



Care and support
through terminal illness



When time really matters:

Fast Track care at the end of life

Executive summary

- Fast Track Continuing Healthcare (CHC) provides the packages of care and support that people with a diagnosed terminal illness, or who are rapidly deteriorating, need to be cared for outside of hospital (if their illness and symptoms can be managed outside of hospital). Department of Health and Social Care guidance in England recommends that Fast Track care packages be delivered within two days of an application being made by a clinician on behalf of a patient. The obvious aim is to ensure that people do not spend any more of their final days or weeks in hospital than is absolutely necessary.
- Despite the clear guidance, we have found that the majority of Clinical Commissioning Groups (CCGs) in England are not delivering packages of care within the guidance timeframes. Only 22% of the CCGs who responded to our Freedom of Information (Fol) requests (and who were able to provide data) were meeting the two-day timescales set out in the guidance. Average delays stretched beyond a fortnight in some areas.
- We found that, in some CCGs, a large number of Fast Track applications are not delivered at all. One CCG reported that over half of the applications it received did not result in a care package being delivered.
- There is a clear correlation between delays in implementing packages of care and the proportion of packages not delivered. Given the criteria for making a Fast Track application, the patients involved are seriously ill and it can be assumed then that they are either deteriorating to the point that they can no longer leave hospital or are dying before the care they need can be put in place. In other words, it is unlikely that people whose care package is delayed are recovering to the extent that they no longer need it to enable them to leave hospital.
- Comparing data from two rounds of Fol requests, submitted one year apart, suggests that CCG performance in delivering Fast Track CHC has not improved during that time. Indeed, it appears to have deteriorated, with fewer CCGs meeting the two-day guidance and substantially more falling into the 2–7 days bracket. Among the poorest performing CCGs, there are a number who are only delivering half, or even less, of the Fast Track CHC applications they receive.

Contents

Context	5
What is Continuing Healthcare?	6
The Continuing Healthcare assessment process	7
Fast Track Continuing Healthcare	8
Why Fast Track matters	9
Methodology	9
Data shortages in Fast Track Continuing Healthcare	10
Widespread delays	12
Disparities in Fast Track delivery rates	15
Understanding the relationship between delays and non-delivery	17
Why is this happening?	19
Conclusion	21
Recommendations	21

Context

In October 2017, we at Marie Curie published *Making every moment count: The state of Fast Track Continuing Healthcare*. This report examined the performance of Fast Track CHC across England. We found that many CCGs were not meeting the timescales for Fast Track care packages set out in Department of Health and Social Care guidance and many were not gathering the information they needed to make meaningful assessments of how well they were performing against the guidance.

NHS England has been given a significant injection of funding to meet the challenges it faces over the coming years and the recently published long-term plan sets out how this money will be used. There has, however, been little progress on social care reform, which is an essential element in packages of care that enable people to leave hospital. Against this background, NHS England is still aiming to achieve £855 million of accumulated savings in the cost of CHC by 2020/21. The Public Accounts Committee has scrutinised NHS England's plans to achieve these savings and expressed concern about how they will be achieved, given that the administrative spend on CHC is only £149 million per year.¹

There have also been positive developments. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care has been updated, providing welcome clarification in some areas that will improve people's experience. For example, the updated Framework makes clear that re-assessments should focus on whether a person's care package is still meeting their needs, rather than on the individual's eligibility. In addition, from April 2017, NHS England requires CCGs to gather more Fast Track CHC data. Although, as this report shows, significant gaps remain that need to be addressed urgently.

We followed up our initial Fol requests a year later with a second round of similar questions aimed at establishing what changes there had been since the first round. In this second round of Fols we expanded the scope of our questions to attempt to establish the proportion of Fast Track applications that result in a package of care being delivered.

1. House of Commons Committee of Public Accounts. NHS continuing healthcare funding. Thirteenth Report of Session 2017-19. 2018. Available at www.publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/455/455.pdf (accessed February 2019).

What is Continuing Healthcare?

It is important to understand exactly what CHC is and how it functions. NHS CHC is a free care package for patients to enable them to be cared for outside of hospital. It is funded and arranged by the NHS. It is not means-tested. It is aimed at patients with health, not social, care needs that do not require in-patient care. A patient's local authority would fund the cost of care and support if someone's needs were primarily for social care (although this is a means tested provision). CHC shifts the funding responsibility to the NHS for patients with a primary health need. This is described by the National Framework as:

“...an individual has a primary health need if, having taken account of all their needs... it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality.”

