma and how it presents, transference, mentalising, what suicidal thinking is about, etc – this will help to plan accordingly and be preventative in itself. Feeling safe can be brought about in a person when they are validated and mentalised, when their emotions are understood and they feel that they are “seen”. This is what the person’s social environment needs to understand. Often a service user may not have insight into their illness, so more carers need to be educated so they do not add to their person’s distress.*

”

“

*I have never felt safe in hospital, I really did not. In hospital you are surrounded by other people who are incredibly unwell. There is a hierarchy in that, you can get bullied, it is a really horrible environment and it certainly made me worse. I finally argued with my carers to get me out of hospital and had a really good, successful programme with the home treatment team. **It is about what safety planning means to the individual. People may feel safer in their own home with people visiting them rather than in a hospital environment which can feel the very opposite of therapeutic.***

”



5 Developing a culture of safety

To what extent are you involved in conversations about safety?
Do you feel like your perspective is adequately valued?

“ Yes, but there has been times that I have been at risk and it was failed to be recognised by the teams until it was too late; I was too ill when they finally noticed. When I spoke to the professionals to tell them that I was feeling like I was going to be really unwell, they did not take it seriously and I ended up being admitted to hospital the same day. ”

“ Yes, I have no insight when I am unwell and my team of professionals are aware of this. Sometimes they do not take it seriously, so I remind them that I have been sectioned on four occasions to date and I have been under Section 3 two times. ”

“ I am currently involved in safety in mental health settings and we are rolling out co-produced training across the London Trusts. Safety is key to wellness and at the heart of both - service users and staff need to feel safe in their environments, as without safe spaces there is no chance of service users feeling they are able to be vulnerable and open. ”

What are the weaknesses in how you are currently presented with / engaged in safety planning around the CPA? Are there any examples of where this has been done thoughtfully?

“ CPA was good at recognising triggers but not good at all in how to prevent triggers or give the support in the community through payment of a Personal Budget to hire Carers or Befrienders. ”

“ We must allow for people to not be shut down or feel stifled or controlled by safety planning but rather reassured and confident they are being supported and protected when there is a need. ”

How could the system improve conversations around safety in a way which benefits service users?

“ The Local Authority has a duty of care. However, they should be more integrated with NHS services to improve safety for patients. ”

“ Open forums on safety with service users and carers and having frequent check ins with staff around any worries etc. ”



6 Specific considerations for older adults

My husband now falls into the older adult category with dementia and you get very little in the way of help from services. It is not like that in physical health and it should not be like that in mental health but unfortunately that is what has happened.

When completing DIALOG with older adults, there are some considerations around the relevance of some of the questions so you can follow up with some supplementary questions (for example: the question around job situation could be replaced to refer to financial situation).

Additional general feedback

Please refrain from using the word “problem” in connection with mental health. It is evidenced in the academic literature that it is unhelpful and keeps the person stuck in their difficulties. Language is of utmost importance in mental health.

In at least one borough, mental health services now discharge patients if the service has had no contact with the patient for 45 days. It is an arbitrary number that has no evidence. Discharge is not discussed with patients and even if the service cannot get hold of them and agree some plan or signposting, etc they just send out a generic, dispassionately worded letter telling the person they were discharged and to get in touch with the GP.

First and foremost, like there are advanced / senior peer workers, people with lived experience of caring have to be employed in similar roles. At the moment only peers with lived experience of mental illness are recruited for jobs, but there are virtually no equivalent jobs created for carers. Carers may be well experienced, have a good employment history, have university degrees and lots of transferable skills.

For three years where my son was receiving a service from the Early Intervention service, I experienced really good support, our relationship with the clinical care coordinator was really good, and with the psychologist and social workers, they were all very responsive. Some of the difficulties is that continuity support offer and continuity in relationship – going from the Early Intervention service to CMHT or primary care where there is absolutely no support. That is the problem, to maintain continuity of support for transition in the system. Carers experience frustration if no support is offered when needed. There is nothing more difficult than to have no options when someone is in crisis but to ring the mental health crisis line to find that there is nobody at the end because the service is busy.

It does not matter what professional it is, they need to be mentally healthy and thoroughly understand what mental unwellness is about, that most of it stems from unmet childhood needs, invalidating environments, traumatic experiences and that trauma, if left unrecognised / untreated is cumulative.



Additional resources

DIALOG RESOURCES



1	2	3	4	5	6	7
Totally Dissatisfied	Very Dissatisfied	Fairly Dissatisfied	In The Middle	Fairly Satisfied	Very Satisfied	Totally Satisfied



HLP has developed the following DIALOG resources

- Using DIALOG in measuring impact of Mental Health services
- Using DIALOG in a meaningful way in Older Adult services
- Using DIALOG data to understand population needs
- Using DIALOG in an Inpatient Setting



To access these and other DIALOG resources, click on the icon >>>



Exploring different peer and community connector roles in London

HLP interviewed last year people working in these roles and clinical leads and produced three videos to explore:

- The different roles and responsibilities across London and how each benefit and contribute to supporting a person with severe mental health difficulties and the wider community mental health transformation.
- How these roles add value to a multidisciplinary community mental health team- identifying what works well and areas of development to effectively integrate these roles.
- The supporting infrastructure, leadership and personal and professional development that is required to ensure that these roles are effective, add value and are sustainable.



To watch the videos and access the posters, click on the icon >>>



Support for and involvement of carers

Resources outlined in the NHSE CPA position statement:

- [The Carers Trust's Triangle of Care](#)
- [NHS England and NHS Improvement's carers toolkit](#)
- [NHS England and NHS Improvement's Supporting carers in general practice: a framework of quality markers](#)
- [NICE guideline NG150 on Supporting adult carers](#)
- [Information on the use of Family Intervention approaches](#)
- [Specific resources for supporting young carers](#)

➤ Click on the links to be directed to each resource

Acronyms used in this document

- Care Programme Approach (CPA)
- Central North West London NHS Foundation Trust (CNWL)
- Community Mental Health Team (CMHT)
- Complex Emotional Needs (CEN)
- East London NHS Foundation Trust (ELFT)
- Health Equity Assessment Toolkit (HEAT)
- Multidisciplinary Team (MDT)
- Mental Health (MH)
- NHS England (NHSE)
- Older Adult (OA)
- Older Adult Mental Health (OAMH)
- Patient Reported Outcome Measure (PROM)
- Primary Care Network (PCN)
- Professional Records Standard Body (PRSB)
- Public Health England (PHE)
- Standard Operating Procedure (SOP)
- Voluntary, Community and Social Enterprise (VCSE)

This document has been developed by Healthy London Partnership in collaboration with a group of experts by lived experience including service users and carers, Mental Health Trusts in London and across the country, ICS colleagues and voluntary care sector partners

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