

Delayed Transfers of Care: What it's like for patients and families.

A snapshot of people's experiences of delayed transfers of care from hospitals in Cornwall, during July 2019.



About Us

Healthwatch Cornwall (HC) is an independent, publicly-funded organisation. We have statutory duties and a remit to ensure health and social care services in Cornwall are the best they can be for people, now and in the future.

By listening to your experiences of publicly funded health and social care services we are able to inform decisions made by the commissioners and providers of them. This means your voice is heard by those planning and delivering services and can influence positive outcomes.

Background

At the Transformation Board in January 2019, University Hospitals Plymouth highlighted work they were undertaking with Livewell Southwest and Healthwatch Plymouth: Patient Experience of the Discharge Pathway from hospital to home (known as Home First). As such, the Board requested HC undertake a similar piece of work to be presented in the May Board meeting. Due to both the escalation status at RCHT and workload and capacity challenges within our small team at HC, it was necessary to postpone this work until July 2019. Throughout July, system pressures continued with a Major Incident being declared at RCHT on the 9th of July.

During subsequent discussions about this work, the emphasis placed on the need to consider patient experience even at times of high pressure in the system was reiterated. While health and social care system often refers to the statistics related to delays in transfers of care, sometimes known as ‘bed blocking’, there is inevitably a risk of de-humanising the flow of people through the system, at what can be a highly worrying time for patients and those close to them. For this reason, the opportunity to hear more about how this feels for people, in particular during times of high demand, was most welcomed.

Staff’s thoughts are often reflective of patients and families: the system is working at full capacity, staff are incredibly busy, but despite pressures, they continue to go the extra mile for people. Patients are aware they need to leave the hospital and do feel the pressures of their bed being needed. Knowing what is happening and when for both patients and staff is a challenge, as we try to support people to access appropriate onward care in a timely way. Helping patients and families make informed choices during times of anxiety where people are often facing life-changing decisions can be challenging, but also rewarding.

Our intention in this report was to gather a snapshot of people’s experiences. However, we felt it important where possible, to seek the views of frontline staff relating to the discharge of patients from their hospitals.

How we conducted this Report

While the focus of this research is undoubtedly about what patients and those close to them told us, it would have been remiss not to include comments from staff. We were also aware of work being undertaken by Newton Europe, to build an evidence base from across the system for opportunities to improve outcomes for older people in Cornwall and the Isles of Scilly. As such, our intention was to compliment this work, by gathering the perspective of patients and families in this particular aspect of their journey, during their inpatient stay.

We worked with staff from both Royal Cornwall Hospitals Trust (RCHT) and Cornwall Partnership Foundation Trust (CPFT) to understand which patients were appropriate for us to engage with. We attended a patient flow (SAFER) meeting at RCH and spent time with the Onward Care team based at RCH. This included shadowing an onward care nurse employed by CPFT, talking with the onward care

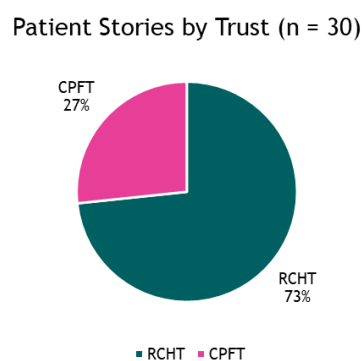
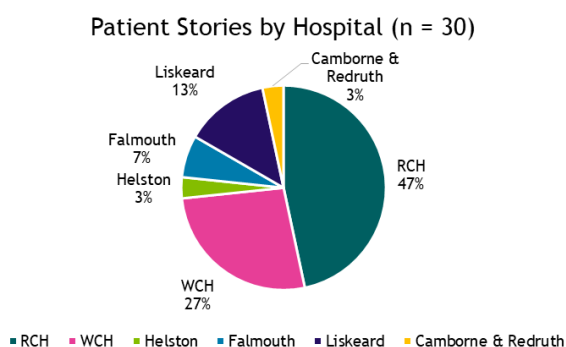
nurses from both trusts, along with social workers from Cornwall Council. This process was facilitated on the wards by talking with ward managers and staff from across six hospitals. With the emphasis being on people’s views, we did not benchmark people’s experiences against specific practice or processes, but we did review complaints data relating to discharges during the previous year at RCHT.