Assessment of primary health needs takes account of the nature, intensity, complexity and unpredictability of the patient's health and care requirements. Once a CHC application is approved, there are no limits on the setting in which a care package can be delivered – for example, a patient's home or care home – or on the type of service it can offer.

CHC costs around £3 billion per year in England, at an average cost of £19,190 per patient. CHC costs are expected to rise to £5.2 billion by 2020/21 as a result of population growth and increasing demand. NHS England's efficiency plan requires CCGs to achieve savings in CHC of £855 million over the same period. This is, and will continue to be, a tough ask given the limited scope for these savings to be made out of administrative spend on CHC (which stands at just £149 million).²

2. National Audit Office. Investigation into NHS continuing healthcare funding. 2017. Available at www.nao.org.uk/report/nhs-continuing-healthcare-investigation (accessed February 2019).

NHS England has provided a breakdown of how it expects these saving to be achieved:

- Working with the Department to provide clarity around the National Framework and improving the way CCGs deliver the National Framework. This includes interventions such as improved data and benchmarking information and reducing the number of CHC assessments in an acute hospital setting – circa £361 million
- Improving the commissioning of care packages – circa £122 million
- Improving CHC processes including the supporting of staff with Training and Development – circa £79 million
- CCGs locally delivered improvement initiatives – circa £293 million.³

While this breakdown provides clarity on how NHS England expects the savings to be achieved, it also raises some important questions. For example, what exactly are the ‘improvement initiatives’ expected to save £293 million and how will they be achieved against a background of growing demand and complexity of need?

The Continuing Healthcare assessment process

The process for putting a CHC package in place consists of several stages. First, a patient or their carer must apply for CHC funding, at which point a social or health worker will assess them using a checklist tool. If the patient is deemed to have a primary health need, they then go through a more in-depth assessment process known as the Decision Support Tool (DST). The DST is conducted by social workers, carers and health workers and is a more detailed examination of the patient’s needs. DST assessments are then sent to the local CCG, which makes the decision on whether to approve funding. Once approved, a care package that reflects the individual needs of the patient is put in place within 28 days. Individuals receiving CHC support are re-assessed after three months and then annually to establish whether they still require support.

3. HM Treasury. Government response to the Committee of Public Accounts on the Twelfth to the Nineteenth reports from Session 2017-19. March 2018. Available at www.parliament.uk/documents/commons-committees/public-accounts/Cm-9596-Treasury-Minutes-march-2018.pdf#page=18 (accessed February 2019).

Fast Track Continuing Healthcare

If a patient's condition is deteriorating rapidly or they have entered a terminal phase, the Fast Track Pathway can be followed. Fast Track CHC allows a clinician with appropriate knowledge of the patient to apply for CHC support on behalf of the patient without the need for the lengthy checklist and DST assessment process. Fast Track applications can also be made by clinicians from voluntary or independent bodies that specialise in end of life care (for example, Marie Curie or independent hospices). The Fast Track Pathway Tool is a far simpler process and can be completed quickly by a single clinician.

Between the third quarter of 2017 and the second quarter of 2018, 96,000 people started the Fast Track CHC process – representing 56% of the total number of people applying for CHC. The data we received from CCGs suggest that the actual proportion of Fast Track packages (those CHC applicants deemed to be eligible) is, in reality, over 60%⁴

Once a clinician submits a Fast Track application, the local CCG is required to immediately approve a package of care and have it in place as soon as possible. The National Framework recommends this is done within 48 hours.⁵ This timeframe reflects the importance of appropriate care for patients near the end of their life and the reality that, for them, every moment counts when it comes to having the right care in place.

How CHC works



4. NHS England. NHS Continuing Healthcare and NHS-funded Nursing Care. 2018. Available at www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc (accessed December 2018).

5. Department of Health and Social Care. National framework for NHS continuing healthcare and NHS-funded nursing care. 2019. Available at www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care (accessed February 2019).

Why Fast Track matters

Fast Track CHC is crucial to ensuring seriously ill and dying people are not denied speedy access to the specialist support that they and their families need to get them through an extremely traumatic time. It is essential to enable someone to die in the place of their choice. Delays to this process can ultimately mean that people die in hospital before a package of care can be put in place. This can cause significant distress for both patients and their families and there is no second chance to get it right. Delays that mean patients are waiting beyond 48 hours for their CHC packages of care are unacceptable, yet it is something that is happening on a regular basis in England.

