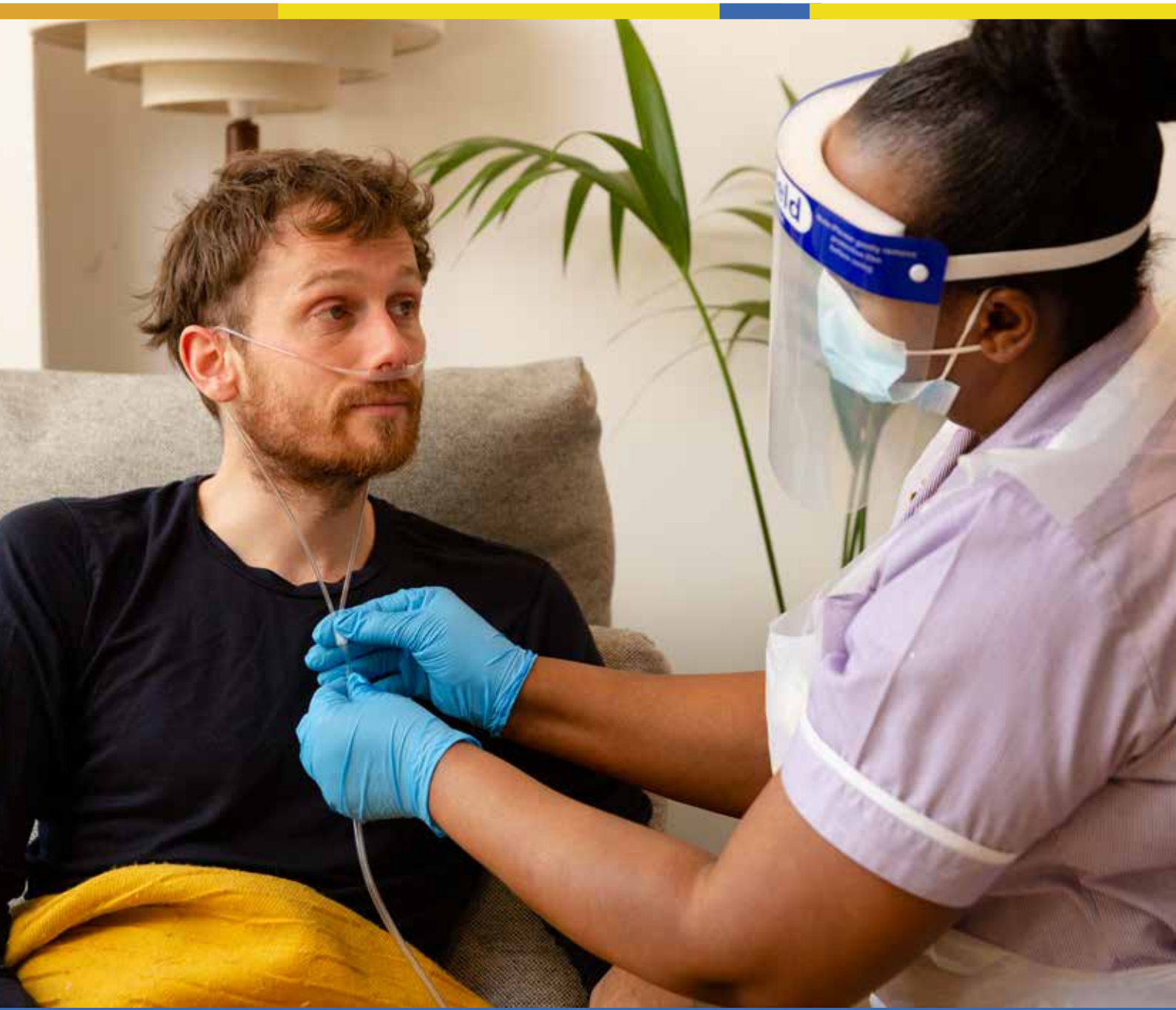
Marie Curie

Care and support
through terminal illness

No time to wait

The state of Fast Track Continuing Healthcare in England



Executive summary

Fast Track Continuing Healthcare (CHC) funding enables people to be cared for outside of hospital at the end of their lives if their condition is deteriorating rapidly and may have entered a terminal phase. Guidance for English Clinical Commissioning Groups (CCGs) recommends that Fast Track CHC packages be commissioned within 48 hours of an application being made – this supports patients to be cared for at home or in the community and spend no more time in hospital at the end of life than they need to.

Fast Track CHC is crucial to ensuring seriously ill and dying people receive the appropriate support they need to enable them to leave, or prevent admission to, hospital. This is often the key factor that allows people to die in the place they choose. Delays to this process ultimately can mean people dying in hospital before a package of care is put in place, causing significant distress for those at the end of their lives and their loved ones.

Building on three previous reports published between 2017 and 2020, this report analyses data from 182 CCGs in England that responded to Freedom of Information requests from Marie Curie based on their performance at delivering Fast Track CHC in 2019/20.

For the fourth consecutive year, we have found that the majority of CCGs in England are not meeting the 48-hour standard set out in the National Framework. Despite some improvement in 2019/20, only 46% of CCGs are, on average, delivering Fast Track CHC packages within 48 hours from the point of application. In the worst-performing areas, delays are lasting for significantly more than a week.

In 2019/20, two in five CCGs failed to deliver a package of care in at least 10% of Fast Track CHC applications, with a small number failing to deliver half or fewer than half of the packages applied for. This underlines the clear relationship between significant delays and a large proportion of packages not being delivered at all. This is unsurprising given the profile of Fast Track CHC patients – long delays are likely to see them become too ill to leave hospital or, in some cases, die before a package of care is arranged.

More than half of CCGs are not meeting the 48-hour standard in the National Framework

More than half of CCGs continue not to meet the 48-hour standard on average, despite evidence of year-on-year improvement and significant delays of more than a week becoming rarer across most of the country. Despite overall improvement, this gives us little confidence that the worst-performing CCGs are adequately addressing these issues.

For the first time, we have been able to identify individual CCGs demonstrating the poorest performance in delivering Fast Track CHC, indicative of a postcode lottery for patients in Fast Track care. Patients in some areas can expect to wait far longer than those in others before they can leave hospital. In many cases, they will be waiting far longer than patients in neighbouring CCG areas, although there are also some geographical 'clusters' of poor performance covering multiple neighbouring CCGs.

The data in this report concludes at the onset of the Covid-19 pandemic. During the first six months of the pandemic, significant changes were introduced to Continuing Healthcare to support the discharge of patients who did not need to be cared for in hospitals and those already in the community. The NHS fully funded all new CHC packages between 19 March and September 2020, as well as delaying CHC assessments for this period.

This greatly reduced the time it took to put CHC packages in place and discharge

patients from hospital. In many cases during this period, people were able to leave hospital within hours and be cared for at home or in another community setting. Beginning in September however, CHC assessments were reintroduced and backdated, requiring CCGs to assess everybody who began receiving CHC without an assessment since March. Marie Curie is concerned that this is creating an unmanageable backlog for CCGs and further delays, and we will be exploring this when data for 2020/2021 becomes available.

