The state of Fast Track Continuing Healthcare in England 2018-19 data briefing

Executive Summary

Fast Track Continuing Healthcare (CHC) is a free care package for patients to enable them 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 CCGs from the Department of Health & Social Care 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.

In 2018/19, for the third consecutive year the majority of CCGs in England were not meeting the 48hour guidelines. Despite some improvement in 2018/19, only 40% of CCGs were, on average, delivering Fast Track CHC packages within 48 hours from the point of application. In the worstperforming areas, delays were lasting well over two weeks.

This data also confirms the 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. Nearly one-third (32%) of CCGs were 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.

Comparing data from 2018/19 to data obtained by Marie Curie in previous years, we can see that CCGs had improved their delivery of Fast Track CHC somewhat and the most significant delays of more than a week were becoming a rarity. However, too many CCGs were still failing to meet the expected performance level set out in the National Framework.

The 2018/19 data confirms the relationship between delays in providing a package of Fast Track CHC care and non-delivery - when a CCG failed to meet the 48-hour deadline set out in the National Framework, it was more likely to see a significant rate of packages undelivered, with the rate of undelivered packages rising as the average time rose.

The inconsistency in delivery of Fast Track CHC across England means too many patients faced significant delays leaving hospital at the end of their lives and too many were unable to end their lives where they wished to.

Emergency measures to address the Covid-19 pandemic have improved the situation in Fast Track CHC since March 2020 - these measures are welcome and have helped many more people get out of hospital quickly when they do not need to be there. However, these measures are temporary and likely to end when the crisis has passed. We cannot return to the situation revealed by this data with demand for Fast Track CHC likely to rise in future as more people die needing end of life care, it is vital that the performance issues revealed in this data are addressed permanently.

Background

What is Fast Track Continuing Healthcare?

NHS Continuing Healthcare is a free care package for patients to enable them 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 or their carer must apply for CHC funding, at which point a health or social worker will assess them for a primary health need and conduct an in-depth assessment and examination of their needs. This assessment is then sent to the local CCG, which makes a 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 CHC is available to patients whose condition is deteriorating rapidly, or who have entered a terminal phase. A clinician with appropriate knowledge of the patient can apply for support on behalf of the patient without the need for a lengthy assessment process. CCGs are required to immediately make a decision on a Fast Track CHC package and have it in place as soon as possible; the National Framework recommends this is done within 48 hours₁.



Fast Track CHC is crucial to ensuring seriously ill and dying people are not denied access to the specialist support they need to enable them to leave, or prevent admission to, hospital. Often, this will make the difference that allows them to die in the place they choose, which is usually very important to the individual and their loved ones. Delays to this process 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 families.

In the financial year 2018/2019, more than 97,000 people started the Fast Track CHC process - representing more than half (57%) of the total number of people applying for CHC in England2.

In June 2019 Marie Curie submitted Freedom of Information requests to English CCGs to establish the current state of Fast Track Continuing Healthcare (CHC) performance. Our first two reports on Fast Track CHC in England, *Making every moment count* (October 2017) and *When time really matters* (April 2019) found significant inconsistencies in the delivery of Fast Track CHC, with many CCGs failing to meet the Department for Health & Social Care (DHSC) guidance that a Fast Track CHC package should be commissioned within 48 hours of an application being made, and many CCGs not gathering the information needed to assess their performance against the guidelines.

¹ Department for Health & Social Care. National framework for NHS continuing healthcare and NHS-funded nursing care. March 2019. Available at www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

² NHS Continuing Healthcare and NHS-funded Nursing Care. 2019. Available at <u>www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc</u>

Data shortages in Fast Track Continuing Healthcare

Our first two reports found significant gaps in the data that CCGs were able to provide Marie Curie on Fast Track CHC performance. This situation improved somewhat in 2018/19 - whereas last year more than one-third (35%) of CCGs were unable to provide any of the requested data, this year only four (2%) were unable to provide any data. In addition, all CCGs responded to Marie Curie's request for the first time.

