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THE COMPLETE CARE COMMUNITY PROGRAMME

Table of Contents	
Executive Summary	3
Introduction	4
The Complete Care Community Programme	6
CCCP Evaluation Approach	7
Service User Evaluation	8
Methodology	8
Results	8
Key and Sub-Themes	11
Sub-Themes – A Closer Look	12
Discussion	14
Conclusion	15
References	16



Executive Summary

The Complete Care Community Programme (CCCP) is now in its fourth year of operation. It was developed to address a key challenge facing the NHS; namely how to address health inequalities in a sustainable way. By creating a national learning network, the shortcomings of previous attempts to scale findings from successful project work to the wider care system was also to be examined and potentially solved.

The CCCP is an umbrella structure that has grown from an initial 26 sites launched in April 2021 to a national coverage in England of 65 sites by April 2023 and whose aggregated population base is circa 3 million people.

The CCCP was constructed to:

- · Assess the extent to which different models of integrated care and cross-sectoral working across local systems within the CCCP demonstrator sites are effective and what impact the new architecture of the NHS can make on addressing health inequalities
- Contribute to the developing evidence base about the success factors that help facilitate effective partnership working to reduce health disparities for specific and clearly defined population groups
- Identify factors which may support or hinder the long-term sustainability of projects and collate case studies and thematic reviews designed to address health inequalities
- Help to build an understanding of what role ICPs and ICBs can play in supporting Primary Care Network (PCN) population health initiatives focussed on reducing health inequalities

The Programme has utilised the Quadruple Aim for optimising health system performance as a framework for the long-term assessment of the impact of the CCCP approach.

This report provides a further evaluation of the Care Community Programme (CCCP) based on feedback about service

service users' experience. In this second national evaluation the aim was to examine person-centred care was being enhanced, with a focus on the needs of the person rather than the needs of the service, and assessing the extent to which inclusion and agency can be achieved in the delivery of care to an individual.

CCCP projects have been supported by a central team, whose mentorship is to help focus the delivery teams on the enrichment of the experience of an individual in a care system with heightened satisfaction particularly in relation to good access and short waiting times.

The Programme has adopted a population health management approach to health and care delivery, utilising demonstrator sites that are focused on addressing both the existing health and care needs in their local areas and the wider determinants of health. It seeks to identify those factors which can lead to sustainable approaches in addressing the health inequalities of marginalised groups, whose connections to the existing care services may be weak, and how those factors can be translated for spread and scaling throughout England.

Each site is made up of host Primary Care Networks (PCNs) and local system partners (including statutory and non-statutory bodies), that aim to work together collaboratively to target local health priorities through locally agreed interventions. This includes development of new provider teams combined health and care professionals, along with other community-based services.

This report considers how the services offered through the Programme were perceived by its service users, the ease of initial access to the programme, the ease of ongoing participation and how the users of the Programme felt they could be helped after its discontinuation.

It found that initiatives set up within the Programme were welcomed by service users

THE COMPLETE CARE COMMUNITY PROGRAMME

National Evaluation: Service User Reports

and suggests that they reached people who had been lost to the healthcare system. The indicators of successes and challenges from the perspective of its service users are discussed further, in this report, and there are also considered learning points for recommended improvements to any future programmes.

Introduction

Health inequalities (HI) are "avoidable, unfair and systematic differences in health between different groups of people" (Williams et al., 2022). They may result in premature mortality, reduced quality-adjusted life years (QALYs), an increase of behavioural risks, poor educational attainment and have a significant effect on the economy (Lewis at al., 2022; NICE, 2024). Evidence shows that there is approximately a two-decade gap in healthy life expectancy between the most deprived privileged and the most areas/neighbourhoods in England (NICE, 2022).

Intersectionality of factors such as ethnicity, socioeconomic status, gender, disability. geography, religion, and being part of a vulnerable group often influences HI for individuals (NICE, 2022; Williams et al., 2022). Access to health, care and other services is also a contributory factor to expectancy (Dahlgren healthy life and Whitehead. 1991). In England, life expectancy has fallen over the last decade, that social and economic suggesting progress has halted (Marmot, 2020). The health of a nation can often be determined by the health of its occupants; it is dependent on including many factors resources. employment, geography, and housing status often referred to as 'The Social Determinants of Health' (Marmot, 2020).