In respect of the patient journey, our focus was on a specific part of the discharge pathway through the system. All data included in this report relates to patients in situ in hospitals staff identified to us between the dates of the 4th and the 24th July, 2019, who were deemed as the following:

Medically fit for discharge, who were awaiting discharge from the hospital, where their transfer of care was delayed for any reason including awaiting: a package of care, community hospital bed, nursing or residential care, further assessment, accommodation, family choice, disputes etc.

We conducted our conversations while sitting at the patients’ bedside, as such, we followed a semi-structured framework for discussion - questions one to nine featured in this report. This allowed us to be flexible when considering patients’ well-being, and so as not to interfere with any care being delivered. For patients who were cognitively impaired, we spoke with relatives or those close to them, seeking their views about their involvement in the discharge process. We included the detailed accounts by numerous staff of three patients included in this data.

Nearly two thirds of this data (73%) relates to patients and those close to them, at Royal Cornwall Hospitals Trust. The remaining 27% relates to patients at a number of Cornwall Partnership Foundation Trust hospitals. While we visited both trusts, the number of patients we were able to engage with at the community hospitals during this limited timeframe was smaller for a number of reasons including: smaller number of beds and therefore patients, greater number of sites to visit with limited time/HC capacity, challenges with finding patients who were able to communicate with our staff, mainly due to cognitive impairment or the availability of friends and family.



People we engaged with	Numbers
Total number of patients directly spoken to, with or without family/people close to them	24
Total number of family members spoken to where the patient was not able to communicate effectively	3
Number of staff accounts included in the data	3
Number of staff spoken with from a variety of roles across all sites visited.	30
Total	60

With more time and capacity, HC would have liked to have spoken with a range of patients on different wards across all hospitals. This would have given us a better understanding of any site or

ward based differences and good practice. The views of patients and families post discharge in a variety of settings beyond the hospital could also be considered in the future.

Acknowledgements

Healthwatch Cornwall would like to thank all staff from RCHT, CPFT and Cornwall Council for their support in enabling us to speak with patients, their friends and families. Your welcoming, helpful approach and seeing the value in this work was much appreciated. We would in particular like to thank nursing staff in the onward care team at RCH for allowing us to spend time with you and shadow you in your work.

KEY FINDINGS:

“I have good and bad days. It feels like I’ve been in hospital a long time - too long. It feels a bit funny (she smiles). It sometimes feels a bit... (she makes a sad face). I have no idea when I’m leaving. The doctors haven’t spoken to me about leaving here yet. I’m worried about money. It’s not always possible to get what you want. I’m from a large family and wish I could be with them now. But I’m quite happy here on the ward. The food is good, and I’m well looked after.”

She drifts on to an account of an old family recipe for Cornish pasties...

We visit the patient again seven days later. It was like visiting a different patient. Last week she was engaging and although clearly had a level of cognitive impairment, she had a degree of understanding and seemed happy and talkative. Today she seemed upset and distressed and kept repeating that she wanted to go home.

Staff told us it was indeed very sad that she is still here and are doing all they can to get her discharged to a suitable home. Due to struggles with family preferences, they were considering the compulsory discharge letter and were in agreement that RCH wasn’t the best place for her to be.

- Staff are under immense pressure to ensure patients leave the hospital in an appropriate and timely way. There are clear pressures in respect of how much time staff are able to spend with patients and families and to engage with them about their discharge.
- Staff were proud of how they support patients in getting to where they want to be cared for next. They were committed to ensuring the best care and discharge experience for patients and those close to them. Nearly all patients, their friends and family praised the care and treatment they received during their stay, regardless of their experiences related to delayed discharge.
- While most people (86%) knew where they would be discharged to, nearly three out of four people (72%) did not feel they were communicated with regularly about their discharge. Nearly two thirds (62%) said they did not feel involved in discharge planning. Only a quarter of people (24%) felt involved. Two thirds (66%) did not know when they would be discharged. This contrasts

somewhat with staff's views of how they communicate with patients and involve people in their discharge.