Methodology

We at Marie Curie submitted FoI requests to every CCG in England asking them about the average time taken to deliver a Fast Track CHC package from the point at which the application is received and from the point that an application is approved. These FoI requests also asked for data on the number of Fast Track applications received and the number of packages that were actually delivered. Figure 1 shows a full transcript of the FoI requests.

Fig 1: Freedom of information request to CCGs made by Marie Curie in August 2018

Question 1: What was the average time period in your CCG in days/hours from the point at which a Fast Track CHC application is made to the care package being provided for the financial year 2017/18?

Question 2: What was the average time period in days/hours from the point at which a Fast Track CHC application is approved to the care package being provided for the financial year 2017/18?

Question 3: During the financial year 2017/2018, how many applications for Fast Track CHC did the CCG receive?

Question 4: During the financial year 2017/2018, how many applications for Fast Track CHC were funded?

Our aim was to secure a clearer picture of how Fast Track CHC is being delivered. Understanding the extent to which packages are being delayed and, crucially, the frequency with which applications are not resulting in delivered packages of care enables us to identify the scale of the challenge in ensuring seriously ill and dying people get the care they need to leave hospital quickly.

Data shortages in Fast Track Continuing Healthcare

Our last report on Fast Track CHC identified widespread gaps in the data that CCGs were able to provide. A similar situation has been found in response to our second round of Fols. Only half (51%) of the CCGs that responded to our Fol requests were able to provide data for all the questions asked. More than a third (35%) were unable to provide any of the requested data (Figure 2).

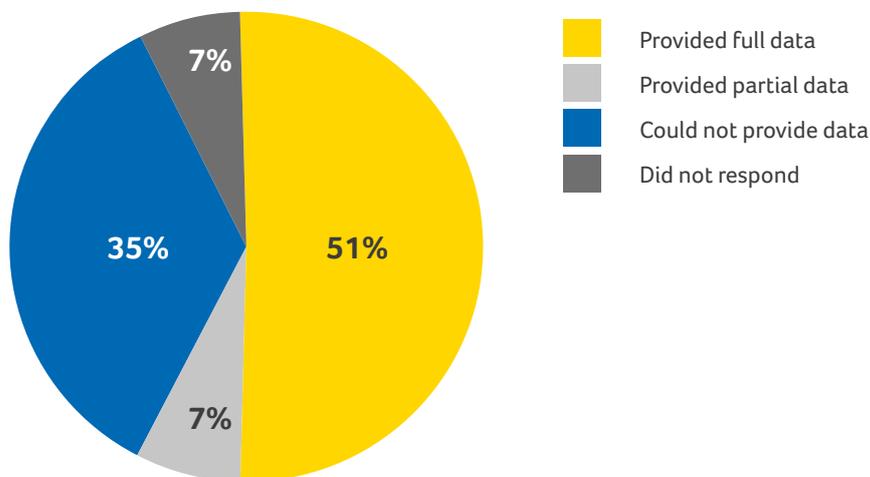


Fig 2: CCG responses to Fast Track CHC delivery time enquiry (n=197)

There are a number of reasons given for why CCGs were not able to provide data, the most common being that data were not recorded or recorded in such a way that makes it prohibitively expensive to gather. For example, a CCG may hold data in individual patient records but not transfer that information to a central database. This means that to secure the data we requested the CCG would have to undertake a retrospective trawl through hundreds or even thousands of patient records, resulting in the CCG refusing to provide the data on the basis of cost – there is a cost limit of £450 for public bodies other than central Government, for which the limit is £600.

Our data requests were not complicated; how many applications for Fast Track CCGs were received, how many packages of care were put in place and what was the average time taken to deliver Fast Track care packages?

The Department of Health and Social Care guidance makes clear the importance of swift implementation for Fast Track packages of care, stating:⁶

“Action should be taken urgently to agree and commission the care package. CCGs should have processes in place to enable such care packages to be commissioned quickly. Given the nature of the needs, this time period should not usually exceed 48 hours from receipt of the completed Fast Track Pathway Tool. CCGs should ensure that they have commissioned sufficient capacity in the care system to ensure that delays in the delivery of care packages are minimal. It is not appropriate for individuals to experience delay in the delivery of their care package while concerns over the use of the Fast Track Pathway Tool are resolved.”

6. Department of Health and Social Care. National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. October 2018. Available at www.events.england.nhs.uk/upload/entity/30215/national-framework-for-chc-and-fnc-october-2018-revised.pdf (accessed February 2019).