This report highlights the unacceptable variations in Fast Track CHC performance in place on the eve of the pandemic. It underlines the need to ensure we learn the lessons of these emergency measures – that significant improvements in Fast Track CHC performance are achievable with sufficient attention and resources – to drive long-term improvements in future performance.

Marie Curie welcomes proposals in the recent NHS White Paper to allow CHC assessments to take place after patients have been discharged; this will improve the speed at which patients can leave hospital and be cared for in the community. We also welcome the proposal to give NHS Digital a new duty to have regard to the benefit of sharing data that it holds. If CCGs are required to report shareable information on their Fast Track CHC performance as part of this new duty, CCGs can be held accountable for poor performance against the National Framework.

In addition to these proposals, Marie Curie recommends:

- Improving training and support for staff working on Fast Track CHC
- Adequately resourcing community care services to support discharge into the community
- Sharing best practice from CCGs who are meeting the required standards with those who are failing to do so.

Just 7% of us say we would wish to die in hospital and more than two thirds would prefer to die at home. Fixing the problems in Fast Track CHC is a vital step towards ensuring everyone is able to die in the place of their choosing in future.

Ben Goldn/Marie Curie

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Background and context

Marie Curie published its first report on the performance of Fast Track Continuing Healthcare (CHC) in England in 2017. We found significant variations between English CCGs in how quickly people were getting the packages of care they need through Fast Track CHC. Many CCGs were failing to meet the timescales for Fast Track CHC set out in guidelines from the Department for Health & Social Care (DHSC). Not only this, but many CCGs were not gathering the information needed to make a meaningful assessment of how well they were performing against these guidelines.

This report was followed by a second report on the state of Fast Track CHC in 2019. Due to the Covid-19 pandemic, Marie Curie published a shorter data briefing in 2020 on Fast Track CHC performance. These reports continued to find significant inconsistencies in the delivery of Fast Track CHC throughout England. They found that many CCGs were still failing to meet the DHSC's guidance that a Fast Track CHC package should be commissioned for a patient within 48 hours of an application being made. There was also significant correlation between CCGs failing to meet the 48-hour timescale and non-delivery of Fast Track CHC packages.

Marie Curie submitted new Freedom of Information requests to CCGs in July 2020 to establish the current state of Fast Track CHC performance and how this has changed over the past year. As we now have four years' worth of data, this report shows year-on-year trends in the performance of CCGs in delivering Fast Track CHC.

The data in this report covers the financial year 2019/20 and therefore is unable to explore the performance of Fast Track CHC during the Covid-19 pandemic. Emergency measures introduced in the initial stages of the pandemic greatly improved the speed at which CCGs were able to put CHC packages in place for patients.

We welcome proposals in the NHS White Paper to allow CCGs to conduct CHC assessments after patients have been discharged from hospital. This should enable patients to leave hospital much more quickly and prevent a return to the situation highlighted in this data, with unacceptably high variations in Fast Track CHC performance across England and a postcode lottery for patients. Too many people faced significant delays before they could leave hospital at the end of their lives, with many ultimately unable to leave at all.

With 6 million people expected to die in the next decade[1] and 75% of them likely to need end of life care[2], now is the time to address these issues and put Fast Track CHC on a sustainable footing of better performance over the long-term.

What is Continuing Healthcare?

NHS Continuing Healthcare (CHC) funding enables people to be cared for outside of hospital if they have a primary health need. It is funded and arranged by the NHS and is not means-tested. It is aimed at patients with health, not social, care needs that are serious but do not require in-patient care in a hospital.

A patient's local authority would fund the cost of care and support if someone's needs were primarily for social care – for example, if they needed help with personal 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 [who] 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 an average of £19,190 per patient (this figure is an average of both Fast Track and non-Fast Track CHC patients). NHS England's efficiency plan required CCGs to achieve savings in CHC of £855 million over the period ending 2020/2021. As the National Audit Office has identified, this is a significant challenge given the limited scope for these savings to be found from administrative spend on CHC (which accounts for only £149 million)[3].

NHS England has taken steps towards achieving these savings (as set out in HM Treasury's response to the Public Accounts Committee's inquiry into CHC funding[4]), including improving processes and exploring ways to improve the commissioning of CHC packages. However, it remains unclear whether NHS England is on course to achieve the savings identified without impacting the quality of CHC for patients – especially in the context of growing demand for CHC and increasing complexity of need.

The Continuing Healthcare assessment process

The process for putting a CHC package in place consists of several stages. First, a person with care needs is identified, 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.

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.

In the financial year 2019/20, more than 103,000 people started the Fast Track CHC process – representing more than half (59%) of the total number of people applying for CHC in England[5].

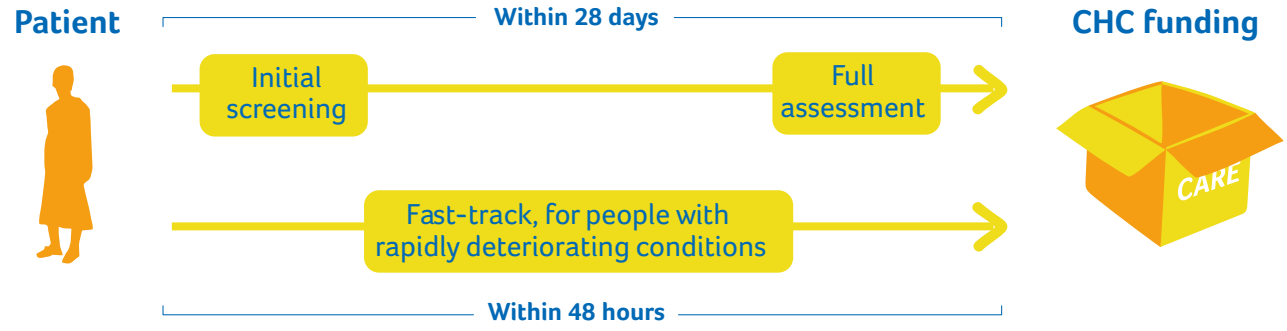
Once a clinician submits a Fast Track application, the local CCG is required to immediately approve a package of care and have it in place as soon as possible. The National Framework recommends this is done within 48 hours[6]. This timeframe reflects the importance of appropriate care for patients near the end of their life and the reality that for these patients, every moment counts when it comes to having the right care in place.

Why Fast Track matters

Fast Track CHC is crucial to ensuring seriously ill and dying people who are deteriorating rapidly are not denied access to the appropriate support they need to enable them to leave hospital or avoid admission. It is often the existence of this system that allows the person to die in the place they choose, which is usually very important to the individual and their loved ones. Delays to this process can ultimately mean people dying in hospital before a package of care is put in place, causing significant distress for those at the end of their lives and their families. There is no second chance to get it right.

Delays which lead to people waiting more than 48 hours to get the care package they need in place are unacceptable. Yet our research over the past four years has shown that delays continue to happen far too often, and in far too many CCGs.

How CHC works



Methodology

In July 2020, Marie Curie submitted Freedom of Information (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 at which an application is approved. We also asked CCGs to provide data on the number of Fast Track CHC applications they received and the number of packages that were delivered. Figure 1 shows a full transcript of the FoI requests.