However, while the number of CCGs able to provide full data has increased slightly (from 51% to 58%), two in five CCGs (40%) are still only able to provide partial information.

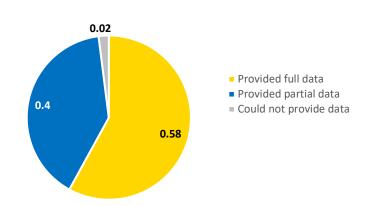


Fig 1. CCG responses to Fast Track CHC Fol enquiry (n=197)

The most frequently missing data was in relation to the average time from a Fast Track CHC application being made to a care package provided (64 non-responses) and the average time from a Fast Track CHC application being approved to a care package being provided (74 non-responses). By contrast, only four CCGs were unable to provide us with any information on the number of Fast Track CHC applications received or delivered in 2018/19.

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 commission and 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.

We are concerned that many CCGs remain unable to provide information on how quickly Fast Track CHC packages are being delivered. There is a clear correlation (as outlined later in this briefing) between delays in delivering a package and that package ultimately being undelivered, which has now been in evidence for each of the three years that Marie Curie has been collecting data on this issue.

This is unsurprising, as given the needs of patients eligible for Fast Track CHC - their condition is deteriorating rapidly, or they have entered a terminal phase - 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.

Delays in delivering Fast Track care packages

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 were missing the two-day implementation period set out in the National Framework. Only 40% of the CCGs who provided information were putting Fast Track CHC packages in place, on average, within 48 hours of an application being made.

Figure 2 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.

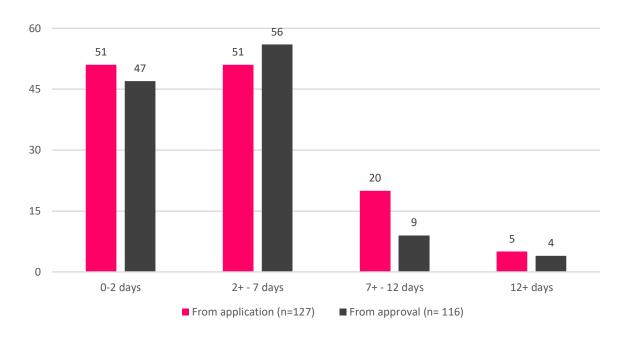


Fig 2. Average time taken to implement Fast Track CHC packages, 2018/19

While the number of CCGs delivering packages within 48 hours of an application being made has risen compared to the previous year (from 23% to 40%, see Figure 3) nearly two-thirds of the CCGs that provided data were still failing to meet the 48-hour guidelines set out in the National Framework. Of these, most were able to implement packages on average within a week; but 25 CCGs (one in five of those who provided data) were on average taking more than a week to deliver Fast Track CHC packages from the point of application.

In a majority of CCGs that provided information, it took more than two days on average from the point of approval for a package to be delivered, in 2018/19. While approval of an application may, in some cases, be delayed - 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 59% of CCGs (69 of 116 that provided data), it took more than two days to implement packages from the point they are approved.

Comparison to previous years

Figures 3 and 4 on the next page compare 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.

It is important to note that the number of responses received is not the same year on year; in 2018/19 Marie Curie received responses from 127 CCGs compared with 96 in 2016/17 and 107 in 2017/18. This complicates our ability to directly compare the data received in each year.

