Complete Care Community

The Complete Care Community Programme:

Emerging Findings – Children & Young People

June 2023

healthworks

Arden&GEM

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Background - Health and inequality challenges

The last century saw dramatic improvements in health and disease prevention with life expectancy rising from 45 years in 1900 to over 80 years by 2010. Whilst preventive health care and clinical services made a significant contribution, improvements to broader living conditions including housing, nutrition, employment, air and water quality, and education had a greater impact.

Now, after more than a century of improvement, increases in life expectancy have stalled. For example, for women in the most deprived communities in England (using the Index of Multiple Deprivation) there has been a decline in life expectancy in the last decade. The gap in life expectancy between the most deprived and the least deprived deciles for women is about 7 years, and for men about 9 years.

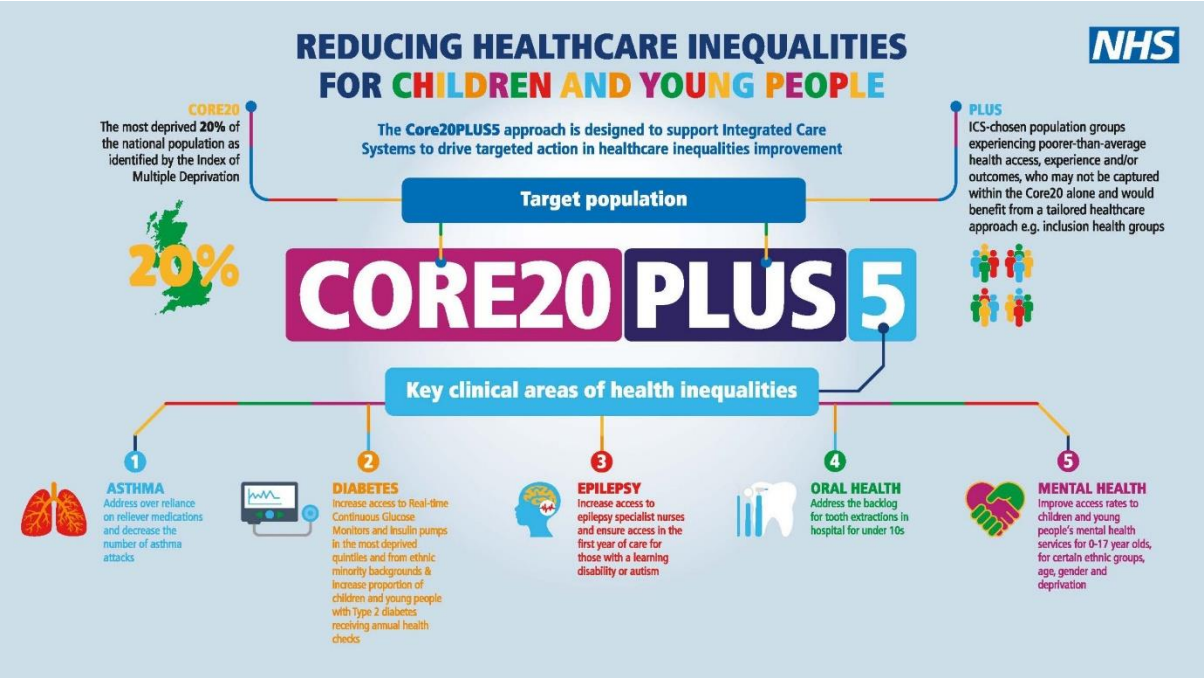
The evidence is clear: the future of effective prevention requires continued development of both preventive clinical services and action to tackle the broader determinants of health.

Current challenges include:

a. Since 2010, the rate of rise in life expectation has slowed, stopped and now reversed.
b. Following the COVID-19 pandemic and now with the cost-of-living crisis, increases in life expectancy are reversing, falling by 1.3 years for males and 1.0 year for females in 2021 with excess mortality attributable to both COVID and non-COVID causes.
c. The benefits of the dramatic improvements in health have not been equally spread across society. Over the last 100 years – apart from war time and the first decade of the 21st Century - inequalities between rich and poor in expectation of life and most other measures of health have widened continuously.
d. Expectation of life has increased faster than expectation of healthy life, so whilst people live longer, more people spend more years of their life in less than full health, typically living with multiple long-term conditions such as depression, diabetes and heart failure.

These challenges are well recognised by the NHS and are reflected in initiatives such as Core20PLUS5 - NHS England's approach to inform action to reduce healthcare inequalities at both national and system level. The approach defines a target population – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement.

The approach, which initially focused on healthcare inequalities experienced by adults, has now been adapted to apply to children and young people.