Our aim was to obtain a clearer picture of how Fast Track CHC is being delivered across England. We needed to understand the extent to which packages are being delayed and, crucially, the frequency with which applications do not result in delivered packages of care. Doing so enables us to identify the scale of seriously ill and dying people who are not receiving the care they need to leave hospital quickly at the end of their lives because of these delays and failures to deliver packages of care.

Fig 1. Freedom of Information request to CCGs made by Marie Curie in July 2020

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 2019/20?

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 2019/20?

Question 3: During the financial year 2019/20, how many applications for fast track CHC did the CCG receive?

Question 4: During the financial year 2019/20, how many applications for fast track CHC were funded?

Phil hardman/Marie Curie

Data shortages in Fast Track Continuing Healthcare

Our previous three reports had found significant gaps in the data that CCGs were able to provide Marie Curie on Fast Track CHC performance. This situation continues to improve – in 2018 more than one-third (35%) of CCGs were unable to provide any of the requested data, but this year only two (1%) were unable to provide any data.

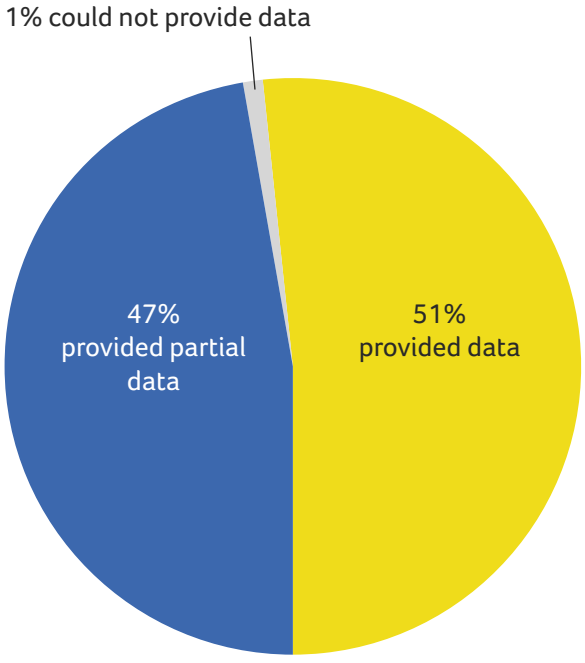
However, the number of CCGs able to provide full data for each question asked has fallen slightly from last year (from 58% to 51%), and nearly half of CCGs (47%) are still only able to provide partial information.

The most frequently missing data was in relation to the average time from a Fast Track CHC application being approved to a care package provided (Question 2, 85 non-responses) and the average time from a Fast Track CHC application being made to a care package being provided (Question 1, 81 non-responses). By contrast, only two CCGs were unable to provide us with any information on the number of Fast Track CHC applications received or delivered in 2019/20.

There were a number of reasons given for why CCGs were not able to provide data on the length of time it takes them to deliver a Fast Track CHC package from application/approval. Most commonly, CCGs reported that data was not recorded, or that it was 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, requiring a manual search through patient records in order to comply with the request. As public bodies other than central Government are exempt from responding to FoI requests where the cost of complying with them would exceed £450, many CCGs refused to provide the data on this basis.

Fig 2. CCG responses to Fast Track CHC FoI enquiry (n=182)



It is unacceptable that many CCGs remain unable to easily provide information on how quickly Fast Track CHC packages are being delivered. There is a clear correlation (as outlined later in this report) between delays in delivering a package and that package ultimately being undelivered, which has now been in evidence across all four years that Marie Curie has been collecting data on this issue.

This is unsurprising given the profile of patients who are eligible for Fast Track CHC; typically their condition will be deteriorating rapidly or they will have entered a terminal phase. As such, any delays are highly likely to increase the risk that the patient will become too ill to leave hospital by the time the package is ready or, in many cases, will have already died.

The Department for Health & Social Care makes this point clear in the National Framework[7]. It is critical that CCGs can judge their performance against this framework and benchmark themselves against other CCGs; the fact that 47% of CCGs are still unable to provide full information remains a significant source of concern. Being unable to do so leaves too many CCGs unable to reliably identify and address issues with their own performance. It ultimately leaves an unacceptable number of patients at risk of not receiving the care they need.

Continued evidence of delays

Of the CCGs that were able to provide Marie Curie with information on how long it takes them to deliver a Fast Track CHC package, a majority are missing the two-day implementation period set out in the National Framework. Only around 45% of the CCGs who provided information are putting Fast Track CHC packages in place, within 48 hours on average of an application being made.

Figure 3 shows the average time taken by CCGs to implement a Fast Track CHC package from application and approval to delivery. '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.

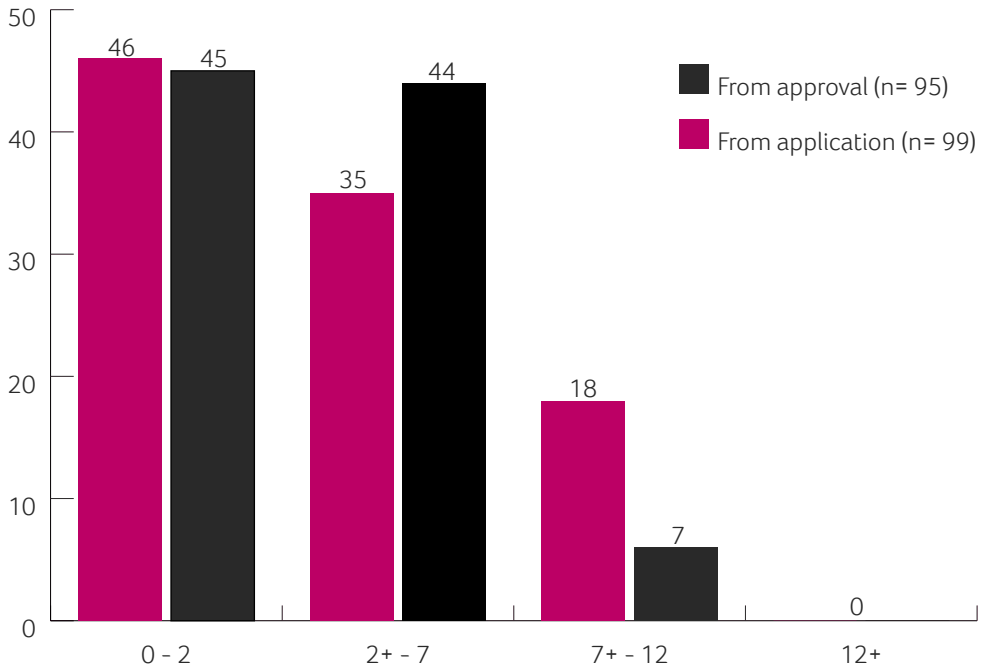
According to the National Framework, a CCG should be approving all Fast Track applications without delay provided that the required information is included on the application form.

Consequently, there should be little difference between the time taken to implement a Fast Track package from application or from approval.