- While hospital processes and practice should ensure discharge is discussed at the beginning of an inpatient stay, this is not translating into what patients told us. Only one in four people (28%) remembered or felt discharge planning started at the beginning of their stay in hospital.
- NICE guidelines recommend people are informed about their inpatient stay and discharge planning in a variety of formats. Our understanding is that hospitals provide a discharge planning leaflet to patients on entering the hospital. However, only 7% of patients recall receiving any written information related to this.
- Patient and family/friends' suggestions for improvements to their experiences of delayed discharge were primarily related to greater communication and involvement, choices and preferences, and to reducing the length of stay.
- There is a clear disconnect between people's choices and preferences in relation to discharge, and their involvement in the discharge process. There is therefore, a potential link between people's choices and preferences and how we are involving and informing them to effectively manage their expectations.
- Where transfers of care involved residential or care settings, patients and those close to them wanted to be as close to home as possible and frustrations occurred when this was not possible.
- Patients with complex care needs were experiencing greater challenges in leaving the hospital and accessing appropriate onward care. This sometimes impacted upon their physical and mental health, with staff raising concerns in some settings about the environment and a lack of stimulation for patients living with dementia.
- Staff reported patients approaching the end of life who required ongoing care through the NHS continuing healthcare (CHC) fast-track pathway, were also facing challenges in accessing services and leaving the hospital. There were issues identified in the processes and practice related to fast-track forms.
- There were clear challenges faced by homeless patients and those with housing issues resulting in delayed discharges.
- Some staff felt greater flexibility of current working patterns could lead to earlier discharges in cases where key meetings required family involvement, or staff such as occupational therapists were key in patient discharges.

Recommendations and considerations for the future

- **We must continue to hold the experience of patients and those close to them in the highest regard.** In doing so, we should ensure future service or system-wide reviews, projects and processes implemented to improve patient flow show due consideration of this.
- Public communication strategies should consider the need to change our language and approach to communication with the public in order that hospitals are seen as an 'emergency' or 'urgent' place of care only. It should be made clear if people do need to stay in hospital, **conversations about onward care should shift to an approach of managing people's expectations rather than choice.** The language of choice should be reserved in respect of people's permanent places of care.

- We need to improve how we communicate with patients and families from the outset and inform them regularly. We need to better involve them in decision making, checking their understanding and helping them to make informed decisions.
- **Communication from all staff needs to be consistent**, being clear from the outset that things can change, without blaming other roles or departments and ensuring people are kept updated if they do.
- **We need to consider different formats for keeping people informed** (posters, pre-admission information, TV, hospital WiFi), whether written or verbal, and to check patient's understanding so that expectations can be managed.
- **We need to explore and understand the family pressures and influences on decisions to leave the hospital setting** in order to appreciate how to manage this effectively in the future. With all aspects of communication, involving patients and families in designing solutions in a co-productive way should be considered.
- While good documentation provides evidence of who has seen the patient and what has been planned or discussed, this is not always translating into people feeling informed and involved. **Knowing what has been said to whom and checking people's understanding is key.** Seeing so many healthcare professionals can be confusing. People do not always understand job roles or titles in respect of their involvement in the discharge process.
- **Give patients permission to ask questions and be clear that staff do not see this as a burden.** Communicate this in a range of formats so that patients and those close to them know what to expect and who they can speak with, regardless of their role within the multi-disciplinary team.
- Consider flexible ways of working to enable essential meetings with family to take place and to ensure roles crucial to the discharge process are available.
- Given time pressures on staff, consider **a role for volunteers in spending time with patients and those close to them, in providing reliable information, supporting them with decisions about discharge and in managing expectations.**
- **Provide the public with easily accessible and reliable information to help them make informed choices.** This should include approved information about NHS Continuing Healthcare.
- There was a clear call to **address some ward environments and the lack of stimulation for patients living with dementia.**
- **There needs to be a deeper, system-wide understanding of the scale of issues relating to the discharge of patients approaching the end of life, and of those accessing onward care through the continuing healthcare fast-track pathway.**
- Evidence within this report has highlighted **concerns about the equitability of the brokerage system** in accessing care, whether due to cost, complexity of patient needs, or geography. This should be further explored.
- In reviewing discharge processes, teams and services across the health and social care sector, **we need to listen to staff about what's working well and what could be better.** A strengths-based approach could be a potential methodology to achieve this and in co-designing solutions.

- **There is an opportunity to understand how supported or trained staff feel in managing discharge.** This would include implementing the reluctant discharge/patient choice policy and in managing discharge during times of high pressure, including out of hours and at weekends.
- **Consideration could be given to what can be done in the care sector to support, train or educate staff** to ensure patient risk can be better managed.
- While we have not commented on the practice of specific wards, we did hear of good practice and ideas relating to discharge on some wards. Any future review could consider how these processes could be adopted, or indeed what has prevented this from happening on other wards thus far.