It is essential that CCGs are able to judge their performance against the National Framework on the number of packages being delivered and, crucially, the amount of time it takes to implement those packages. The fact that so many CCGs did not have this information to hand is a significant cause for concern. Without these crucial data being available to CCGs, issues in the service will be harder to identify and prevent, with service improvement becoming much more challenging to accomplish as a result.

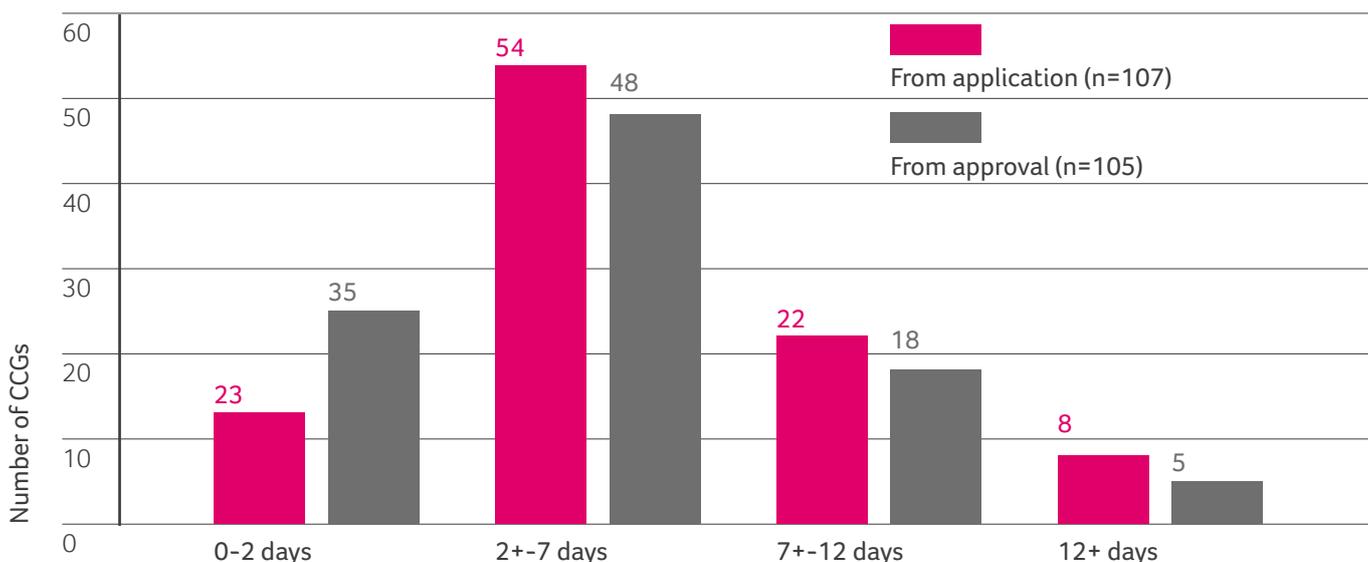
Widespread delays

Among the CCGs who were able to provide data we found that the majority are missing the two-day implementation period for Fast Track CHC, as recommended in the National Framework. Only 23 CCGs (22%) reported implementing packages of care within an average of 48 hours of an application being made.

Figure 3 shows the distribution of CCGs in terms of time taken to put Fast Track packages in place from application and approval. 'Application' means from when the CCG receives an application for Fast Track CHC from a health professional on behalf of an individual deemed to be in need of a package of care. 'Approval' is the point at which the CCG approves the application and should be working to put a package of care in place.

According to the National Framework, a CCG is required to approve all Fast Track applications without delay provided that the required information is included on the application form. Consequently, there should be little difference between the time taken to implement a Fast Track package from application or from approval, but this is not always the case. In some CCGs we see the approval stage taking a day or more, significantly slowing the process down. This is shown clearly in Figure 3, where the number of CCGs meeting the two-day guidance jumps from 23 from application to 35 from approval.