HI have been a problem for many years with urgent calls for change being documented as early as 1980 in 'The Black Report', and by an independent inquiry led by Sir Donald Acheson in 1998 (Lewis et al., 2022). Professor Sir Michael Marmot (2008) conducted a review on policies/strategies undertaken to reduce HI in England which highlighted that action by central and local governments, along with the NHS and third/private sectors would be required (Marmot, 2010; NICE, However, in a follow-up review in 2020, Marmot established that in fact the HI gap widened and health was declining further for populations in England (Marmot, 2020). Barr et al in 2017 confirmed the improvement of health inequalities between 2003 and 2010 and deterioration thereafter. Additionally, health systems can be hard to access and to navigate, with poor health literacy directly correlating to worse outcomes relating to chronic disease and contributing to HI (Public Health England, 2015).

The need to reduce health inequalities was enshrined in the Health and Social Care Act. Although some areas of the act were successful. fundamentally the evidence showed that inequalities widened even further with little attempt to incorporate HI into the local systems (Lewis et al., 2022). This issue was pre-empted some years before in Marmot's review (2010) which suggested that to achieve effective delivery in local areas there needs to be willing participation at local level and that national policies will not work without local input (Marmot, 2010).

Failing to reach policy objectives over the last few decades seems suggest that a



change in strategy may be required. A 'onesize-fits-all' approach has proven ineffective;

perhaps highlighting the need for 'grass knowledge-based, community-led roots'. interventions designed and delivered with the help of local people (Nickel & Knesebeck, 2020).

In 2020, the Health Devolution Commission was set up to reshape how the NHS and local partners tackled HI with the main focus on local autonomy via the devolution of health from national to local areas (Lewis et al., 2022; Warren, 2020). This was followed by The Health and Care Act (2022) which formalised Integrated care systems (ICSs) to become legal entities with an aim to promote integrated working between the NHS, local government/authorities, and local voluntary sector organisations in order to reduce HI Naylor, (Tiratelli & 2023). A commissioned by the King's Fund (2023) established that in order to make positive outcomes in reducing HI at a local level, it is imperative that district councils become important elements of each ICS as they are strong components of influencing the wider determinants of health (Tiratelli & Naylor, 2023). Additionally, it is important to consider that poor health literacy contributes to widening or reducing HI (NHS, n.d.; National Institute for Health and Care Research [NIHR], 2022). In the UK, 43% of adults aged 16-65 years, experience health literacy issues, this increases to 61% for health information including numbers and statistics; resulting in a reduced understanding of public health information (NHS, 2023; Public Health England & UCL Institute of Health 2015). Community-based Equity, interventions have been embarked on for well over a decade to help improve HI at local level and have shown some promising results (NICE, 2016; Nickel & Knesebeck, 2020; O'Mara-Eves et al., 2023). The focus of community engagement involves utilising local communities to develop, design and evidence-based interventions. deliver programmes and activities to empower local communities to help improve HI (NICE, 2016).

There are numerous barriers to engaging with hardly-reached groups - cultural, linguistic, distrust of government, local authorities and community members, feeling powerless, gender imbalances depending on the ethnic communities, trying to engage those that have already participated and left other groups, lack of childcare and transportation to meetings (Rong et al., 2023).



The Complete Care Community Programme

The CCCP was created by Professor James Kingsland and then developed by a small group of experts in primary care, under the administration of Healthworks Ventures Ltd. Its primary aims are to explore why previous approaches to addressing health inequalities in England might not have been sustainable, support the new architecture of the NHS and in particular Primary Care Networks (PCNs) to address a locally-identified area of health inequality, and gain insight into the necessary steps and project design to tackle a specific local aspect of inequality in health outcomes successfully.