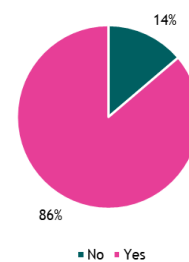
Detailed Analysis

Discharge:

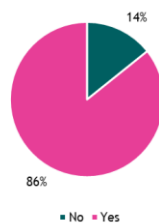
1. Do you know where you will be discharged to?

Most people (86%) knew where they were going to be discharged to next, regardless of where they were an inpatient. However, there were still a number of patients (14%) who did not know where their onward care destination would be.

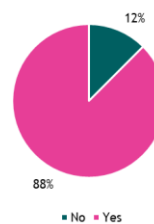
Do you know where you will be discharged to?



RCHT: Do you know where you will be discharged to? (n = 22)



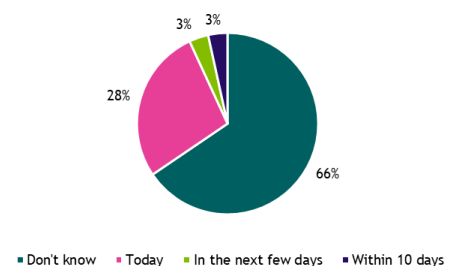
CPFT: Do you know where you will be discharged to? (n = 8)



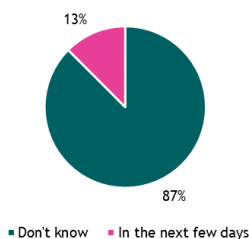
2. When? Do you know when you will be discharged?

Overall, two thirds of people (66%) were not aware as to when they would be discharged. This was similar for those in a community hospital, with nearly half (48%) of patients at RCHT being unaware of when they would be discharged.

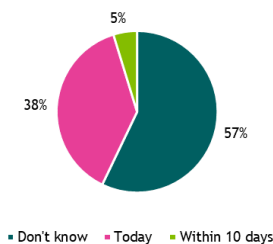
All: Do you know when you will be discharged?



CPFT: Do you know when you will be discharged?



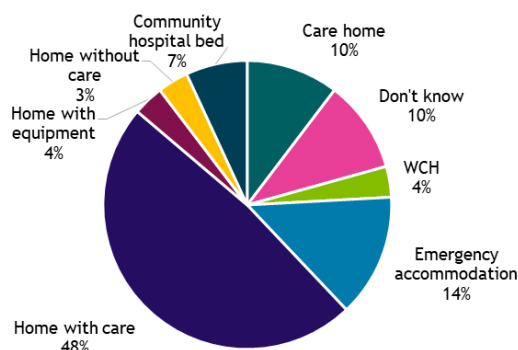
RCHT: Do you know when you will be discharged?



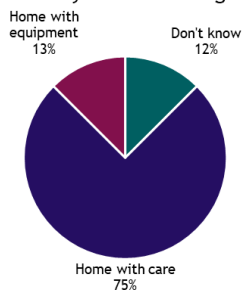
Where are you being discharged to?

Nine out of ten people able to speak with us were aware of where they were being discharged to, with 'home with (a package of) care' being the most common option across both settings. Only 10% of patients we spoke with at RCHT were awaiting a community hospital bed, which is lower than the NHSI acute setting data (appendix 1). However, we did speak with a higher proportion of people than the same data set who were accessing emergency accommodation (4).

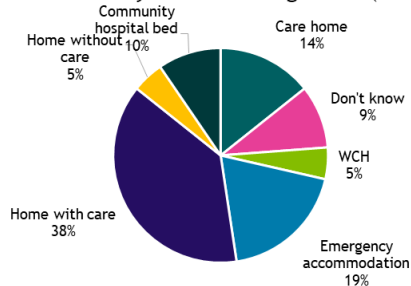
All: Where will you be discharged to? (n = 30)



CPFT: Where will you be discharged to? (n = 8)



RCHT: Where will you be discharged to? (n = 22)



"Emergency accommodation, but not sure where yet."