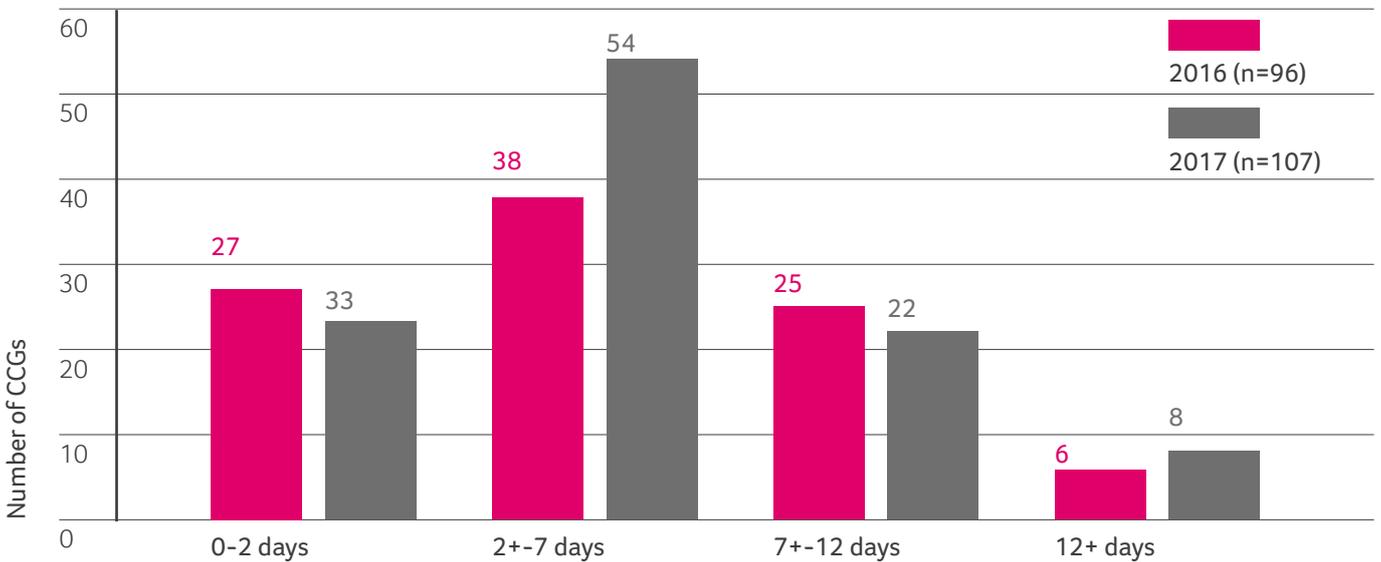
Fig 3: Average time taken to implement Fast Track CHC packages



Almost four in five (78%) CCGs are not meeting the two-day guidance for implementing Fast Track packages; this is not acceptable. Most CCGs (51% of those who could provide data) fall within the 2–7 days range, but it is particularly troubling that 30 CCGs (28%; or almost a third of those who provided data) reported average delays of more than a week, of which eight CCGs had delays of more than 12 days. Such a significant number of CCGs reporting such long delays strongly suggests that there are systemic problems that warrant focused attention.

Comparing these data to the responses that we received a year ago suggests that there could be a trend of increasingly long delays (Figure 4). We will be repeating our FoI requests annually to establish whether such a trend exists.

Fig 4: Average time taken to implement Fast Track CHC packages from application



When comparing 2016 and 2017 data it is important to note that the number of responses we received was not the same each year; in 2017 we received responses from 11 more CCGs than we did in 2016.

Notwithstanding this, our latest data show that fewer CCGs are meeting the two-day guidance and substantially more are falling into the 2–7 days bracket. The results suggest that CCG performance in delivering Fast Track CHC has not improved in the year between the two rounds of FoI requests. Indeed, it appears to have deteriorated. If this is a trend then the implications for the care people receive at the end of their lives is concerning.

Disparities in Fast Track delivery rates

The data also address the frequency with which applications for Fast Track CHC are delivered. CCGs have a responsibility to immediately action any Fast Track application that they receive, provided the Fast Track Pathway Tool is completed correctly. As a result, the number of packages delivered should be close to 100% of the applications received.