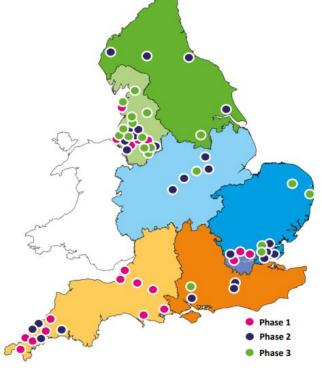
The Programme provides real world evidence about sustainable approaches to reducing health inequalities (Healthworks, 2024). The programme received funding from England NHS to provide а modest contribution (up to £40,000) to selected PCN sites across England to develop a local integrated team and explore, identify and address an area of HI and contribute to a deeper understanding of the barriers and enablers to deliver successful, sustainable and transferrable approaches.

Demonstrator sites within the CCCP address a wide range of population health and complex care issues. They target different sections of their local community, in locally tailored ways, and focus on long-term improvements in health outcomes.

The CCCP sites whilst anchored in PCNs are led by different partners within each local health economy and work in different ways to meet local need and harness local innovation. relationship between Given the outcomes and access to services, sites have often explored non-standard approaches to their initial contact and ongoing engagement with service users.

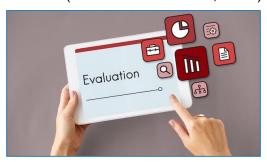
However, there is a broadly consistent approach to service integration across all sites. with cross-sectoral collaboration and multidisciplinary team working being adopted. Taken as a whole, demonstrator sites cover a suite of interventions and approaches to deliver personalised care and services to individuals, groups, and the wider population.





CCCP Evaluation Approach

Comprehensive evaluation policies/strategies is essential to help establish how effective strategies and/or interventions are (Garzon-Orjuela et al., 2020). It is important to evaluate the improvements in HI within all groups, as data based on whole populations alone may indicate improvements in health that may not be experienced by the sub-groups. This could be a result of improvements made by the more advantaged sections of the target populationtherefore not identifying HI within the subgroups (Nickel & Knesebeck, 2020). It is important to consider that the more advantaged groups may find it easier to attend intervention-based due sessions availability of transport, time, etc., benefiting them over hardly-reached groups, further health inequalities widening the within communities. (Nickel & Knesebeck, 2020).



Care needs to be taken to avoid a widening of inequalities as a result of policy interventions. with attrition from all sections of the subgroups closely monitored to avoid bias when reporting results (Nickel & Knesebeck, 2020). Within these hardly-reached groups there will be factors that increase the HI such as lower education status, lower socioeconomic status (SES), and those for whom English is not their first language. For example, health inequalities are often experienced by some BAME populations within the UK, which can result in higher incidence of cardiovascular disease in South Asian populations, higher incidence of stroke and hypertension within African-Caribbean populations, and higher incidence of diabetes within Bangladeshi populations (Kings Fund, 2024).

Certain minority populations have particularly low engagement with healthcare compared to the overall population. Higher incidence of mental health issues are seen in African-Caribbean populations. Instead of accessing the mental health system through health services, some individuals enter through the criminal justice system (Schuch et al., 2019).

The CCCP programme provides a rich data source that can enable valuable insight into the challenges of HI and approaches to address them. This project intends to learn from local people, communities, within organisations each network. identifying barriers and facilitators engagement with hardly-reached groups in tackling HI.



The aim of this report is to explore the experiences of the users of services supported by the CCCP whilst part of the programme, to identify the successes and challenges local. of tailored. and community-informed interventions engaging with hardly-reached populations with evident HI within the Programme. Furthermore, it will help to:

- identify barriers and facilitators engagement with healthcare and lifestyle advice among communities experiencing health inequalities
- · explore how the service was perceived by its users, the ease of access and participation to the Programme, and how they felt they could be helped following the completion of the Programme.

Service User Evaluation

METHODOLOGY

Evaluation design and setting

This was a qualitative evaluation. All 65 sites were invited to take part. Sites were invited to conduct short interviews with people support from the **CCCP** receivina programmes, referred to here as 'service users'. Interviews were either scribed or audio recorded. Audio recorded interviews were transcribed before returning to the evaluation team. All completed interview transcripts were returned via Microsoft Teams. Ethical approval was granted by the University of Central Lancashire (UCLAN) research ethics committee.

A concise semi-structured interview was employed to explore 4 key issues;

- · How does it feel to be part of this (service)?
- How easy has it been to take part?
- What has helped/hindered you to become involved?
- What would help further?

