



Care and support
through terminal illness



Making every moment count

The state of Fast Track Continuing Healthcare in England

What is Continuing Healthcare?

Continuing Healthcare (CHC) is a free care package, funded and arranged by the NHS, to enable people to leave hospital to return to their own homes (which may be a care home). It can also be used to avoid a hospital admission.

It is for people whose healthcare needs are particularly serious, but can be provided outside hospital.

Usually, the patient's local authority would pick up some or all of the cost if someone's care needs are primarily social in nature – for example, if they need help with personal care and buying groceries. The CHC system shifts this responsibility to the NHS for patients with a 'primary health need'. This is described by the CHC framework as:

“... 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.”

Primary health needs assessments will take 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 restrictions 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.

Currently CHC costs around £3 billion per year in England, at an average cost of £19,190 per person. CHC costs are expected to rise to £5.2 billion by 2020/21 due to population growth and increasing demand. However, NHS England's efficiency plan requires Clinical Commissioning Groups (CCGs) to achieve savings in CHC of £855 million by 2020/21. While some savings could be made by reducing administration costs, the National Audit Office's investigation into CHC funding found that, as a whole, only £149 million is spent annually on the administration of CHC.¹ This raises serious questions about how CCGs will be able to make savings without compromising the quality or extent of care.

The CHC assessment process

The process of getting a CHC package of care in place consists of a two-stage assessment. A patient or their carer must apply for CHC funding, at which point a social or health worker will assess them using a nationally agreed checklist tool.

If the patient is deemed to have a primary health need, they then go

¹ National Audit Office (2017), 'Investigation into NHS continuing healthcare funding', available at nao.org.uk/report/nhs-continuing-healthcare-investigation/

through a more in-depth assessment process (again agreed nationally) known as the Decision Support Tool (DST).

The DST process is undertaken by social workers, carers and health professionals and is a more detailed examination of the patient's needs. DST findings are then sent to the local CCG, which then takes the decision on whether to approve funding.

Once approved, a care package should be in place within 28 days. People with a package of care funded by CHC are re-assessed after three months and then annually to review whether or not they still require support.

Fast Track Continuing Healthcare

If a person's condition is deteriorating rapidly or they are entering a terminal phase, the **Fast Track CHC pathway** can be used.

Fast Track CHC allows a clinician (which can be a doctor or a nurse) with appropriate knowledge of the patient to immediately assess that they should receive CHC-funded support without

the need for the lengthy checklist and DST assessment process.

Fast Track applications can also be made by clinicians working in the voluntary sector that specialise in end of life care (for example, Marie Curie or local hospices). The Fast Track pathway assessment tool is a far simpler process and can be completed quickly by a single clinician.

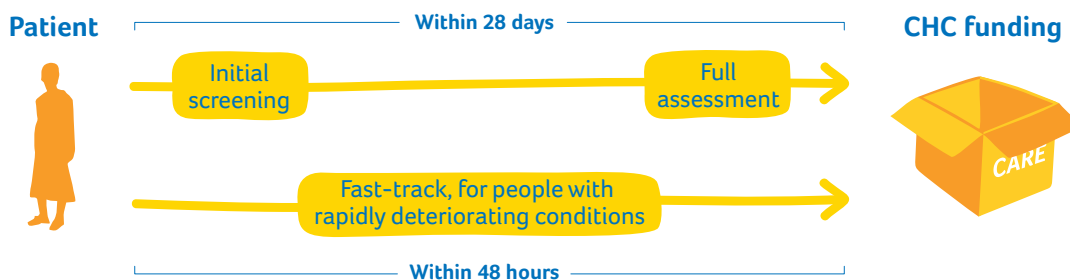
Once a clinician decides that a Fast Track package of care should be provided, the local CCG is required to immediately approve it and have it in place as soon as possible. The national framework for NHS continuing healthcare and NHS-funded nursing care recommends this is done **within 48 hours**.² This timeframe reflects the importance of having appropriate care in place for people 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.

The National Audit Office (NAO) found that in 2015/16 there were 83,000 fast track applications, 40% of all CHC applications. Of the 83,000 applications, 79,000 people received funded packages of care.³

² Department of Health, National framework for NHS continuing healthcare and NHS funded nursing care, available at gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

³ This is due to the NAO calculation being based on the number of CHC applications rather than the number of packages of care actually in place, as only 62% of standard CHC applications receive approval.