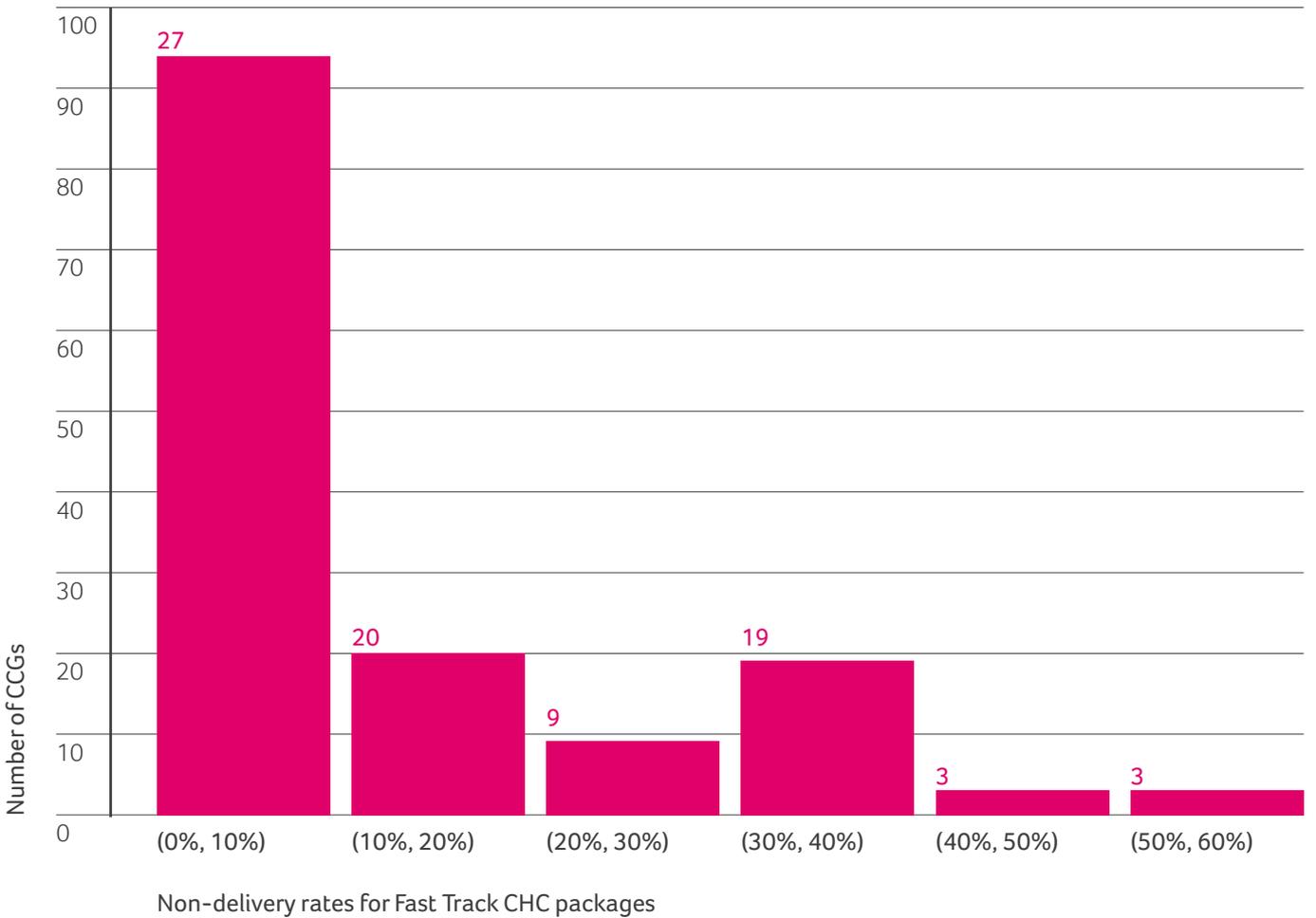
There are a number of reasons why an application for Fast Track CHC may not result in a package of care being delivered. They are:

- The application form was filled in incorrectly or the application was incorrectly made for an ineligible person
- The individual's condition deteriorated to the point that discharge from hospital was no longer possible and a package of care was no longer required
- The individual died while waiting for their package of care

In the first scenario the issue is one of clinicians not completing the Fast Track forms correctly or misunderstanding the purpose of Fast Track CHC; either of these suggests a lack of training and support. In the latter two scenarios the question must be whether faster delivery of a package of care would have resulted in a different outcome. There will, of course, be some people whose condition deteriorates so rapidly after their application is made that it simply will not be possible to put a package of care in place quickly enough to meet their needs.

We received data on application and package delivery rates throughout 2017/18 from 149 CCGs. The average proportion of applications not being delivered upon was 10%, with almost two-thirds of CCGs reporting non-delivery rates of 10% or below. Figure 5 shows the distribution of CCGs in their non-delivery rates.

Fig 5: Distribution of CCGs in non-delivery rate for fast track CHC (n=148)



The high proportion of CCGs in the lowest non-delivery range is positive, but it is important to recognise that a third of CCGs have non-delivery rates of more than 10%. Among the poorest performing CCGs, there are a handful of CCGs that are only delivering packages for half, or even less than half, of the applications they receive. In total, 17% of the CCGs we heard from had non-delivery rates exceeding 30% of all the applications they received.