Local action: The need for the NHS to be a better partner to local agencies and communities

The NHS has previously adopted an approach to health that is heavily focused on the diagnosis and treatment of illness. Its preventive services are largely delivered to one person at a time e.g. vaccination, screening, blood pressure treatment, cholesterol treatment and genetic advice with much of the focus being on secondary prevention activity. Whilst this approach is successful in many ways and makes a contribution to health, there is still the opportunity to impact further on the wider determinants of health, for example through ICPs and partnership working.

The Complete Care Communities Programme

The Complete Care Communities Programme (CCCP) has been designed to explore if, and how, the NHS can also work with local people and local organisations to better address the broader determinants of health, and to generate evidence about how this can be achieved. The programme supports more than 40 primary care networks to tackle aspects of inequality in their local communities by working beyond the traditional 'medical model'. This short paper summarises some of the emerging findings from that work, with particular reference to Children and Young People (CYP). The CCCP complements, reinforces and informs the CORE20PLUS5 approach work on inequalities among CYP.

The CCCP itself, the 46 communities and the inequalities they are tackling, are described in the Complete Care Community Demonstrator Project Prospectus (Appendix 1), July 2022 and first year report. Each site is supported by an experienced mentor provided by Healthworks and the programme management team from NHS Arden & GEM CSU. 16 of the sites set out to tackle an aspect of inequality or disadvantage affecting CYP, with more than half of these targeting as aspect of CYP's mental health, one of the five clinical areas of the Core20PLUS5 for CYP.

Emerging Findings - Method

The actionable emerging findings described in this paper have been distilled from:

- Monthly progress reports from all the sites
- Discussion among mentors sharing their insights from the sites they support
- Sharing and refining the insights at plenary meetings to which all sites were invited
- Focused conversations with a selection of sites supporting CYP.

The emerging findings of the CCCP are not yet definitive and will be explored further as part of a more formal evaluation of the programme.

Emerging Findings

Engagement

- Engagement has the potential to achieve multiple goals. It can:
  - Build trust
  - Set agendas agreed with local communities, prioritising what matters most in people's lives and re-define what success looks like
  - Enable effective co-design and delivery of services that will reach and meet the needs of the target group
- Successful engagement is more likely when:
  - It is undertaken face-to-face
  - The team undertaking engagement includes someone with an obvious link to the community being engaged
  - It is undertaken in settings in which those being engaged are comfortable
  - The agenda and actions of those undertaking the engagement is *genuinely* open to influence
  - The person, and role of whoever initiates the engagement, is trusted

Examples

- A site wanting to work with young single mothers and their children got only one response from attempts at engagement by text and email. By contrast, personal contacts and invitations to events made face to face during other encounters led to well attended meetings and informative 1:1 consultations. Once people had the chance of a face-to-face conversation they were much more likely to respond to written communications (texts more than email, more than letter).
- One of the reasons mothers of young children gave for not responding to written attempts was that the vocabulary can inadvertently be off-putting. For example, in one site which used the word 'social' as in 'social prescriber', this was associated in mothers' minds with 'social services' and the fear that, if they engaged, they would be judged as parents with the underlying threat that if found wanting, their children could be removed.
- Another site working with 11-19 year olds found young people reluctant to engage in events held at GP premises. The reasons given included the belief that the surgery was for 'problems', it was for 'old people', and that they were not confident that anything they said would remain confidential.

- Several sites employed someone who lived in, or was a member of, the community that was being engaged. These sites made more progress more quickly that those whose teams had less first-hand knowledge of the community.
- Building a process of continuing engagement is helpful: e.g. a community panel that meets in person and can be contacted remotely.
- In multiple sites, the system's priorities turned out to be less important among the target population than to system staff chasing targets. Most communities wanted other issues addressing first - for example, in several sites working with CYP, the timing and location of service provision. For example, not for them to be delivered in traditional premises and not in school hours was important to them as they were concerned with educational outcomes, stigma, and service access.
- In several sites, engagement identified problems with existing service provision that had not previously been recognised, e.g. with the quality and relevance of translation services which, even when provided, bilingual community members reported that both the written and verbal translations were not trusted, lacked accuracy and could sometimes even impede and distort communication. This led to re-writing a range of leaflets, testing them with community members, and a review of the in-person translation service. This had not previously been on the agenda of the local NHS.