How CHC works



Why Fast Track matters

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 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 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 it is something that our research shows is happening far too often.

Marie Curie Freedom of Information (Fol) requests

We wanted to assess how well Fast Track CHC is being delivered in England.

We approached NHS Trusts and Clinical Commissioning Groups (CCGs) across the country with Freedom of Information (Fol) requests. We asked them a series of questions relating to Fast Track CHC, listed in Table 1.

Our aim was to secure an overview of how well Fast Track CHC is being delivered against very clear national guidance. The timeframes within which Fast Track CHC packages of care are put in place are fundamental to how well the system is working and how well the NHS is performing at a local level.

After analysing the responses to our first round of Fol requests, Marie Curie sent a further set of Fol questions to NHS trusts and CCGs. These second Fol requests asked questions focussing on specific areas of the national CHC framework – whether auditing of Fast Track CHC was being done; whether there were dedicated Fast Track CHC staff; and what training and support was in place to support clinical staff in their roles in assessing and deciding on Fast Track CHC packages of care.

Table 1: FoI questions put to NHS Trusts and Clinical Commissioning Groups in England (First round)

Clinical Commissioning Groups	
1	How many people in all the hospitals within your CCG have died in hospital awaiting the start of a package of Fast Track Continuing Healthcare?
2	What is the average time period in your Trust in hours/days from the point at which a Fast Track CHC application is made to the care package being provided for the 12 month period to the end of September 2016?
3	What is the average time period in hours/days from the point at which a Fast Track CHC application is approved to the care package being provided for the 12 month period to the end of September 2016?

NHS Trusts	
1	How many people in all the hospitals within your Trust have died in hospital awaiting the start of a package of local authority social care broken down: <ul style="list-style-type: none"> a As a single overall figure for the 12 months up to the end of September 2016 b By month for the 12 months up to the end of September 2016?
2	How many people in all the hospitals within your Trust have died in hospital awaiting the start of a package of Continuing Healthcare broken down by: <ul style="list-style-type: none"> a Those that have been identified as meeting the Fast Track criteria b Those that have not been identified as meeting the Fast Track criteria?
3	What is the average time period in your Trust in hours/days from the point at which a Fast Track CHC application is made to the care package being provided for the 12 month period to the end of September 2016?
4	What is the average time period in hours/days from the point at which a Fast Track CHC application is approved to the care package being provided for the 12 month period to the end of September 2016?

Table 2: **FoI questions put to NHS Trusts and Clinical Commissioning Groups in England (Second round)**

Clinical Commissioning Groups	
1	Does your CCG have a system in place for auditing the use of the Fast Track Pathway tool for Continuing Healthcare?
2	How many packages of Continuing Healthcare did you approve in the financial year 2016/17 (including Fast Track packages)?
3	How many Fast Track Pathway packages of Continuing Healthcare did you fund in the financial year 2016/17?
4	How many people are there in your Continuing Healthcare team?
5	How many people are there in your Continuing Healthcare team dedicated to processing Fast Track Pathway packages of care?

NHS Trusts	
1	How do you ensure that the doctors and nurses you employ are aware of the Fast Track Pathway Continuing Healthcare eligibility criteria and of how to process an application?
2	How do you ensure that you comply with paragraph 107 of the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (see below)? <ul style="list-style-type: none"> a 107. NHS continuing healthcare assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner, as part of the individual's overall end of life care pathway, and should reflect the approaches set out in the national End of Life Care Strategy, with full account being taken of patient preferences, including those set out in advance care plans.