Understanding the relationship between delays and non-delivery

Comparing delivery rates with data on average Fast Track CHC delays provides a picture of the relationship between delays and non-delivery of CHC packages; there is a clear correlation between the two. Figure 6 plots these two performance indicators against each other for CCGs that provided us with both of these data sets.

“All legitimate fast track referrals are approved for funding. However, some patients may pass away prior to the commencement of the package hence why funding may not be put in place.”

CCG in the Midlands

The correlation between the two indicators demonstrates that there is a link between long delays and high non-delivery rates. This, intuitively, is what would be expected; the longer a person who needs Fast Track CHC waits to receive their package of care, the more likely that their condition will deteriorate to the point that they cannot leave hospital or that, sadly, they die.

Fig 6: Fast Track delivery times against application non-delivery rate

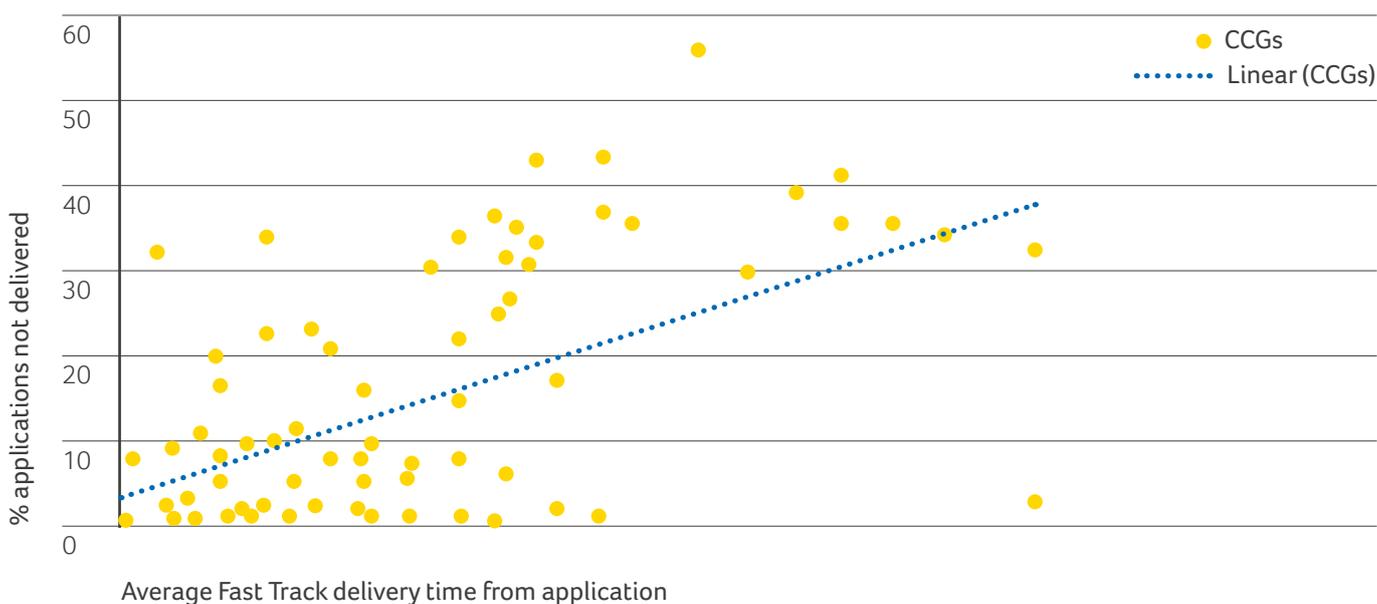


Figure 6 also demonstrates the variation in the length of wait for a package of care that people living in different parts of England have. Some CCGs do meet the guidance delivery timescale, which suggests that it is not an impossible target. Yet, in some parts of the country, people can experience average waits of as much as 19 days for this crucial and urgent care. Furthermore, there are some areas of England where more than half of the applications being made for Fast Track CHC are not resulting in delivered packages of care. It is not acceptable that where someone lives should have such a substantial impact on their experience, particularly at a time when every moment of their life counts for so much.

Why is this happening?

We have identified some key reasons for why the issues revealed in the data are occurring. In the context of the time taken to approve packages of care these are:

- Errors in CHC applications meaning that clarification has to be sought from the applying clinician before approval can be given
- A lack of suitable beds in care homes to discharge people into
- CHC approval services only functioning Monday to Friday and/or in office hours
- Patient deterioration preventing discharge from hospital
- Family members not being able to view care homes quickly enough to make their choice of preferred place of care
- A lack of market capacity and other local provider issues.