Programme attendees

The sites' target populations were people in groups identified locally as experiencing health inequalities as a result of factors such as living areas of deprivation and with in high characteristics such as but not limited to, ethnicity, disability, low socioeconomic status, homelessness, and/or those with poor mental health.

Data Protection

All data were kept confidential. Participants' were removed and participants names assigned a number analytical for confidential purpose. This information is being stored securely in accordance with the EU General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

Qualitative Analysis

Thematic analysis was conducted. Key issues, concepts and themes arising from the data were identified to create a coding framework. Transcripts were coded and analysed thematically.

Coding allows researchers to categorise label segments and with similar characteristics to observe patterns in data and when repeated multiple times, codes are condensed and often relabelled or dropped. One transcript was analysed by researchers to increase trustworthiness.

Pre-coding facilitated familiarisation participants' feedback through highlighting and annotating certain passages and quotes. Data was then disassembled and organised into categories to allow deeper insight and formation of themes. The inductive coding approach ensured that codes were developed from the data and enabled an inclusive approach. Once codes were established, they were grouped and assembled into key and sub-themes.

RESULTS

CCC Programme Attendees

Not all programme attendees completed a semi-structured interview. The majority of the questionnaires were completed anonymously and provided basic demographics.

Using completed interview scripts, basic attendee demographics, the number of attendees that were happy to complete an interview. and group they the were attending on the programme was ascertained. This is detailed in table 1 below.

Table 1 Participant characteristics: Number of attendees completing the short interview, the programme they were attending, and basic attendee demographics.

Group details	
No. of participants in total	65
No. of participants from each of the following groups	
parent of child/youth	7
mental health	17
no-fixed-abode	11
weight management/ health	13
social event	4
general patient or programme specificity unknown	13
Age (years)	
under 18	6
18-25 years	4
26-35 years	1
36-45 years	6
46-55 years	15
56-65 years	11
Over 65 years	13
unknown	9
Gender	
Male	
Female	
Non-binary	
unknown Ethnicity	6
White British	53
Black British	
Welsh	
Mixed British	
Somali	
Latvian	
unknown	
First language	
English	58
Not- English	4
unknown	3

Key Themes and Sub-Themes

Thematic analysis of the service user semistructured interviews revealed key and subthemes. From the semi-structured interviews, it was ascertained that there was a need to make people feel comfortable, understood, listened to, respected, which in turn results in a more positive experience. Additionally, participants identified a need for reducing waiting lists, addressing stagnant services, improved knowledge and enabling understanding, and the need for continuity of care. The key and sub-themes are detailed in Table 2 and figures 1- 4 below.

Table 2: Themes and sub-themes

Key theme	Sub-themes
Limitations of	Care not moving forward
routine	Long waiting times
healthcare	Lack of understanding of
	individual circumstances (gaps in
	services/ particular mental health
	constraints/ conditions specifics)
Addressing	Understanding of socio-
health literacy	demographic circumstances
	Accessibility - timing, continuity of
	care, practicalities
	Lack of knowledge and
	understanding of Health Care
	Professionals (HCPs)
Acceptability of	Value
programme	Keenness
	Support
	Respect
	Valued voice
	Peer support
	Encouraged by positive
	experience
Patient journey	Moving forward with their care
	Increased understanding
	Effective signposting to what is
	available to them

Figure 1: Sub-themes related to 'Limitations of routine healthcare'

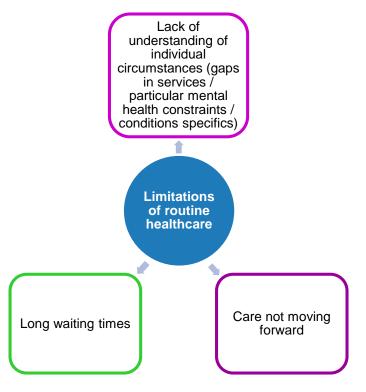


Figure 2: Sub-themes related to 'Addressing health literacy'