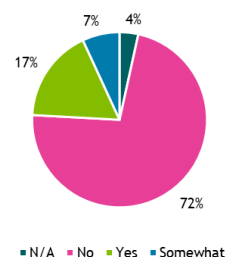
Communication:

3. Have you been communicated with regularly about this?

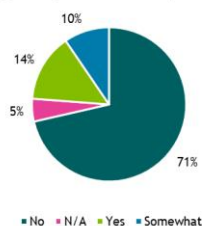
Nearly three in four people (72%) felt they were not being communicated with regularly about their discharge.

**N/A refers to the staff accounts in this data*

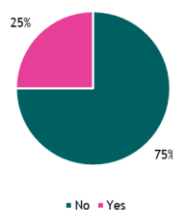
All: Have you been communicated with regularly about this? (n = 30)



RCHT: Have you been communicated with regularly about this? (n = 22)



CPFT: Have you been communicated with regularly about this? (n = 8)



“No-one has spoken to her about this”

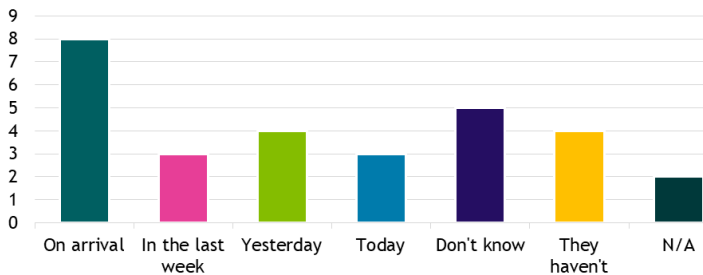
“Very regularly and very well, we haven't wanted for anything.”

These comments and responses are not reflective of what staff told us as to how regularly they felt they were informing people. It is acknowledged, it can be confusing for patients and families during times of high anxiety and concern to recall all aspects of conversation in relation to discharge. Patients are interacting with many different members of staff on a daily basis, sometimes without real clarity as to who is responsible for informing them or making decisions about their discharge.

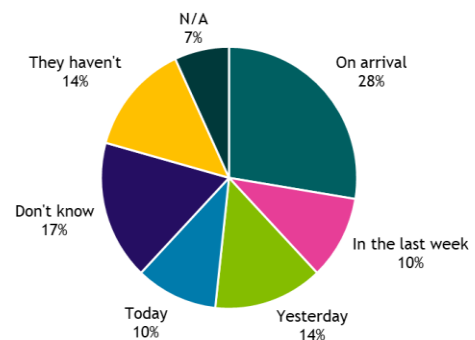
4. When did staff first start talking to you about when you might be discharged?

Despite the guidance that planning for discharge should take place on arrival, this data signals that patients (deemed as medically fit for discharge, experiencing a delayed transfer of care) felt planning was not discussed on arrival. On average, just over a quarter (28%) remembered or felt discharge planning started at the outset of their stay, with 17% saying discharge had either not been discussed or they didn't know when it was discussed (14%). One in ten felt discharge plans had been discussed in the last week, 14% yesterday and 10% on the day we spoke to them.

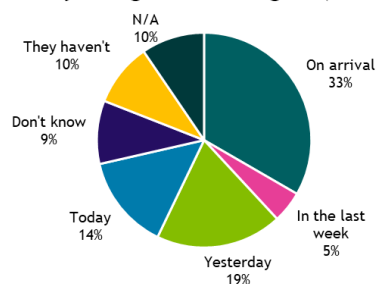
All: When did staff first talk to you about when you might be discharged? (n = 30)



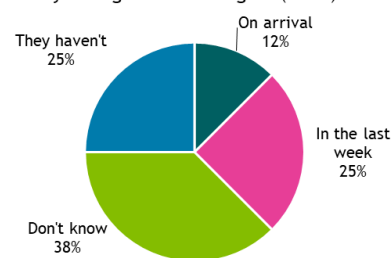
All: When did staff first talk to you about when you might be discharged? (n = 30)



RCHT: When did staff first talk to you about when you might be discharged? (n = 22)



CPFT: When did staff first talk to you about when you might be discharged? (n = 8)



*N/A refers to the staff accounts in this data

We are mindful that staff's perception of this information may be somewhat contradictory. Views we gathered from staff would indicate a much greater confidence in when discharge planning began, feeling this would have happened at the outset of an inpatient stay.

“They first mentioned it within one or two days of admission and said [relative] should be out in a few days, but then we think they saw she was worse than expected and decided to keep her in longer.”

“No, only talked about it yesterday. [relative] felt it was all a bit of a rush. Was given a lot of information for going home e.g. emergency numbers and others.”