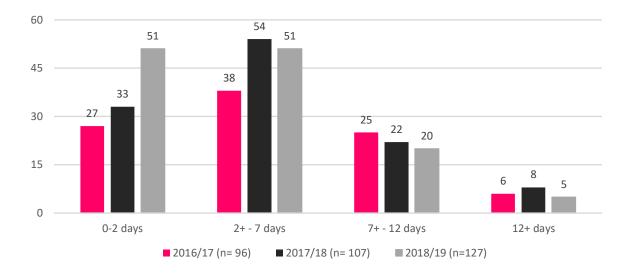
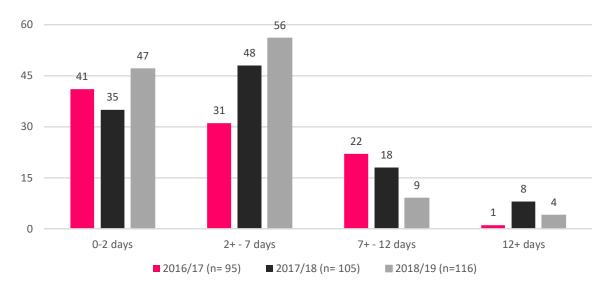


Fig 3. Average time taken to implement Fast Track CHC packages from application (last 3 years)

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



Comparing 2018/19 data to responses over the previous three years shows some improvement in 2018/19 in the proportion of CCGs meeting the 48-hour guidelines for delivering a Fast Track CHC package, with 51 (40%) meeting this in 2018 compared to just 27 (28%) in 2016/17.

After increasing in 2017/18, the proportion of CCGs failing to meet the 48-hour timescales has now fallen. Notably, the number of significant delays (more than 7 days) has fallen overall over the last 3 years of data. In 2016/17, 32% 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 and 24% told us it took them more than one week from the point an application was approved. In 2018/19, only 19% of CCGs reported that it took on average more than 7 days from application to deliver a Fast Track CHC package and just 11% report that it took more than this from the point of approval.

This suggests that CCGs have improved their delivery of Fast Track CHC somewhat and the most significant delays of more than a week are becoming a rarity. However, too many CCGs were still failing to meet the expected performance level set out in the National Framework.

Disparities in Fast Track delivery rates

The 2018/19 data shows 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.

There are some reasons why an application may not result in a package of care being delivered:

- 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

However, under normal circumstances we would expect the number of packages delivered should be close to 100% of the applications received. While 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, 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 2018/19 from 187 CCGs in England. The majority (68%, 129) of CCGs were delivering 90% or more of packages applied for. Figure 5 shows the distribution in non-delivery rate across England.

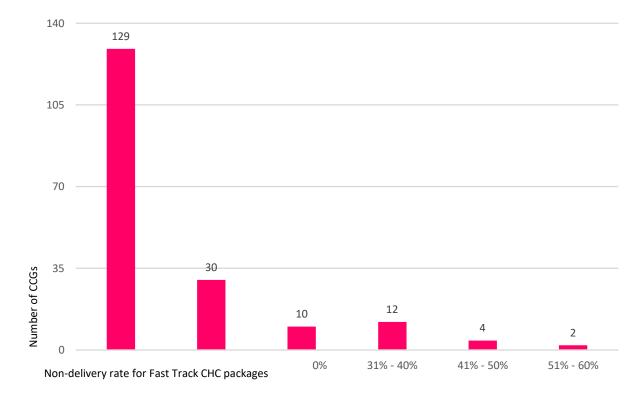


Fig 5. Distribution of CCGs in non-delivery rate for Fast Track CHC, 2018/19 (n= 187)

Nearly one-third (32%) of CCGs were failing to deliver a package of care for at least one in ten Fast Track applications, with a small number failing to deliver half or fewer of the packages applied for. Overall, nearly one in ten CCGs in England have non-delivery rates in excess of 30% of the Fast Track CHC applications they received in 2018/19.

Relationship between delays and non-delivery

In 2017/18, Marie Curie's report *When time really matters* 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.

The 2018/19 data confirms this relationship - as Figure 6 highlights, if a CCG takes longer on average to implement a Fast Track CHC package, it is 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 by the time it is ready to the point they will be unable to leave hospital or, sadly, have already died.