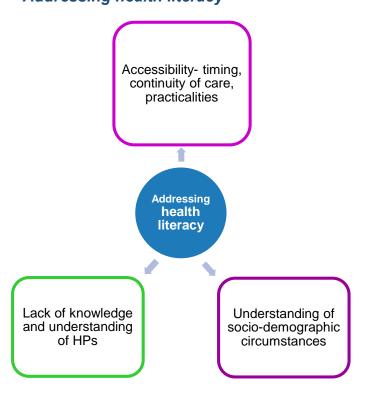
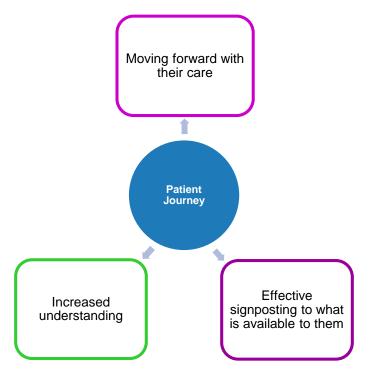


Figure 3: Sub-these related to 'Acceptability'



Figure 4: Sub-themes related to 'Patient Journey'



Sub-Themes – A Closer Look

Limitations of routine healthcare

Feedback from the users of the services offered by CCCP sites revealed that many were concerned that healthcare treatment was difficult to access due to long waiting lists. Additionally, once treatment had started, there was a lack of understanding from HCPs regarding individual circumstances. This often resulted in care stagnating or not moving forward as required (taken from 65 responses). Some quotes are shown in figure 5 below (participant number follows quote).

Figure 5: Limitations of routine healthcare

Key for patient coding for figures 5-8

PC- parent of child/youth

MH- patient attending a mental health programme

H- patient attending a programme whilst having no-fixed-abode

WH- patient attending a weight management/ health related programme

SE- patient attending a social event programme

G- general patient or programme specificity unknown

"Sometimes you know you can only be an emergency so I tend not to ring, I tend to put up with things, which I know I shouldn't do but you do don't you, I think everybody feels like that" P1MH

you aren't getting anywhere or being heard" P5MH

...you get told we will get support, and nothing materialises...you are given 'lip service', but the care and support disappear" P4MH

"It's difficult to get appointments and the care providers aren't sympathetic" P2H

Felt like we were stuck with how to move forward with support to meet her increasing needs" P2PC

Addressing Health Literacy

Health literacy concerns were evident after analysis (fig 6). Service users' feedback illustrated а lack of knowledge understanding of HCPs, with a concern that many GPs and staff do not thoroughly individual socio-demographic understand circumstances. Data showed accessibility to services, continuity of care, practical issues, and signposting to services and resources were all issues that were of concern (taken from 65 responses).

Figure 6: Addressing health literacy quotes

"...being supported by services who provide feedback. appointments aren't kept and not knowing who she is seeing..." P5PC

...GPs do not have the specialist knowledge provided by this service" P2PC

They helped me get housed and also started my journey into recovery from addiction" P10H

"We have had a few appointments with the service and was not just seen once and left" P2PC

Acceptability

Service users provided feedback (Fig 7) suggesting that they felt respected and valued whilst attending the CCCP. This resulted in a more positive experience related to their healthcare, enabling them to have a stronger 'voice' than previously; inevitably increasing autonomy (taken from 65 responses).

Figure 7: Acceptability - quotes

'From start to finish I was treated like a human being, as opposed to a number" P16MH

"It's respectful and you listen to what we need and go at our pace" P4MH

"It has made a big difference; I feel really different now" P6WH

"Previous places have been more judgemental. It's difficult to get appointments and the care providers aren't sympathetic" P2H

"...because I feel like somebody cares" P₁MH

"Main thing is being listened to but also heard me..." P8MH

The delivery of care comes across as genuine- not feeling like idiots" P4MH

Patient Journey

Service users highlighted that they were happier with their healthcare services whilst attending the CCCP. They felt their care was moving forward, that there was an increased understanding of individual needs from the HCPs, and that effective signposting enabled a better understanding of services available for them (taken from 65 responses).

Figure 8: Patient journey - quotes

"...everything that I sort of asked for was addressed. You know asking me what I wanted was really brilliant" P1MH

"We have also been signposted to services that I never knew existed or would have not been able to cope any longer without" P1PC

"It's easier as you have explained things, and you know you just made things a lot easier..." P1MH

...been a huge help in supporting us to get the right support from the local authority" P2PC

...after first appointment our everything seemed to move up the ladder" P3PC

Discussion

This evaluation set out to document how, through the CCCP, people living in areas of high deprivation felt about the care they were receiving. It also tried to establish why these people had found it difficult or had been reluctant to engage with available services, often with inequity of access e resulting in unfair and unequal outcomes from ill health.