However, this is clearly not always occurring in practice. In a majority of CCGs that provided information, it takes more than two days on average from the point of approval for a package to be delivered. While approval of an application may be delayed in some cases – for example, if all the necessary information is not provided initially – where an application has been approved there should be no cause for further delays to the process. Yet in more than half of CCGs (52%, 50 of 95 that provided data), it is taking more than two days to implement packages from the point they are approved.

While the number of CCGs delivering packages within 48 hours of an application being made has risen compared to last year (from 40% to 46%, "year (from 40% to 46%, see Figure 4) more than half of the CCGs that provided data are still failing to meet the 48-hour guidelines set out in the

Fig 3. Average time taken to implement Fast Track CHC packages (days), 2019/20



National Framework. Of these, most are able to implement packages on average within a week. However, 18 CCGs (almost one in five of those who provided data) are on average taking more than a week to deliver Fast Track CHC packages from the point of application. Such significant delays are a source of ongoing concern and highlight serious issues with the performance of the CCGs in question.

Figures 4 and 5, below, compares the average time taken to implement Fast Track CHC packages, as reported by CCGs over the past 3 years' worth of data obtained by Marie Curie. We are unable to compare across all four years for which Marie Curie has been collecting data due to changes in methodology between the first and second years.

Fig 4. Average time taken to implement Fast Track CHC packages from application, days (last 3 years)

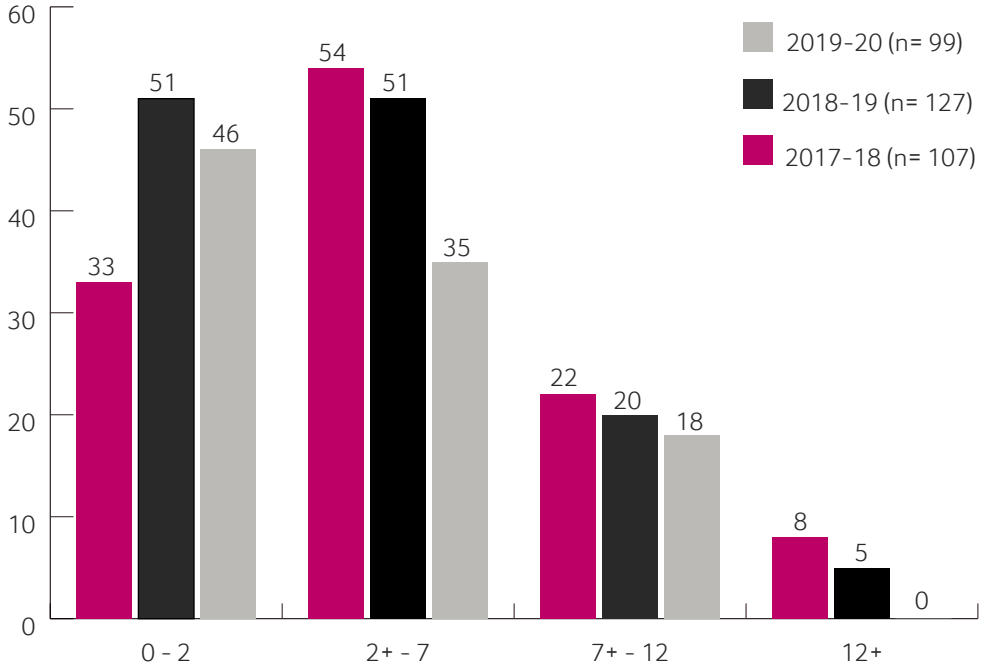
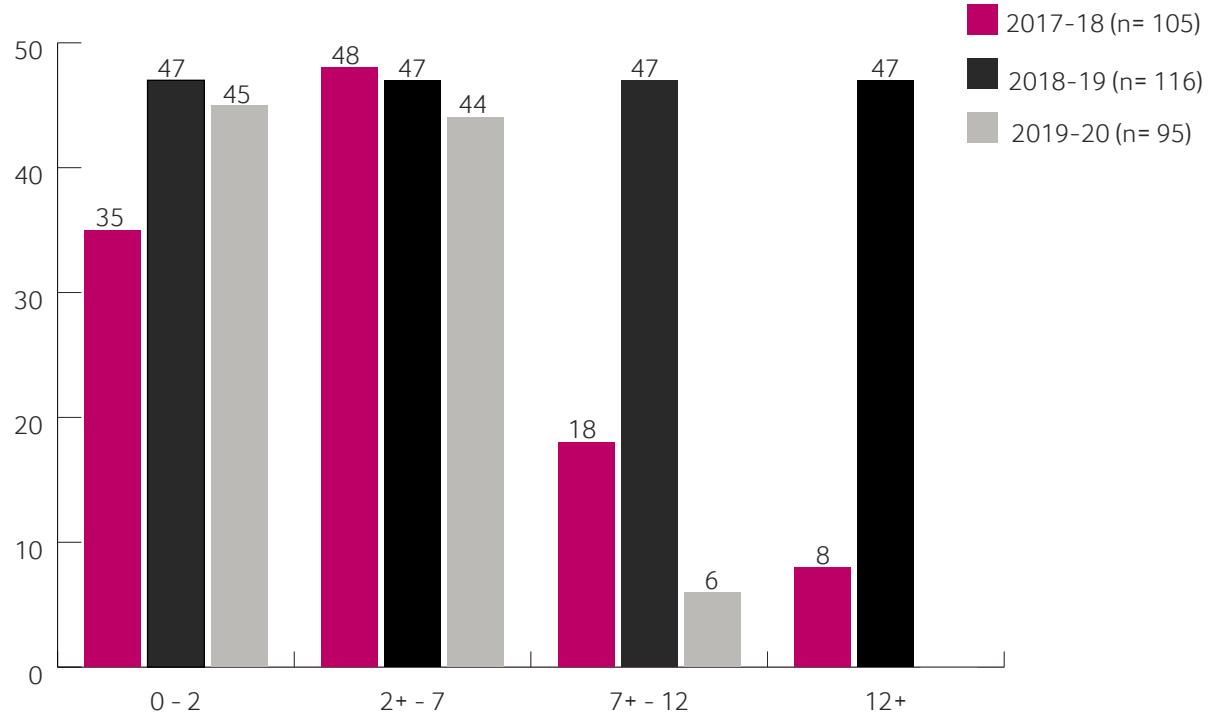


Fig 5. Average time taken to implement Fast Track CHC packages from approval, days (last 3 years)



While a smaller number of CCGs reported meeting the 48-hour guidelines for delivering a Fast Track CHC package in 2019/20 than in 2018/19, it should be noted that fewer CCGs provided information on this metric. This is due to a combination of CCG mergers and proportionally fewer CCGs providing information on this metric. It is therefore necessary to compare the proportion of CCGs meeting this metric as a percentage of the total number of CCGs who provided data.

As noted above, there is evidence of a significant increase in the proportion of CCGs meeting the 48-hour standard over the past three years. In 2019/20, 46% of CCGs reported that on average, they met the 48-hour standard for delivering a Fast Track CHC package from application, compared to 40% in 2018/19 and 31% in 2017/18. Similarly, 47% of CCGs reported delivering care packages within 48 hours of an application being approved in 2019/20, compared to 40% in 2018/19 and 33% in 2017/18.