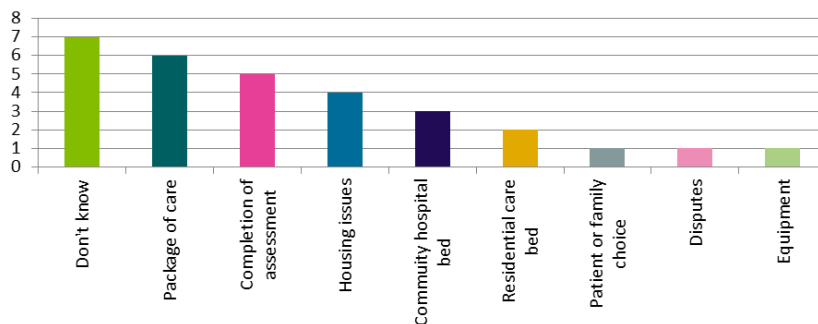
“On the final day I was communicated with very well. Until then felt they had been dropped off the edge of a cliff, especially when moved to [another] ward. Staff in the Medical Admissions Unit were informative and caring.”

Cause of delayed transfers of care:

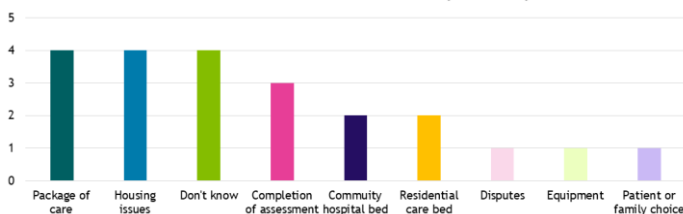
5. What has been your cause of delay?

When asked about the cause of delay, the most common response was ‘I/we don’t know’. The two subsequent most common reasons were that people were awaiting a package of care, or for further assessments to be completed. This signals room for improvement in terms of helping people to understand the cause of their delay, in respect of involving them more. While only one cause was deemed to be due to a ‘family choice’, we were in fact aware of several more examples of where family choice had been an influential factor in the delay.

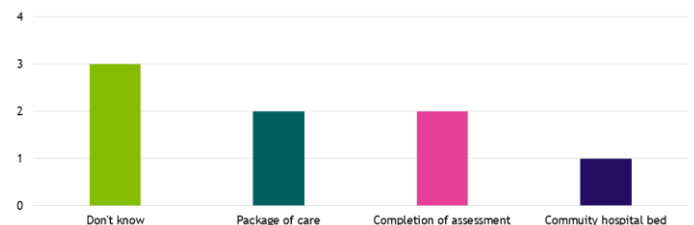
What has been the cause of your delay? Awaiting...



RCHT: What has been the cause of your delay?



CPFT: What has been the cause of your delay?



RCHT:

The three most common patient/family reported causes of delay in the acute setting were awaiting a package of care’, ‘housing issues’ and ‘don’t know’. NHSI data (appendix 2) show the number one cause of delay is ‘Awaiting further, non-acute NHS care (including intermediate care, rehabilitation services etc)’ which is not a direct comparison.

Community Hospital:

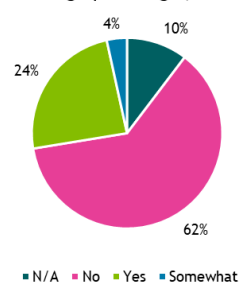
NHSI data (appendix 1) showed the two most common causes of delay in the acute setting were ‘awaiting a package of care’ and ‘awaiting an assessment’ which is more in line with the reasons provided above.

Involvement of patient and those close to them in discharge planning:

6. Have staff involved you or those close to you in discharge planning?

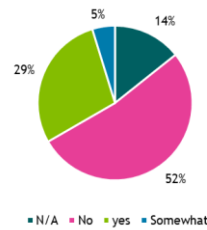
Just under two thirds (62%) of patients and those close to them, told us they did not feel involved in planning their

All: Have staff involved you or your family in the discharge planning? (n = 30)

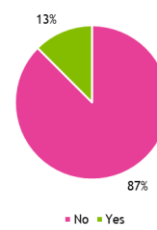


discharge, with nearly one in four (24%) feeling involved. This would appear much lower than anticipated. More patients at RCHT than CPFT felt involved in planning their discharge.