Actionable insights

- ***Trust cannot be taken for granted. It is worth exploring peoples' fears openly and explicitly so they can be dealt with directly. Vocabulary and tone matter both orally and in writing. Words staff use regularly e.g. 'social' may create suspicion and disengagement. This lack of trust can extend to existing NHS apps and information services.***
- ***It can be helpful to involve multiple agencies in the engagement process from the outset.***
- ***Listening is at least as important as telling.***
- ***The nature and venue of engagement meetings matter. Think carefully about the feelings that different places may engender in different groups.***
- ***Simple things make a difference – e.g. the provision of tea, coffee, fruit and biscuits.***
- ***Create opportunities for face-to-face engagement to complement written approaches.***
- ***It is important to be visibly responsive to the engagement: "you said, we heard, and together we have agreed to do… ", and that when expectations are raised and promises made, those promises should be kept and expectations met.***
- ***Try to involve someone in the engagement team who has first-hand knowledge of the community being engaged.***
- ***Do not use the phrase 'hard to reach'. It's not the population that is hard to reach, it's that the engagement or the services are inappropriately designed for their target population. We suggest 'inaccessible service' instead of 'hard to reach' people.***
- ***One site turned their initial engagement participants into the core of a youth panel that became central to service design and then its continuous improvement.***
- ***Engagement can identify fixable problems in current service provision that were previously unrecognised by the NHS e.g. the quality of translation services.***
- ***One site uses LA youth workers, Children and Young People's Mental Health Services, MIND and primary care staff in an initial engagement about young people's mental health services. One of the unanticipated benefits was that the different services learnt about***

each other's capabilities and improved the trust which had knock on benefits in other services where they are trying to work together.

Co-design

- Where engagement has been successful, built trust and achieved agreement of the goals that the community of interest want to work towards, it leads naturally to meaningful community involvement in co-design.
- An effective process of co-design is likely to lead to a more usable, more reachable and more effective services, that typically are better value for money services that do not get used by their target population.
- Co-design can also be used as part of the process of creating agency in the local community which, as well as improving outcomes, can also support sustainability (see below).

Examples

- Across the country, the pandemic has been associated with a rise in mental distress and mental ill-health among CYP. In several sites Children and Young People's Mental Health Services have not been able to respond swiftly or effectively to the demand.
  In one site, effective multi-agency engagement led to the establishment of a CYP panel that became central to the design of new multi-agency service delivered from novel sites including schools, in novel times i.e. outside school hours, with novel means of access e.g. new apps allowing under 16s to book directly (existing NHS booking services do not allow under 16s to make appointments).
  It also led to the establishment of group sessions at which facilitated conversations about topics such as social anxiety, low mood, bullying and teasing, friendship tensions, young carers, drug and alcohol etc are discussed. Attendance is high and the feedback positive.
- One site found the ARRS CYP practitioner service that was not co-designed was under used, not least as the majority of their employed hours and service provision were during school hours. Value for money for a new co-designed service delivered out of school hours is better.
- A co-designed service to reduce isolation and improve the activity of single mothers has led to the establishment of swimming, buggy walks and other social forms of physical activity. Many of these services are increasingly well attended and being promoted by attendees using their own social media, and many of those attending had been labelled 'hard to reach' as they had previously not been attending traditional services offered by the local NHS.
- Sites reported learning a great deal about partner providers when they worked side by side in co-design with potential service users. One NHS staff member said "I had no idea that the things we were asking of schools were so unreasonable, we've got a much better mutual understanding now and our collective offering is much improved."
- Several sites report asks from the local community for 'one stop shop' type services that would both reduce transport costs and be more convenient and as a means of reducing 'DNAs'. Many sites have had difficulty responding effectively to such requests as the component services are managed independently and were not all involved in the engagement and co-design processes. Where all relevant services are involved in the co-design process, it is more likely that a properly integrated response can be delivered.

Actionable insights

- ***Where there has been good initial engagement, meaningful co-design is a natural next step.***
- ***Co-design can lead to very differently provided services that challenge traditional approaches to provision. For example, co-design is likely to lead to a better reflection of the lives of those the services are intended for example, recognising the importance of education of CYP, requiring (or wanting) non-emergency health services for school age CYP to be provided out of normal school hours in facilities that are accessible for CYP.***
- ***Involving a full range of stakeholders and partners in co-design is likely to result in a better integrated across partners of any new services.***
- ***Where engagement and co-design raise expectations, it is important to meet those expectations.***

Agency and Paternalism

- If people and communities are to make changes that will improve their health, they need the ability and confidence to act, i.e. they need agency. Too often that agency is weak or lacking, resulting in over dependency on services and/or avoidable ill-health.
- A related and sometimes compounding issue is that the NHS often fails to recognise its paternalism – too often thinking it knows best and doing things to people rather than with them or enabling them to take responsibility for themselves. Even our language can be paternalistic; for example, NHS gives 'opinions' and 'prescribes' to its patients. In contrast, lawyers 'take instruction' from even their most vulnerable and disadvantaged clients. There is no everyday language in the NHS for servant leadership, and limited practical processes of accountability to local communities.
- An emerging theme from the CCCP is that successful sites are adopting less paternalistic approaches which allow agendas to be set by citizens, services to be designed with citizens and there is active work to give agency to individuals and communities.