Notably, the number of significant delays (more than seven days) has fallen significantly over the last three years. In 2017/18, 28% of CCGs told us it took them on average more than one week from the point of application to deliver a Fast Track CHC package. 25% told us it took them more than one week from the point an application was approved. In 2019/20, only 19% of CCGs reported that it took on average more than seven days from application to deliver a Fast Track CHC package and just 7% report that it took more than this from the point of approval.

This is a positive development and shows evidence of year-on-year improvement, with significant delays of more than a week becoming rarer across most of the country. However, more than half of CCGs continue not to meet the 48-hour standard on average and are therefore still failing to meet the expected performance level set out in the National Framework. While the increase in CCGs meeting the standard set out in the guidelines is welcome, it is unacceptable that fewer than half are still meeting this on average.

This is a concern that suggests further systemic issues with Fast Track CHC performance. Despite overall improvements in performance, the data we have available gives us little confidence that the worst-performing CCGs are adequately addressing these issues.

Marie Curie will continue to monitor Fast Track CHC performance by English CCGs over the coming years. In particular, we will pay close attention to the effect of emergency measures taken in the early part of the Covid-19 pandemic on performance across 2020/21.

Why are delays occurring?

There are several reasons why CCGs may be failing to meet the timescales set out in the National Framework by packages of care in place within 48 hours of a Fast Track CHC application being made, including:

- Errors in CHC applications leading to delays in applications being approved
- A lack of suitable beds in care homes to discharge people into
- CHC approval services only functioning Monday to Friday and/or during office hours
- Patient deterioration preventing discharge from hospital
- A lack of market capacity and other local provider issues.

Recommendations to address these issues are highlighted later in this report.

We will be exploring the extent to which emergency funding made available during the early stages of the Covid-19 pandemic led to a reduction in delays delivering Fast Track CHC when full data for 2020/21 becomes available.

Gaby's story

Gaby's father John died at the age of 89 from vascular dementia. Gaby speaks about how the local health and social care agencies failed to provide the care her dad needed in the final weeks of his life.

"Dad went into hospital 11 weeks before he died, with a bleed unrelated to dementia. He was extremely unwell and totally confused and distressed. He had surgery on the Tuesday, and they insisted on discharging him on the Friday, with a catheter, despite our protestations. We were saying that we couldn't cope with him with a catheter when he doesn't even understand what it is. It just wasn't safe.

He ended up getting taken back to hospital late the next day after he found scissors and cut off his catheter. The nursing staff couldn't cope with him because he roamed in the night, was confused and tried to pull out his catheter.

Nobody mentioned CHC. The only type of care package that was even mooted was a ten-minute get him up in the morning and a ten-minute put him to bed at night. Which would have been useless. We were told there were no night sitters in the area. It was impossible to get any real help."

After more than a month in hospital, Gaby and her family took John home, but they were unable to cope and found him a temporary emergency place in a care home.

"[The care home] couldn't cope with him, said they wouldn't have taken him had they known how ill he was, and that he needed nursing care. On the Friday, the care home said he had to be out by Monday. I was desperately trying to get the CHC assessment done, so that we could get more assistance.

I kept phoning the service saying that he urgently needs to be assessed for CHC. They kept putting it off, saying that he wasn't ill enough, that there was no point in rushing it and that we needed to wait. I was crying on the phone saying, 'Please, he needs nursing care. He needs it, they can't cope.'

After phoning around countless homes, we found one that provided nursing care and had a place available. On the day he was moving I insisted that we needed ambulance transport to move him, but nobody would take responsibility for it. I drove him, myself and my mum trying to keep him calm, to this place that we'd never seen. The new care home didn't realise how ill he was, because the community psychiatric nurse (CPN) kept saying he wasn't ill enough for CHC.

When the CPN finally saw him, she was clearly shocked at how bad Dad was. She said that she would fast-track the CHC application, something I had been pleading for. We just wanted him home. We never wanted him in a care home but couldn't get the support to keep him at home.

She did fast-track it, it appears subsequently, but he died on the Tuesday morning. So, it was just too late. Several weeks later Mum got just a letter in the post saying the CHC's been approved.

Had it been addressed sooner, none of that needed to happen. We could have kept him at home, the whole thing would have been much smoother."

Disparities in Fast Track delivery rates

In addition to widespread and continued evidence of delays, this year's data continues to show significant variation across England in the delivery rate of Fast Track CHC – that is, the percentage of packages applied for that ultimately lead to a Fast Track package being 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 under normal circumstances. Certainly, a large proportion of packages being undelivered is a cause for concern and would likely be evidence of systemic issues with Fast Track CHC delivery at a CCG.

While we would usually expect a delivery rate close to 100% of applications received, there are some reasons why an application may not result in a package of care being delivered, including:

- 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.

Phil Hardmann/Marie Curie

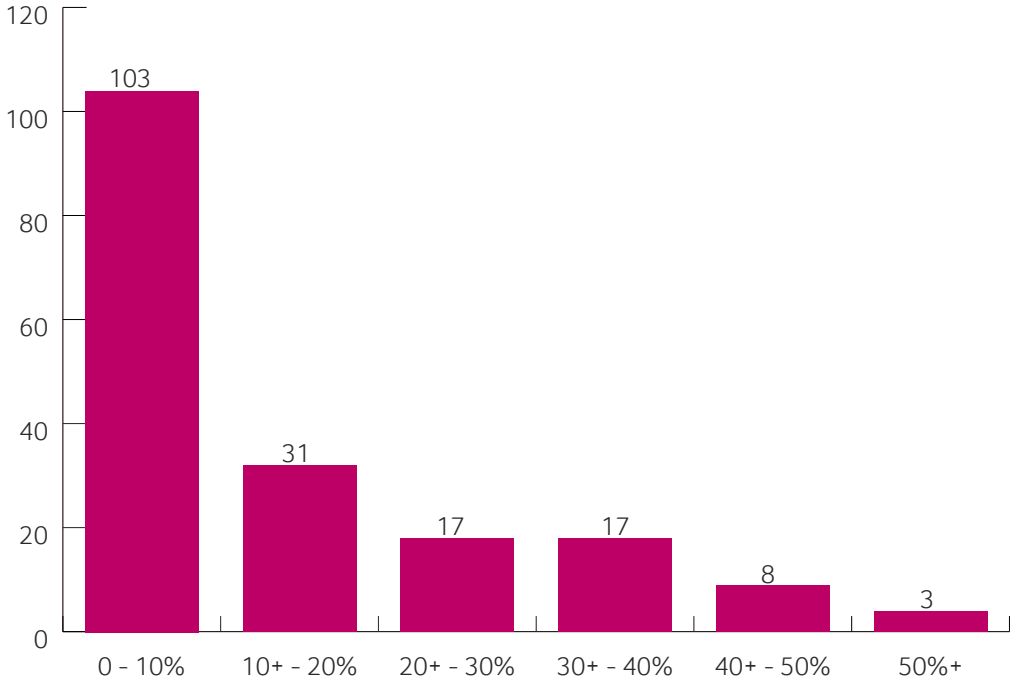
The first reason would be indicative of clinicians making errors – either incorrectly completing forms or misunderstanding the purpose of Fast Track CHC and who is eligible. Given that Fast Track CHC was introduced in 2007, widespread errors by clinical staff should no longer be expected and would suggest deficiencies in staff training. In the latter two cases, it is likely that the failure to deliver a package could be avoided by faster delivery of a package of care.