RCHT: Have staff involved you or your family in the discharge planning? (n = 22)



CPFT: Have staff involved you or your family in the discharge planning? (n = 8)



“Wasn’t told where I was going to be discharged to - very frustrating, as I told staff that in order to make the flight back to the Scillies I would need collecting from RCH by 3PM.”

(This conversation took place at 4pm. An ambulance came to take the patient to West Cornwall hospital for the night - the patient felt this could have been avoided if transport had been organised)

“Very regularly and very well, relatives haven’t wanted for anything.”

“Staff are fantastic, but I don’t feel well-informed.”

“No, staff are wonderful, but no one has been to speak to me about it.”

A patient who was deemed medically fit for discharge had been in the hospital for approximately three weeks. The family were very distressed, anxious and concerned about the adequacy of their current care package. They told us:

“Staff are excellent in the hospital and the ward. Medically fit, is she? We haven’t spoken to anyone properly yet and don’t know when they will be discharged or how far along the process we are. We would have liked to have discussed this with someone. We’ve been in daily and no-one has spoken with us since the meeting was cancelled last week”.

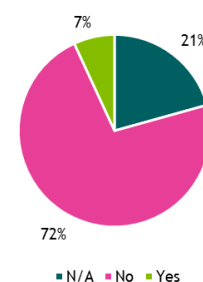
Information:

7. Have you received any written information about your discharge?

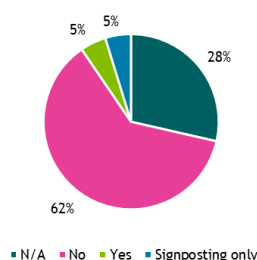
The majority of patients told us they had not received any written information about their discharge, with only a small number of patients (7%) recalling having received any written information. Our understanding is that hospitals provide a discharge planning information leaflet upon admission. NICE guidelines state that information should be provided to patients and carers regularly and a variety of formats should be considered.¹

*N/A refers to the staff accounts in this data

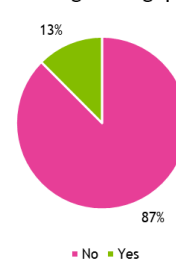
All: Have you had any written information about your discharge? (n = 30)



RCHT: Have you had any written information about your discharge or signposting? (n = 22)



CPFT: Have you had any written information about your discharge or signposting? (n = 8)



¹ <https://www.nice.org.uk/guidance/ng27/chapter/Recommendations#overarching-principles-of-care-and-support-during-transition>

“No written information or leaflet and I’m not sure what’s happening”

- With many patients being elderly and often with a level of cognitive impairment, verbal conversations about discharge and planning had the potential to be confusing. For relatives, it was important to be able to speak to the right person and to be present when such conversations occurred, which staff often tried hard to accommodate. Our observation is that it can be difficult to remember everything you are told verbally with nothing actually being written down, especially as plans for onward care often change throughout the stay. For example, one patient was told they could go into residential care, then offered a community hospital but refused due to distance. They were then told their refusal had meant a residential home was now not possible and offered a number of different community beds. It can be hard to make decisions during such a stressful time with very little or no information to consider.

People’s views and experiences:

8. Your/family experience: How has this been for you?

Nearly all patients and family we spoke with commented positively about the care they had received as an inpatient. Many recognised how busy staff were, and were aware of the pressures to get people discharged, making comments such as:

“Can’t fault the care but I’m aware they need my bed.”

What patients and those close to them told us could be better about the discharge process:

9. Is there anything you think that could have been done differently, to make your discharge from here better?

Comments provided generally reflected the need for more communication with patients and families about what’s happening, discharge processes and causes for delay. People wanted to find a suitable onward care placement earlier.

“I think he should have been discharged already.”

“Could communicate more often - very nice staff and they do give answers when then can, but you have to ask.”

“The nurses have done their best in the time they have but could have more time to communicate with people - I would like this”

There were also concerns about the lack of stimulation for some patients and environments not being conducive to recovery based on noise, confused patients wandering and presenting with challenging behaviour.

Patient and staff feedback: themed qualitative analysis

Given nearly two thirds (62%) of people did not feel involved in planning their discharge, and with 72% feeling they were not communicated with regularly, it is worth considering this disconnect in respect of how ‘the system’ or staff’s views differed from this:

Clear, timely communication and consistency of message:

- It is clear that there were differences between what staff felt they had told patients about their discharge, compared with what patients and family knew. It must also be recognised that this can be a distressing and confusing time for patients and loved ones. One nurse described how a flash

point can be checking people's understanding without patronising. Often partners may also have cognitive impairment or have their own care needs with people being reliant on others to support them.