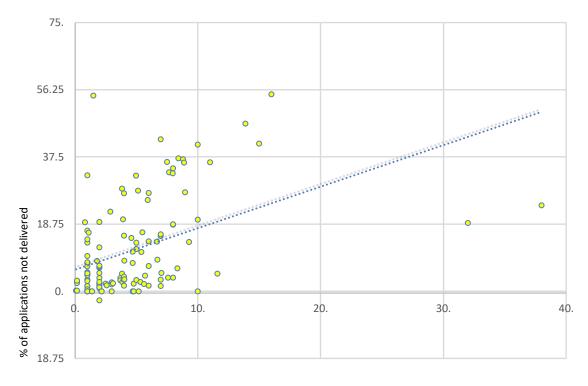


Fig 6. Fast Track delivery times against application non-delivery rate, 2018/19

Average Fast Track delivery time from application

There was significant variation in the time a person could expect to wait for a Fast Track CHC package across the country; from less than a day to, in the most extreme cases, in excess of 30 days. The data also underlines the relationship between delays and non-delivery - when a CCG failed to meet the 48-hour deadline set out in the National Framework, it was more likely to see a significant rate of packages undelivered, with the rate of undelivered packages rising as the average time rose.

40% of CCGs were meeting the 48-hour deadline on average. Furthermore, more than two-thirds (68%) were delivering packages of care for more than 90% of Fast Track CHC applications they receive. This clearly underlines that an acceptable level of performance is achievable and was being achieved in most cases across England; it cannot be acceptable that a significant number of CCGs were not meeting the standard in practice.

Discussion

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 wish to die in hospital and more than two-thirds would prefer to die at home₃.

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, fewer than a quarter of people die at home and nearly half die in hospital⁴. 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 was failing to do so in 2018/19 and each of the years for which Marie Curie has been collecting data.

During the Covid-19 crisis, there have been significant changes to CHC to support the discharge of patients who do not need to be cared for in hospitals. For example, the NHS has been fully funding all new CHC packages since 19 March 2020 and will continue to do so for the duration of the emergency, as well as delaying CHC assessments until the end of the crisis.

This has greatly reduced the time it takes to put CHC packages of care in place and discharge patients who can be cared for outside of hospital. In many cases, patients are now being discharged within a matter of hours and cared for either at home or in community settings.

These measures are welcome - not only have they allowed hospital staff to focus on caring for people with Covid-19 and reduced the risk of transmission of the virus in hospitals, they have allowed people who do not need to be and may not wish to be cared for in hospital to be cared for in a more appropriate setting. Many of these measures should have been in place anyway.

However, these steps are emergency measures and will likely not persist after the present crisis has passed. This data shows that before these new measures were put in place, there was an unacceptably varied level of Fast Track CHC performance by CCGs in England; patients in some parts of the country could expect to wait much longer to get the support they needed than others at the end of their lives, too many were experiencing significant delays and too many did not get Fast Track CHC support at all.

We cannot go back to the situation revealed in this data, where many people at the end of their lives faced significant delays before they could leave hospital, if they were able to leave at all. With 6 million people expected to die in the next decades and 75% of them likely to need end of life care6, it is vital that we permanently improve Fast Track CHC performance in future.

The Covid-19 crisis has demonstrated that the challenges facing Fast Track CHC performance in England are not insurmountable; they can be and have been addressed through focus and the proper funding. When the crisis is over, the Government must ensure that the funding required to maintain this level of Fast Track CHC performance remains available.

⁵ Office for National Statistics. National population projections. October 2019. Available at

³ NatCen Social Research. British Social Attitudes Survey 30. Available at https://www.bsa.natcen.ac.uk/media/38850/bsa 30 dying.pdf

⁴ Office for National Statistics. Rolling annual death registrations by place of occurrence, England. September 2019. Available at <u>https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/10517rollingannualdeathregi</u> strationsbyplaceofoccurrenceenglandperiodendingquarter1apriltojuneoffinancialyear2019to2020

https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based

⁶ I J Higginson et al. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services.' BMC Medicine 2017. Available at <u>https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2</u>