There will always be some individuals whose condition deteriorates so quickly that it will not be possible to put a Fast Track CHC package in place quickly enough. However, these cases should be a rarity if a CCG is performing well with respect to meeting the 48-hour deadline set out in the National Framework.

Marie Curie received data on application and package delivery rates in the financial year 2020/21 from 179 CCGs in England. The majority (57.5%, 103) of CCGs are delivering 90% or more of packages applied for. Figure 6 below shows the distribution in non-delivery rate across England.

More than two in five (42%) of CCGs are failing to deliver a package of care in at least one in ten Fast Track CHC applications, with a small number failing to deliver half or fewer than half of the packages applied for. Overall, 15% of CCGs in England have non-delivery rates in excess of 30% of the Fast Track CHC applications they received in 2019/20.

Fig 6. Distribution of CCGs in non-delivery rate for Fast Track CHC, 2019/20 (n=179



Confirming the relationship between delays and non-delivery

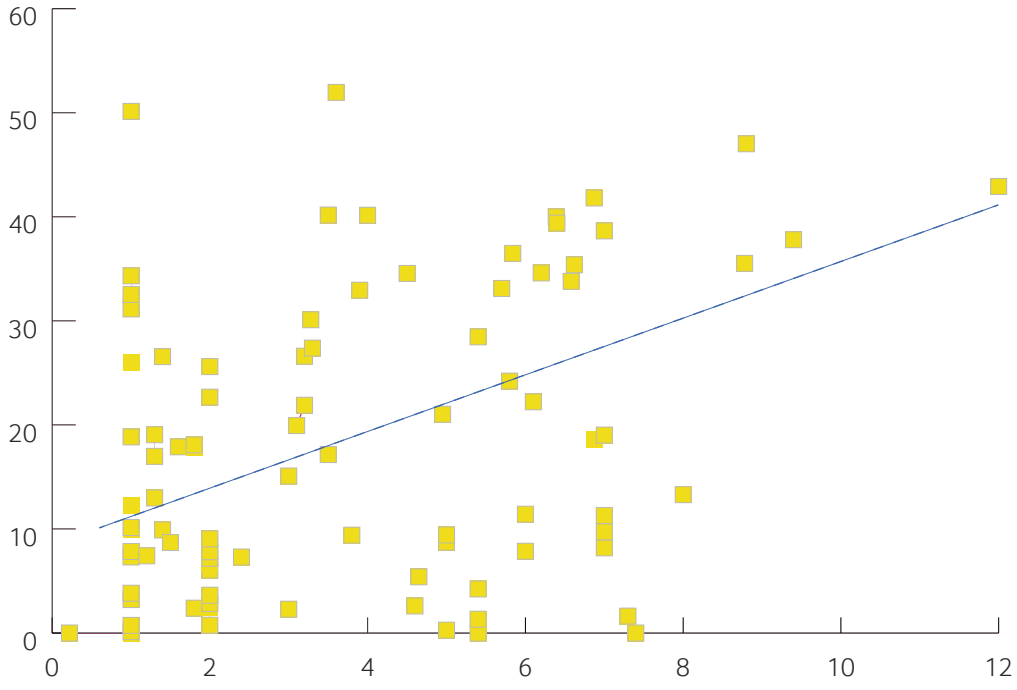
In 2017/18, Marie Curie observed a clear relationship between the time it takes CCGs to implement a Fast Track CHC application and whether a package of care is ultimately delivered; there is a clear correlation between delays and non-delivery. Our data briefing in 2018/19 confirmed that relationship.

As Figure 7 highlights, this correlation continued in 2019/20. If a CCG takes longer on average to implement a Fast Track CHC package, it is more likely that they will have a higher non-delivery rate overall. This is to be expected given the profile of patients eligible for Fast Track CHC. The longer a person who is eligible is forced to wait for a package of care, the more likely it is that their condition will have deteriorated to the point they will be unable to leave hospital by the time it is ready, or sadly they will have already died.

Figure 7 shows the significant variation in the length of time a person can expect to wait for a Fast Track CHC package across England – from less than a day to in excess of 12 days in the most extreme cases. It also underlines the relationship between delays and non-delivery – when a CCG fails to meet the 48-hour deadline set out in the National Framework, it is more likely to see a significant rate of packages undelivered. The rate of these undelivered packages rises as the average time rises.

46% of CCGs are meeting the 48-hour deadline on average. Furthermore, 57.5% are delivering packages of care for more than 90% of Fast Track CHC applications they receive. This underlines that an acceptable level of performance is achievable, so it is disappointing that too many CCGs are failing to do so in practice.

Fig 7. Fast Track delivery times against application non-delivery rate, 2019/20



A postcode lottery in Fast Track care

The variations between CCGs are unacceptable, specifically in the average time taken to implement a Fast Track care package and the rate of Fast Track applications that fail to lead to a package of care being delivered at all. While some areas are performing within the guidelines, too many are failing to meet the minimum standards expected of them.

This indicates serious inconsistencies in how Fast Track CHC is being implemented across England. In practice, this means that access to Fast Track care and the quality of care received by patients in England depends to a meaningful extent upon where in the country they live. This postcode lottery is unacceptable; patients in some parts of the country are forced to wait significantly longer than those in other areas to get the care they need. Furthermore in many parts of the country, your chances of receiving a Fast Track CHC package at all before you die are significantly reduced.

Earlier in this report, we laid out Marie Curie's analysis of data provided by English CCGs over the past three years, identifying some concerning trends in the performance of CCGs. This analysis highlights the extent of this postcode lottery. However, this year we can go further and pinpoint particularly poor performance by individual CCGs.

Tables 1 and 2 on the next pages highlight the lowest-performing 20 CCGs in England in 2018/19. This is based upon the average time it takes CCGs to implement a package of care from receiving a Fast Track CHC application and from approval. We have not highlighted the top 20 highest-performing CCGs as in excess of 20 CCGs reported implementing packages within one day on average, and it has not been possible to rank their performance in more detail than this.

This data underlines the postcode lottery experienced by patients in England and highlights CCG areas where patients can expect, on average, to wait more than a week from the point that an application for Fast Track CHC is made before they will receive a package of care – in the worst-performing areas they are likely to have to wait significantly longer.

Of particular concern is that the majority of the lowest-performing CCGs rank among the lowest-performing on both metrics. This is evidence of serious delays in those CCGs, where patients are likely to not only wait significantly longer than the 48 hours set out in the National Framework for a package of care, but also face delays even after their application for Fast Track CHC is approved.

Patients in these areas can expect to wait far longer – in some cases well over a week longer – at the end of their lives than patients in other parts of the country before a package of Fast Track care is put into place to allow them to leave hospital. In many cases, they will be waiting far longer than patients in neighbouring CCG areas, although there are some geographical 'clusters' of poor performance covering multiple neighbouring CCGs.