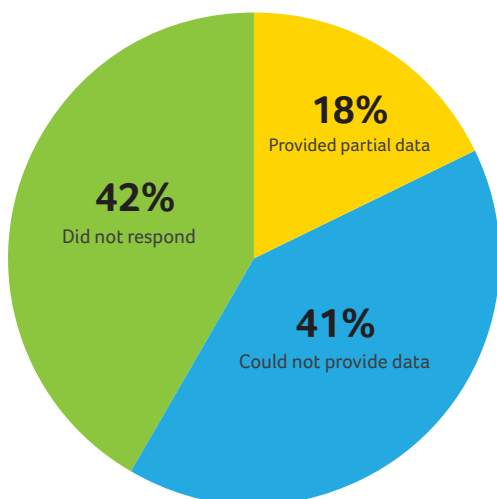
Responses from the first round

In the first round of FoI requests Marie Curie received responses from 90 NHS Trusts (out of 154 requests) and 152 of the 209 CCGs. Most responding organisations were unable to answer all the questions. In the case of NHS Trusts, none were able to provide all the information requested. CCGs' responses were slightly better, though two thirds still could not provide data for all three questions they were asked.

NHS Trust responses

Of the 154 NHS Trusts contacted by Marie Curie, 90 (58%) responded. Partial data was provided by 27 (18%), and 63 (41%) did not provide any data at all. None were able to respond fully to the request (see Figure 1). Due to the

Figure 1: NHS Trust responses to Fast Track CHC data enquiry (n=154)



Due to rounding, totals may exceed 100%

amount of data we received, the sample is too small to present any meaningful analysis.

However, on the basis of the data we did receive from Trusts it is clear that there is poor performance against the guidance they should all be following.

Of the 13 Trusts which gave data for the average time taken to implement a Fast Track package from application, only two were performing within the 48-hour target from when an application is submitted. Without more data, it is impossible to assert just how good, or poor, performance is across England. We are also concerned that the low response rate suggests that the data is not being collected by Trusts and that therefore it is impossible to monitor performance.

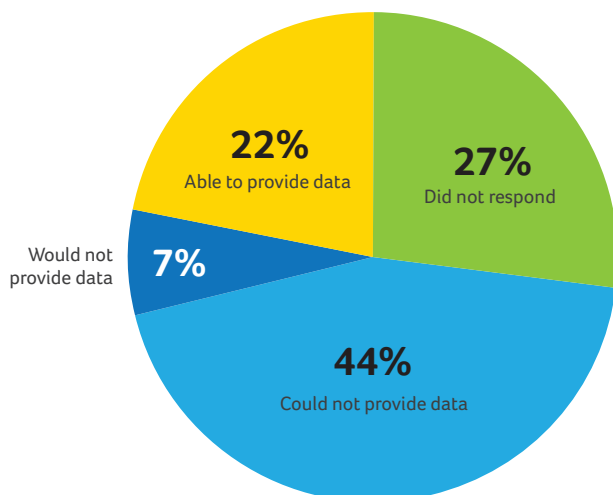
CCG responses

Of the 209 CCGs contacted, just 46 (22%) had data in response to all the first set of FoI questions. Partial answers were received from 57 (27%), 49 (23%) responded to say that they could not provide any data, and 57 (27%) did not respond at all. A closer examination of CCGs that could not provide data shows that while some *refused* to provide information (typically citing costs or in a small number of instances commercial sensitivity), in the vast majority of cases the CCGs were *unable* to provide any data (see Figure 2).

With almost two-thirds of CCGs that responded unable to provide this data, there is clearly a significant shortfall in data collection by CCGs. Many CCGs told us that the data might be available from individual hospitals or hospital trusts (mirroring responses we received from Trusts which said that responsibility for data collection lay with the CCG) or they said that information is not routinely gathered by providers on behalf of the CCG.

In some cases the responses indicated that the information may have been available, but only by manually reviewing individual patient records which would be prohibitively expensive. However, the fact that some CCGs were able to both provide answers to all questions and do so within the FoI cost threshold and time limits brings into sharp focus the performance of those that could not or would not provide the data.

Figure 2: CCG responses to Fast Track CHC data enquiry (n=209)



“... due to the way in which data is recorded and services [are] commissioned it is not possible to accurately correlate or reliably extract and report the time frame between a fast-track application being made and the date on which a care package actually commences.”

CCG in the North West

What the data shows

Where data was provided, we saw wide variations in the time taken by CCGs to get Fast Track CHC care packages in place. Of the CCGs that gave us data based on the time from when a Fast Track CHC application is made to the delivery of a package of care, just **28%** were achieving average times within the 48 hours from application recommended by the CHC framework. **Thirty-two per cent** had average wait times of more than a week, with some CCGs reporting average wait times exceeding two weeks.