“Please take into account that this figure is high due to individual cases of where patients may not be medically fit for discharge, no bed availability or family members are unable to view nursing homes in a timely manner.”

CCG in the South of England

Some of these issues could be resolved relatively easily. For example, where the issue is one of forms being filled out incorrectly the simple remedy is training (or better training) and support for clinicians. Similarly, where the issue is a result of the operating hours of the Fast Track CHC teams the easy solution is ensuring that people are available for more hours and days of the week to approve and arrange packages of care. Indeed, if staff are only available to process applications in office hours this will almost inevitably lead to missing the two-day guidance timescale.

The lack of capacity in community care provision will lead to delays in sourcing packages of care for people approaching the end of their lives. Simply put, without investment in community services there will not be the expertise or capacity available outside of hospital to ensure that people can be properly cared for. Community-based health and care services are a vital component of Fast Track CHC and without them the service will not be able to meet the timescales laid out in the National Framework. We must remember that this is much more than just missing a timescale, it could mean that someone needlessly dies in hospital, rather than their preferred place of death.

Conclusion

In this report we have examined Fast Track CHC in three key areas: data collation and access, time taken to source and deliver packages of care and the proportion of applications for Fast Track CHC that progress into delivered packages of care. The picture that emerges is one of a service varying significantly throughout England.

Inconsistencies between CCGs have a real impact on the quality of care that people receive at the end of their lives. Delays in Fast Track CHC leave people stuck in hospital at an already difficult time. While hospitals offer some of the best care available they are often not the best place for someone to be cared for at the end of their lives, particularly when the care that is needed could be given appropriately outside of hospital.

We know that many people would prefer to die in the community, either at home or in a care home, rather than in hospital. The delays we highlight in this report deny people the opportunity to see those wishes fulfilled. Ultimately, the result is that people are dying in hospital when, with the right care available in the community, they would not have to.

These findings paint a bleak picture of Fast Track CHC in some parts of England. However, it is important to highlight that they also show that there are clear routes to improvement. There are practical measures that could be taken by CCGs and central Government to improve Fast Track CHC performance, but it will require focus and investment, both in effort and resources, to achieve this.

Recommendations

A robust approach to holding CCGs accountable for meeting the guidance set out in the National Framework for CHC

The need for CCGs to be held to the guidance laid out in the National Framework for Fast Track packages remains the most pressing issue identified by our analysis of the data we received. This is not an impossible ambition – we know that some CCGs are able to meet the guidance – but the fact that 80% are not meeting the timeframes is a cause for concern. Until CCGs are made fully accountable for meeting the guidance set out in the National Framework we will continue to see unacceptable variations between different areas of England.

Improving data collection on Fast Track CHC

The decision by NHS England to require CCGs to gather more detailed information on Fast Track CHC was a positive step but it should go further if CCGs are to gain a meaningful understanding of how their Fast track CHC processes are working. Some 77 of the CCGs we contacted (39%) told us that they were unable to provide basic information on how long it takes them to implement Fast Track packages, a fundamental tool for understanding how effectively the service is working. This is a significant impediment to CCGs developing a proper understanding of the service and how to improve it. Until NHS England is willing to place a requirement on CCGs to gather these data, this situation will likely continue.

Ensure that clinicians are given adequate training and support in using the Fast Track Pathway Tool

One of the key issues causing delays in Fast Track CHC is the frequency with which CCGs receive Fast Track applications that do not provide enough information or give inaccurate information, slowing the process while the CCGs seek clarification. In other cases, applications are made in inappropriate circumstances that create an administrative burden with little purpose. Ensuring that CCGs are giving clinicians training in what Fast Track CHC is, what it is for and, crucially, how to complete the Pathway Tool would help to address this. Some simple actions could significantly increase the efficiency of Fast Track processes and help people to get the care they need as quickly as possible.

Ensure community services are adequately resourced to meet demand

Ultimately, delays in Fast Track CHC are going to be an unfortunate reality until services and capacity are adequately resourced. The availability of high-quality care outside of hospital is integral to the ability of CCGs to source and implement packages of care quickly; Fast Track CHC depends on this to help people to leave hospital. If community care cannot cope with demand, delays are inevitable. Ensuring that community services are properly resourced in all CCGs is a huge undertaking, but one which is an absolute necessity if Fast Track CHC is to meet the timescales set out in the National Framework for everyone who needs it.

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