Tables 3 and 4 highlight the 20 highest and lowest-performing CCGs in England for non-delivery of Fast Track CHC packages. The lowest-performing areas have the highest rate of packages applied for that are ultimately not delivered in the country.

This data highlights where patients are significantly less likely to receive a Fast Track CHC package than elsewhere in England. As such, they are more likely to be unable to leave hospital at the end of their lives even if they wish to and should be able to do so.

Table 1. Lowest-performing CCGs – days from Fast Track CHC application to provision, 2019/20

Clinical Commissioning Group	Average days application to provision
NHS North East Hampshire and Farnham CCG	12
NHS North Hampshire CCG	11.4
NHS West Hampshire CCG	10.6
NHS North Staffordshire CCG	9.51
NHS Bath and North East Somerset CCG	9
NHS Cambridgeshire and Peterborough CCG	8.4
NHS South Eastern Hampshire CCG	8.1
NHS Coastal West Sussex CCG	8
NHS Crawley CCG	8
NHS Horsham and Mid Sussex CCG	8
NHS South East Staffordshire and Seisdon Peninsula CCG	7.91
NHS Fareham & Gosport CCG	7.7
NHS Surrey Heath CCG	7.68
NHS Stafford and Surrounds CCG	7.67
NHS Waltham Forest CCG	7.5
NHS Stoke on Trent CCG	7.34
NHS Wiltshire CCG	7.3
NHS East Staffordshire CCG	7.11
NHS Gloucestershire CCG	7
NHS Somerset CCG	7

Table 2. Lowest-performing CCGs – days from Fast Track CHC approval to provision, 2019/20

Clinical Commissioning Group	Average days approval to provision
NHS North East Hampshire and Farnham CCG	12
NHS North Hampshire CCG	9.4
NHS West Hampshire CCG	8.8
NHS North Staffordshire CCG	8.78
NHS Bath and North East Somerset CCG	8
NHS Cambridgeshire and Peterborough CCG	7.4
NHS Coastal West Sussex CCG	7
NHS Crawley CCG	7
NHS Horsham and Mid Sussex CCG	7
NHS Somerset CCG	7
NHS Vale of York CCG	7
NHS Surrey Heath CCG	6.88
NHS South East Staffordshire and Seisdon Peninsula CCG	6.87
NHS Stafford and Surrounds CCG	6.62
NHS Stoke on Trent CCG	6.58
NHS South Eastern Hampshire CCG	6.4
NHS East Staffordshire CCG	6.39
NHS Fareham & Gosport CCG	6.2
NHS Tees Valley CCG	6.1
NHS Trafford CCG	6

Table 3. Highest-performing CCGs in England – non-delivery rate for Fast Track CHC packages, 2019/20

Clinical Commissioning Group	Non-delivery rate (% of packages not delivered)
NHS Cambridgeshire and Peterborough CCG	0
NHS Vale Royal CCG	0
NHS Salford CCG	0
NHS Heywood, Middleton & Rochdale CCG	0
NHS Newcastle Gateshead CCG	0
NHS South Tyneside CCG	0
NHS Manchester CCG	0
NHS Sandwell and West Birmingham CCG	0.13
NHS Basildon and Brentwood CCG	0.22
NHS Rotherham CCG	0.28
NHS Mid Essex CCG	0.33
NHS Shropshire CCG	0.44
NHS Wandsworth CCG	0.53
NHS St Helens CCG	0.73
NHS Barnsley CCG	0.75
NHS Swale CCG	0.84
NHS South Cheshire CCG	1.1
NHS Merton CCG	1.13
NHS West Cheshire CCG	1.33
NHS Doncaster CCG	1.5

Table 4. Lowest-performing CCGs in England – non-delivery rate for Fast Track CHC packages, 2019/20

Clinical Commissioning Group	Non-delivery rate (% of packages not delivered)
NHS East Leicestershire and Rutland CCG	51.96
NHS Bedfordshire CCG	50.14
NHS Dorset CCG	49.24
NHS West Hampshire CCG	47.02
NHS North East Hampshire and Farnham CCG	42.92
NHS South East Staffordshire and Seisdon Peninsula CCG	41.81
NHS Oxfordshire CCG	40.3
NHS Leicester City CCG	40.18
NHS West Leicestershire CCG	40.15
NHS East Staffordshire CCG	40
NHS South Eastern Hampshire CCG	39.4
NHS Vale of York CCG	38.65
NHS North Hampshire CCG	37.8
NHS Cannock Chase CCG	36.49
NHS North Staffordshire CCG	35.53
NHS Stafford and Surrounds CCG	35.4
NHS Fareham & Gosport CCG	34.61
NHS City and Hackney CCG	34.56
NHS Nottingham City CCG	34.33
NHS Stoke on Trent CCG	33.8

The data further confirms the relationship between delays in implementing Fast Track CHC and eventual non-delivery of care packages. More than half of the lowest-performing CCGs (in terms of non-delivery of packages) also feature among the lowest-performing areas for delays. Almost all of them report not meeting the 48-hour deadline set out in the National Framework, on average.

This data is evidence of an unacceptable postcode lottery for patients. No demographic factors adequately explain why these particular areas are performing poorly. The lowest-performing CCGs across all metrics are found in both urban areas and in more rural parts of the country, areas with higher and lower average ages[8], and areas which cover more and less affluent parts of the country[9]. We must therefore conclude that the discrepancies in performance are likely to be related to the way individual CCGs are approaching Fast Track CHC, with poor performance largely indicative of deficiencies in CCGs and not explained by other factors.

Long term performance issues and recent improvements

Unfortunately, many of these performance issues are long-term. A combination of CCG mergers and differences in the proportion of CCGs reporting data in response to Marie Curie's FoI requests prevents us from directly comparing the lowest-performing CCGs in 2019/20 with data we received in previous years. However, several of the CCGs highlighted in this data have reported failing to meet the 48-hour standard set out in the National Framework or a significant non-delivery rate for Fast Track CHC packages in previous years.

Widespread and long-standing delays in providing packages of care may be indicative of problems or failures in commissioning leadership and inadequate staff training leading to errors and time-consuming mistakes. These CCGs should review their performance as a matter of priority and consider how they can urgently improve their delivery of Fast Track CHC.

However, there have been many CCGs which have improved their performance. As outlined earlier in this report, while more than half of English CCGs are failing to meet the 48-hour guidelines set out in the National Framework, the proportion of CCGs delivering packages within the guidelines has risen to 46% overall.

Again, a combination of CCG mergers and differences in the proportion of CCGs responding to Marie Curie's FoI requests prevents us from displaying CCGs that have made particular improvements. However, it is important to note that many CCGs do appear to be making year-on-year improvements in the time taken to deliver packages of care and the proportion of Fast Track CHC packages that are delivered.

The fact that significant improvements in the practice of Fast Track CHC are possible in a relatively short period of time underlines the fact that change is achievable with sustained attention. It may be possible for CCGs to consider sharing best practice so that these improvements are better shared across the system.

Conclusion

Based on data obtained from every CCG in England, we have examined the state of Fast Track Continuing Healthcare in three key areas: the availability of data, the time taken by CCGs to put packages of care in place, and the proportion of applications that lead to a package of care being delivered.