If this is the picture across the whole of England then it means that 56,880 people were waiting longer than the 48 hours set out in the guidance and 25,280 of those were waiting more than a week.

Case study: Jennie Clark is a Marie Curie Expert Voices Group member who cared for her husband Ken at home with help from Marie Curie:

Ken was in hospital 72 hours before he died, but felt he had had enough. He just wanted to go home. He asked to see the palliative care doctor. When Ken was initially diagnosed, I said to him: 'I absolutely hope you will want to fight, but you don't fight for me. When you've had enough, tell me.'

He told me on the Saturday that he this was all he could take. He couldn't get out of bed and he just felt awful – he had had enough. The nurse was saying that the ward consultant wasn't in today, and she said Ken could not be discharged until the next day when the consultant returned. The palliative doctor then said: 'Make it today he gets

home'. The wonderful ward nurses made huge efforts to get the discharge papers signed off.

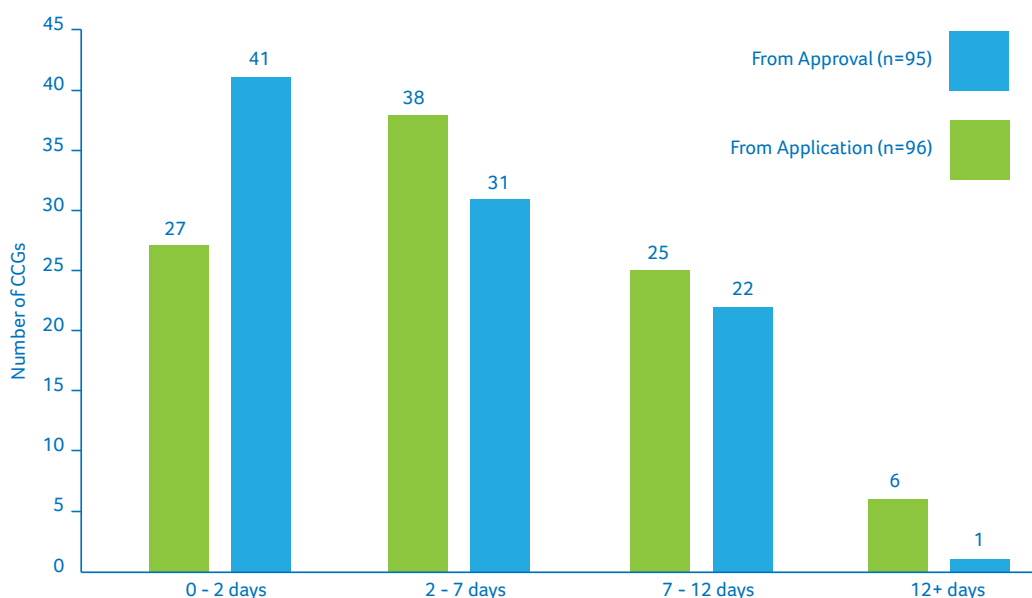
So he came home. It was a bit of a fiasco, to be honest. The nurse from the Chartwell unit sorted out the transport home and arranged a district nurse, which was fine. But then the ambulance didn't arrive and when it did, there was some issue with the paperwork. Once we finally got home, they said they wouldn't be able to lift Ken. Luckily my son and son-in-law were there to lift him. He was a big man so I just wouldn't have been able to do it without them. I don't know what somebody who didn't have someone to help them would have done.

The situation improves only slightly once CCG approval is granted. From then, **fewer than half** (43%) have a package in place within 48 hours while just under a quarter (24%) continue to see delays of **over a week** on average (see Figure 3).

Where CCGs offered an explanation for the waiting times people were experiencing, they identified a number of contributory factors:

- CHC being a Monday-Friday service creating delays over weekends.
- Delays in finding beds in suitable care homes for patient discharge.
- Delays while families visit different care homes to find acceptable accommodation.
- Delays due to market capacity and local provider issues.
- Patient deterioration delaying discharge before a package can be implemented.

Figure 3: **Average time taken to implement Fast Track CHC packages**



What does this mean for Fast Track CHC?