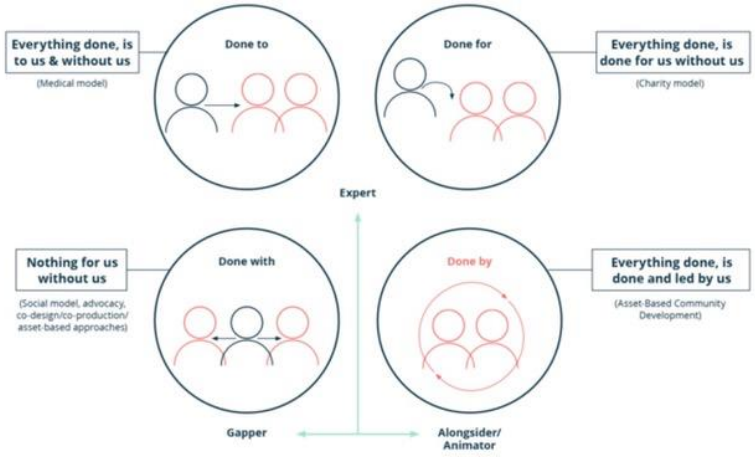
Examples

- Several sites have set up mother and toddler groups to tackle social isolation, create agency and opportunities for multiple agencies top engage with young mothers and their children.
- One site working with young single mothers created opportunities for isolated single mothers to meet each other. The mothers began to support each other e.g. with shared lifts and, with encouragement, many began to engage with activities e.g. swimming, buggy walks, and the gym. One mother who previously said she was 'struggling, depressed, rarely leaving the house' had 'become a different person, losing weight, happier and gone back to gym', and her mother, previously critical, said to her "I'm so proud of what you are doing to improve your life and that of your family."
- Another site with a focus on conduct disorder in CYP has used focus groups with parents, teachers, and children to hold a 'dream event' asking "what is your dream and what would it take to get there?" This is leading to community-led plans to tackle the lack of parenting support, and support in navigating the disparate nature of service provision. As yet, the services have not been able to simplify and better communicate their service offers.

- In one site, a local unemployed resident began helping with the coordination of a focus group used for engagement. This gave her confidence and experience which allowed her to apply for other work. She now has a full-time job with a college on her deprived estate where she is leading work on improving literacy, food banks and physical activity. “I would never have had the confidence or experience without the programme.”

Actionable insights

- ***Many of the benefits of the CCCP are coming from increasing individuals’ and communities’ confidence and ability to make changes that affect their health and well-being i.e. through an increase in agency.***
- ***Creating and increasing agency among is becoming an explicit goal and a priority in many sites. Increasingly it is being seen as fundamental to local work aimed at addressing and ameliorating tackling inequalities and at least of equal importance to the delivery of services to people, it is also particularly important for achieving a sustainable impact (see below) as agency lasts when service funding runs out. It is consistent with the principles underpinning Asset Based Community Development involving moving from a traditional ‘done to’ to a ‘done by’ approach (see diagram). This has implications for the skills, attitudes and training required of project teams and the NHS more generally.***



Source: Russell C. Nurture Development

Sustainability

- Many sites have worried about the sustainability of the impact of their projects, very much aware that many NHS projects stop when either the short-term funding runs out or when the enthusiast driving the project moves on, or gets interested in something else.

Examples

- In one site where Children and Young People's Mental Health Services waiting times had extended to months and years, and many referrals from primary care were being triaged and returned, it meant that many CYP with mental health problems were not receiving any

support. Engagement with young people and schools led to the creation of groups for young people were topics such as school anxiety, friendships, low mood, eating were able to be discussed. Participants included those referred to but not seen by Children and Young People's Mental Health Services who reported being helped by the conversations. The site is confident that these groups will continue beyond the formal project. The case study example demonstrates progress against the Core20PLUS5 for CYP and provides learning for other systems and PCNs looking to develop a similar approach through engagement and codesign.