As in previous years, the picture that emerges from the data is one of significant and unacceptable variations in Fast Track CHC performance throughout England. Some CCGs are performing well and meeting the guidelines set out in the National Framework and we welcome the improvements observed this year, both in the number of CCGs able to provide data and those delivering Fast Track CHC within the 48-hour guidelines. However, too many CCGs are still failing to meet these guidelines, and this year's report identifies some of the poorest performing CCGs for the first time.

These failures are not simply process issues resulting in missed targets – they have a real and irrevocable impact on the quality of care people receive at the end of their lives. Delays can leave dying people without the right care for them, stuck being cared for in hospital when most would prefer to be at home or otherwise cared for in the community, or unable to leave hospital at all.

Hospitals provide excellent care, but they are not always the best place for people to be cared for at the end of their lives. Crucially, just 7% of us say we would wish to die in hospital, and more than two-thirds would prefer to die at home[10]. The inconsistent delivery of Fast Track CHC by CCGs across England means that too many people are at risk of being denied this wish at the end of their lives. We know that whatever their preferences, only around a quarter of people die at home and nearly half die in hospital[11]. Many of these people could have been cared for at home or elsewhere had the right care been available in the community for them to leave hospital.

Fast Track CHC should enable this, but the data shows that in some parts of England it is failing to do so. There are clearly identifiable areas that indicate persistent poor performance, visible over the last several years of data collected by Marie Curie. These CCGs in particular, as well as all of those who are not meeting the standards set out in the National Framework, should look to urgently improve their delivery of Fast Track CHC. However, it is important to underline that we have observed some improvement this year in the proportion of CCGs meeting the standards expected. This is encouraging and indicates that improved performance is possible with sustained attention.

As the UK emerges from the Covid-19 pandemic over the coming year, we cannot return to the situation revealed by this data. The emergency measures put into place at the outset of the crisis show that it is possible for CHC packages to be put into place very quickly – sometimes within hours – when sufficient focus and priority are placed on doing so and sufficient resources are made available to deliver the care patients need. While emergency funding provisions cannot remain in place indefinitely and measures such as the suspension of CHC assessments have already ended, CCGs must ensure that any improvements in Fast Track CHC performance can be retained going forward.

Recommendations

Marie Curie recommends the following steps to improve performance in Fast Track CHC.

Ensure the care needs of people at the end of life are at the centre of arrangements for delivering new 'Discharge to Assess' proposals

We welcome proposals in the Health and Care White Paper to allow CCGs to continue conducting CHC assessments after patients have been discharged from hospital. The government and local CCGs must ensure that meeting the needs of people at the end of life is placed the centre of arrangements for delivering these new proposals.

Ensure consistency in data collection on Fast Track CHC

There remain significant gaps in the information CCGs were able to provide in response to Marie Curie's Freedom of Information requests – with nearly half unable to provide full data. Without this information, it will be impossible for CCGs to self-assess their own performance or for CCGs to be held accountable for poor performance. Many CCGs told us that they did not record this data or that it would be prohibitively expensive to obtain it from individual patient records. We welcome proposals in the recent NHS White Paper to give NHS Digital regard to the benefit to the health and social care system of sharing data that it holds when exercising its functions and developing standards for collecting and sharing that data. As part of this duty, we believe the NHS must urgently develop a consistent set of standards for gathering and recording information on Fast Track CHC, to be followed by all CCGs in England. This is to ensure uniformity of data collection and enable CCGs to be held accountable for their performance.

Hold CCGs accountable for poor performance against the National Framework

Too many CCGs are still failing to meet the 48-hour guidelines for Fast Track CHC set out by the Government in the National Framework. We know it is possible for CCGs to meet the standards required because more than two in five (46%) are now delivering Fast Track CHC packages within 48 hours. Failure to do so, especially repeated failure over several years, is unacceptable. At present, CCGs are not held accountable for failing to meet the guidelines set out in the National Framework, meaning there is little incentive to improve performance. This must be addressed, and a proper means introduced to hold individual CCGs accountable for poor performance in delivering Fast Track CHC. Ensuring that the information sought by Marie Curie is at least reported to Public Health England, which upon publication will allow CCGs to be benchmarked and for poor performance to be monitored, for example.

Improve training and support

A key issue identified in our analysis of Fast Track CHC data across the four years Marie Curie has been investigating this issue is the prevalence of significant and widespread delays across England. Delays will often be caused by applications being made that are incomplete or do not provide the right information for the application to be approved quickly. Fast Track CHC is now well-established and we would not expect to see a significant number of errors; such errors may be indicative of inadequate training for clinical staff, or inadequate support for staff in using the Fast Track Pathway Tool. CCGs must ensure that all relevant clinical staff are given adequate training in Fast Track CHC – including in promptly identifying patients who may be

eligible, when to make applications, and how to properly complete the Fast Track Pathway Tool. This is critical if CCGs are to reduce the incidence of delays in providing packages of care.

Adequately resource community care services

Another principal driver of delays in delivering Fast Track CHC packages is a lack of capacity in community care services. No matter how quickly a clinician completes the Fast Track Pathway Tool or how promptly an application can be approved, if the necessary community services are unavailable or oversubscribed, it will be impossible for some patients to leave hospital. Commissioners and national and local leaders should be mindful that community health and care services are a vital component of Fast Track CHC, and that without greater investment in such services as envisioned by the NHS Long Term Plan, it is unlikely that many CCGs will be able to meet the 48-hour standard in the National Framework. Emergency measures introduced in the early stages of the Covid-19 pandemic demonstrate that with sufficient resources, Continuing Healthcare can be delivered quickly and effectively. We can no longer afford to delay permanently uplifting investment in community care services if people are to be able to end their lives away from hospital.

Share best practice among CCGs

This year's data has enabled Marie Curie to identify those CCGs which are falling shortest compared to the standards expected of them in delivering Fast Track CHC for the first time. These CCGs should urgently look to address the issues that are stopping them from delivering packages of care within the timescales expected and, too often, from delivering packages of care at all. Other CCGs are delivering far better performance against the National Framework and may be a source of best practice for other areas to follow. NHS England must consider how best practice from better-performing CCGs and those that have shown marked improvements can be disseminated for others to follow.

Many of the challenges facing Fast Track CHC are not unique. They are systemic challenges also facing the rest of the healthcare system, which include:

- Ensuring that sufficient data exists to benchmark performance and drive improvements
- The need to adequately resource community and out-of-hours support, reducing the burden on hospital services and supporting people to be cared for where they want to be
- Reducing the prevalence of postcode lotteries by ensuring best practice is shared widely across a system where services are commissioned on a local basis.

However, with 6 million people expected to die in the next decade and 75% of them likely to need end of life care, there is a pressing need to address these challenges now. The above recommendations are achievable reforms that would put Fast Track CHC on a more sustainable footing of better performance for the long term.

Most of us would not wish to end our lives in hospital if given the choice. Fixing the problems in Fast Track CHC is an urgent and necessary step towards ensuring that more people are able to die in the place of their choosing in future.

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