The responses reveal important issues with Fast Track CHC performance and reporting across England. The consequence of poor performance is that people with limited time to live remain in hospital rather than being able to die in their own homes (which most people wish to do). These issues fall into three categories:

1 A postcode lottery in care

The variations between CCGs in the average time taken to implement a Fast Track care package are unacceptable. The fact that some areas are performing within the recommended 48 hours while others are not demonstrates the inconsistency with which the system

is being implemented across England, and the need for a rigorous evaluation so that best practice can be identified and replicated in the poorer performing areas.

We need to know if the circumstances leading to lengthy waits for a Fast Track care package are as a result of issues in the healthcare system or other factors such as lack of capacity in the community or social care resources.

2 Inconsistent data-gathering

The proportion of CCGs unable to provide data on the time taken to implement Fast Track CHC packages or on the number of patients dying in hospital awaiting a care package is very concerning on two levels.

Firstly, it means many CCGs are not recording their performance and, therefore, cannot be aware of how their services are performing and secondly, it has serious implications for wider evaluations of Fast Track CHC now and into the future.

Inconsistency in whether and how CCGs are gathering this data means it is impossible to accurately assess the performance of Fast Track CHC against its very clear guidance and protocols. This leaves the NHS ill-equipped to identify where improvement is needed.

“... we do not record the reason the patient was not discharged before they died so cannot state definitively if it was the package of care that prevented discharge or other reasons...”

NHS Trust in the North West

3 A lack of ownership of data

In many cases it appears that none of the parties involved in CHC have taken ownership of the responsibility to collect and collate data. Marie Curie’s initial request for data went to NHS Trusts. A significant number responded by stating that collecting the data was the responsibility of their local CCG or even their local authorities. When we sent CCGs a similar request, many claimed the data was more likely to be held by individual hospitals or hospital trusts. It is clear that there is confusion over who is responsible for collecting

CHC performance data and that this is falling through the cracks.

Following up – how well is the nationally agreed Fast Track CHC guidance being followed?

Marie Curie’s second round of FoI requests to CCGs and acute trusts asked questions relating to specific areas of the framework guidance: Fast Track CHC auditing, staff training and the degree to which dedicated staff for Fast Track CHC applications are employed. The responses show some concerning trends, among both CCGs and Trusts.

The majority of CCGs are not auditing their use of Fast Track CHC

The national framework for CHC makes clear that CCGs have a responsibility to audit their use of the Fast Track CHC tool, stating that:

‘Each individual CCG should monitor and audit the use of the Fast Track Pathway Tool according to locally agreed processes.’

Despite this, of the 180 responses we received to our FoI request within the 20-day deadline, 36% were not conducting audits of Fast Track CHC. In many cases CCGs instead relied on initial screenings of application or three-month reassessments to assess their performance on Fast Track.

Even CCGs which were identified as performing particularly well in meeting Fast Track targets revealed that they were not auditing their use of the Fast Track tool. This means that the most effective CCGs are unable to identify or evidence why they are performing well, making it impossible or, at least, very difficult to identify and share best practice.

Hospital Trusts have different approaches to managing the Fast Track CHC assessment and decision processes

Our second round of Fols found very little consistency in how Trusts are supporting their staff in implementing Fast Track.

From the 87 responses we received from Trusts within the 20 working day FoI time limit for response, we identified three broad approaches to ensuring that clinical staff are supported or equipped to manage Fast Track CHC applications:

- 1 Training for most or all clinical staff. This approach was employed by 14% of respondents.
- 2 Employing specialist teams to handle all Fast Track applications – 35% followed this approach.
- 3 A mix of the two approaches above – 36% followed this approach.

A small but not insignificant proportion of Trusts (15%) stated that they provided no formal training nor had a dedicated team in place (See Figure 4).

Figure 4: NHS Trust responses to Fast Track CHC training enquiry (n=77)



What is working in CCGs?

Having identified seven CCGs which are performing particularly well in delivering Fast Track CHC packages within the time expected by the national guidance through the first set of Fol requests, we submitted follow-up Fols to them. These requests were designed to help understand whether well-performing CCGs were following some important elements of the nationally agreed guidance.