Actionable insights

- ***Several sites have concluded that a key method of making a lasting impact is to prioritise increasing agency among patients / citizens and their communities rather than creating a short-term new service that can't be funded sustainably. Also, once individuals and communities can support themselves and each other, there is less need for professionally provided support.***
- ***Projects in several sites stopped or stalled when the key person moved on or was unable to continue in their project role. Those projects that ensured that there was a team driving the programme rather than and individual, and paid attention to succession planning have proved more resilient.***
- ***Several sites commented that the pleasure and pride staff got from building relationships with local people and demonstrably helping them address issues that matter for them helped remind them of why they wanted to work for the NHS. This was particularly valuable as across the NHS people are struggling to find joy at work and staff morale retention has become a significant risk to the quality of care.***

Evaluation

- Almost all sites have recognised that traditional evaluation methods in which outcomes and methods are specified in advance do not work well in this sort of work because intended outcomes are identified ***after*** engagement and the interventions are defined as part of the process of project delivery through a process of co-design rather than as a something pre-specified before the project starts.
- Increasingly, sites are coming to understand that they are working in complex adaptive systems in which:
  - most outcomes are influenced by multiple inputs
  - most inputs have multiple outcomes
  - the detail of interventions (e.g. the how engagement is undertaken) matters and,
  - the impact of interventions vary with the state of the system (i.e. the same intervention can have different impacts in different places and at different times).

Actionable insights

- ***The insight is that mixed method study designs are required to evaluate the sort of work being addressed by the CCCP. They need to:***
  - ***include qualitative as well as quantitative elements.***

- ***address the nature of the intervention in granular detail (e.g. what was the detail of the engagement process rather than just recording that engagement took place), and,***
- ***describe the context in detail, as in complex adaptive systems (of which these sites are examples), the impact of interventions vary with the nature and state of the system and interactions are very important.***

- ***Importantly, the detail of the evaluation process is likely to need to adapt as the projects evolve.***

Capability, capacity and training

- Several sites have recognised that the CCCP has led to the identification of gaps in:
  - services that can be addressed in novel ways
  - capability and training, particularly in the methods of community development, engagement and co-design
  - understanding about the capabilities and processes of partner agencies
  - the ability of the different parts of the NHS that comprise the ICS to respond to communities asks e.g. the ability to arrange local 'one-stop' services requiring input from teams managed by different NHS entities
  - understanding about the intervening and evaluating complex adaptive system

Actionable insights

- ***As yet, few ICSs have yet been able to respond effectively to these and similar issues. There is a real opportunity for ICSs to develop novel cultures, ways of working that give greater priority that will increase the NHS's responsiveness and accountability to their local communities. Success is likely to require active input from ICS leadership and training bodies.***

Conclusions

The key finding emerging from the CCCP is that adding skills and augmenting capability and capacity within primary care teams as a part of community development increases their ability to work constructively with local government, voluntary organisations and communities. It increases individuals' and communities' agency to tackle issues such as social isolation and loneliness, unemployment, anxiety, and lack of physical activity. We have begun to see examples of improvements in people's physical and mental health, less dependency on health services and pride in staff and volunteers involved in seeing the transformation in people's lives that they are contributing to.

Early results from the CCCP confirm the findings of the Fuller Review that primary care is well placed to contribute to, and be a catalyst for community development alongside its traditional role. It has a permanent local presence, is largely non-stigmatising, and commands high levels of trust with most local people - successful engagement with communities can result in services being provided in a way that reduces barriers to those whom services are failing to reach. Primary care is also central to delivery of the Core20PLUS5 approach for both adults and children and young people.

Locally, as well as nationally, there is considerable opportunity to better coordinate multisectoral decision making with a view to improving the health generating and disease preventing conditions in which people lead their lives – including education, employment, transport, air quality and more.

Done well, the evidence demonstrates that this makes a big difference.

If these findings are to be applied at scale, the NHS will need to develop news skills, capacity and capabilities to support community development alongside its traditional medical services.

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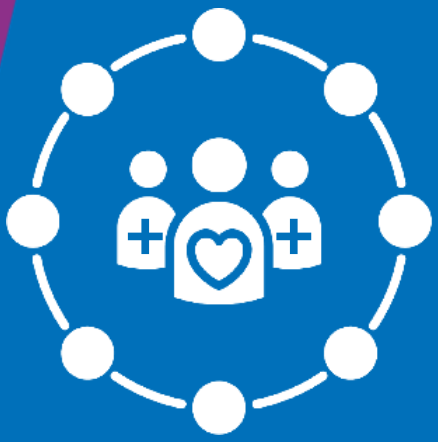
Appendix 1:

The Complete Care Communities programme prospectus of sites and respective projects.

https://www.ardengemcsu.nhs.uk/media/2887/ccc-demonstrator-sites-project-prospectus-final-10-08-2022-1.pdf



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https://www.ardengemcsu.nhs.uk/complete-care-community/