This evaluation was developed and carried out over a period of 6 months by active demonstrator sites. Although this qualitative study recorded just 65 semi-structured interviews, the richness of detail in this approach provides invaluable information and actionable insights, not least as the respondents were previously, in the main, reluctant to engage. This work has practically demonstrated a functional approach to better deliver personalised care and establish those factors that provide agency and delivers a patient-centred approach.

Institutions offering services to people in marginalised groups need to be consider how to establish a depth of understanding and insight into the needs and wants of people with complex care needs, living in deprivation, to provide a service sensitive to the needs of these people.

predominant demographic of interviewees was white British and Englishspeaking individuals. This may be coincidental or represent the majority within the population groups being service, but it does question whether ease of access to certain people is a factor.

Clearly, there should be no doubt about the importance of this type of approach to improving understanding the experience of marginalised and vulnerable groups of people living in areas of high deprivation.

In order to utilise the approach espoused as 'population health management', then the

'management' part of this approach can only be determined through a deep understanding of the need and experience of a clearly defined group of individuals, with similar debility, within a population. Profiling the risk to these individuals including, for example, information from interviews such as were carried out in this evaluation, should also be determined before any new service is developed.

This is however only one component of the programme and this discussion is divided into two parts.

First, the actual results of the qualitative study which, while recognising that the sample only records those who have valued arrangements, there are some important indicators of how the system could change in order to help build agency, engagement and ensure inclusion.

The second aspect is how this work complements the first national CCCP evaluation report, concerning the care delivery system from the providers perspective.

This helps paint a picture of what is needed to achieve a sustainable high performing but inclusive care system, which in turn helps outline the implications for future system design and healthcare reform.

This report reinforces an approach to ensure better outcomes of care are achieved by adopting 'patient or person centred' care.

The themes identified should perhaps not come as any great surprise to those working in the care sector.

 Waiting and access for diagnosis and treatment remains a major issue for all aspects of the care sector. However, what these interviews highlight and thus add to current knowledge was a lack of understanding by users of the circumstances as to why the problem existed. The users valued the care

providers work to help support them, for example by being listened to and were appreciative of the wider team working to meet their needs. The 'connectedness' of the system was important and something patients had limited appreciation of.

- 2. Allied to this was a second theme, the patient journey. Having time to discuss with staff their needs and seeing the efforts to work on their behalf was important and valued. There was a sense that prior to the CCCP, patients as individuals were 'fobbed' off to another part of the system; a disconnectedness from the system as a whole and even when in it, between elements. The individuals were seen almost as the problem, not as having a problem. Whatever the arrangements within the CCCP sites, they appear to have addressed this perception for the respondent sample.
- 3. The above also help illustrate and link to the third element, acceptability. Under the approaches adopted at the CCCP sites, patients reported increased respect and autonomy in their decision making. Whether this is as a direct consequence of the relationship between the patient and the site, or the site and referral point has not been explored.
- 4. A fourth element identified is covered by the overarching term 'health literacy'. If the system is to function efficiently, when success in meeting health needs occurs, the changes required need to be sustained. Ensuring both users and care staff are aware of the circumstances each face, how they impact and what is required to enable sustainable outcomes to support long term health improvement.

Conclusion

To conclude, the Complete Care Community Programme enabled the NHS, working with community teams and other local players to co-design and deliver programmes with users that addressed aspects of the social and economic causes of poor health.

It found that initiatives set up within the Programme were welcomed by service users and suggests that they reached people who had been lost to the healthcare system.

The indicators of successes and challenges from the perspective of its service users are discussed further, and there are considered learning points for recommended improvements to any future programmes.

The highlighted programme has the importance of early engagement and codesign with people from target groups and early and ongoing evaluation to demonstrate how projects can become sustainable.

The results from this second National Evaluation has shown encouraging outcomes Programme suggesting that the achieved the reach and impact that it intended.



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