Analysis of the responses we received showed there was one common approach in many of the high-performing CCGs: the existence of a

single point of contact within the CCG to support hospital staff, facilitate making Fast Track applications and facilitate organising care packages. This individual could be a clinician or someone identified as a complex case manager. This suggests that a single point of contact that can answer queries or offer support with Fast Track applications and organising care package deployment has a real impact on the ability of a CCG area to perform within the national guidance timeframes.

There would be merit in looking more closely at the impact dedicated points of contact have on performance.

Table 3: **Fol questions put to high-performing CCGs**

<p>1 Do you audit the use of the Fast Track Pathway Tool for Continuing Healthcare? If yes, please provide us with (anonymised) copies of the last three audits you have undertaken.</p>
<p>2 Does your Continuing Healthcare team have dedicated staff for implementing Fast Track Pathway packages of care?</p>
<p>3 Does your CCG have a dedicated Fast Track Continuing Healthcare contact for hospital staff and clinicians? If yes, what support do they offer?</p>
<p>4 What steps has your CCG taken to ensure that Fast Track Pathway Continuing Healthcare packages are in place within 48 hours of an application being made?</p>

Conclusion

Delays in getting Fast Track packages of care in place leave vulnerable people who are close to death, and their families, uncertain of how and where they will be cared for in their last days. These delays undermine choice at the end of life and inevitably will lead to people dying in hospital when they want to be, and could be, somewhere else. They also cause unacceptable stress and uncertainty in an already traumatic and difficult period.

There are significant variations between CCGs in how quickly people get the packages of care they need through Fast Track CHC. It is also apparent that too many healthcare systems do not gather the data they need to enable them to know how well they are performing. This lack of data inevitably means that the information needed to take steps to improve performance is missing.

Given that Fast Track makes up at least 40% of applications, and on the basis of the information we received over 60% of funded care packages for CHC, the fact that people in so many areas are experiencing unacceptable delays should and must be a priority for government and the NHS both nationally and locally.

Some areas are performing within the recommended timeframe which

demonstrates that 48 hours is an achievable performance measure. We need to understand why some areas are coping better than others and identify ways of sharing the best practice that leads to good performance.

If Fast Track CHC is to function as it should, central government and NHS England must take action to ensure they have access to the tools needed to measure performance. With more than two thirds of respondents missing timescales explicitly laid out in the CHC framework, current performance levels are unacceptable.

As many as a third of patients are experiencing delays of over a week at the very end of their lives, having a significant impact on their care, with serious implications for the person dying and the legacy of their death for their loved ones.

Recommendations

1 **Ensure that CCGs and Trusts adhere to the national framework**

CCGs and hospital Trusts need to be held to the guidance laid out in the National Framework for Continuing Healthcare, both in terms of the 48-hour timeframe for Fast Track and in conducting audits of the use of the Fast Track CHC. The guidance is already in place to help CCGs and Trusts achieve

good performance in Fast Track CHC and they must follow it and be properly held to account when they fail to do so.

2 Significantly improve consistency and quality of data collection

Central government and NHS England should develop a set of standards for gathering Fast Track CHC data to ensure uniformity across the UK in the information being gathered. Without consistent information gathering, meaningful evaluations of performance are impossible.

With CCGs being required to make savings in their CHC budgets, it is essential that performance against the Fast Track protocols is properly monitored. Any increase in the length of time it takes for someone in their very last days of life to get the package of care they need is unacceptable. If this is further compromised as a result of the CHC savings targets it will further impact on those who have months, weeks and days to live. A person at the end of their life should not spend a day more in hospital than they need to when their choice is to be somewhere else. Performance in getting Fast Track packages of CHC care in place must be transparent.

3 Define responsibility for gathering information

The CHC framework must establish a single point of responsibility for collating Fast Track CHC data and evidence. Currently the lack of a defined responsible organisation means that this information is being gathered piecemeal by different parties – or not at all.

4 Find out what works in staff training and support

Government must examine how NHS Trusts are supporting their staff to understand and use the Fast Track CHC pathway to assess which method works best for the patient's experience and for ensuring that Fast Track packages of care are in place within the timeframe set out in the national guidance.

5 Identify and disseminate best practice

The variation we found in Fast Track CHC performance needs to be addressed urgently. In doing so processes must be put in place to identify how some are performing well. Once this best practice is identified, it must be disseminated so those who are not performing well can improve.

For further information contact

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