- Clear, timely and consistency of message is key. Sometime patients see so many different healthcare professionals it can be confusing. They can receive contradictory information from different members of staff including different roles (nurses, social worker, onward care nurse, doctor/consultant) in relation to both personal preferences or choice of onward care placement, as well as the discharge date, destination and next steps. Staff told us this really does not make it easy for those closely involved with patient care. For example, a consultant might tell a patient they are going to a hospital bed in Newquay (assumption based on where the patient lives) and it can be upsetting for the patient and those close to them if an alternative community bed is the only option available to enable a swift discharge.
- Staff were very proud of how they support patients and families in getting to where they want to be cared for next - particularly those with very complex needs. However, some suggested that staff need to be better at communicating the date and time to patients earlier on and that it be made clearer by all from the outset, that patients may not get their preferred place of care. This highlights a case for better supporting people by effectively managing their expectations.
- Patients and those close to them often recognised that staff were very busy, with many commenting that they do not like to bother staff about their discharge arrangements. Furthermore, people's perception of who was responsible for their discharge varied. Perhaps encouraging patients to ask questions, and being clearer about who can make decisions about their discharge should be made more explicit.

Staff: "Even if patients say staff are open and caring, they still don't feel they can ask."

Patient: "I am awaiting physio, I was going to a community hospital. I don't feel I can ask staff about discharge, but would like staff to talk to me about it."

(do you know when you will be discharged?) "No, I haven't seen the doctor yet."

Thought: Managing people's expectations

One patient in a community hospital told us a social worker had recently visited their home and they were waiting for a social worker to call. They had been recently transferred from RCHT as the hospital was "full" and were happier being closer to home and to relatives. They were clear they were waiting for a package of care. They had spoken with the doctor that morning who was "keeping me walking". Several friends and family were sat at the patient's bedside, confirming they had not been told how long it would be before they could be discharged: "No information or leaflet and I'm not sure what's happening." Both the patient and relatives commented in relation to when discharge would occur, stating: "the doctor hasn't told me/us yet". Despite regular nursing care and interactions from a variety of staff, the patient and family still did not feel clear about what was happening and were of the belief that it would be the doctor's role to inform them when discharge would take place.

Choice, influence of friends and family, and location of onward care:

- Location and rurality influenced people's ability to access a package of care in particular. For those wishing to access onward care at a community hospital, we were made aware of pressures on beds, and in accessing a bed from Bodmin community hospital westwards. This resulted in patients being placed away from home against their preferences.
- Patients and those close to them wanted to have a say in their onward care choices and to have their preferences prioritised where possible. Being placed close to home/near loved ones was a primary concern for people and a factor influencing their preferred place of onward care. People's

ability to travel or visit the patient was a factor, which it must be acknowledged, can be challenging due to transport issues in a rural county. The onward care team at RCHT made us aware of some placements taking place in exceptional circumstances where funding for transport to visit a family member had permitted a successful discharge.

- Influence of friends and family on choices relating to onward care was evident. Through conversations with staff, patients and those close to them, it was clear this was one of multifactorial reasons contributing to delayed discharge. According to the ‘Summary of Diagnostic Findings’² presentation of the Embrace Care Project diagnostic phase work by Newton Europe, July 2019, family choice and preferences was a key influencing factor on discharge, with family choice being a significant driver for 18% of non-ideal outcomes at every stage of the pathway. This raises questions about how we need to inform and involve patients and those close to them in the choices they face when supporting loved ones to leave the hospital. We need to explore these influences in order to better understand how to manage this to ensure non-ideal outcomes are avoided. This will include aspects of how we manage people’s expectations in moving through the health and social care system.

Thought:

We witnessed a conversation with a patient, family member and staff from the onward care team who were approaching a discussion about a patient’s discharge. We were aware the patient’s preferences for discharge to a hospital close to home could present a challenge. The family had been well informed previously. They promptly took it upon themselves to explain to their relative why it would be best for them to leave the acute hospital and access rehabilitation at a community hospital which was not the one closest to their home. The family quoted written information they had reviewed and a conversation that had taken place. This helped them to explain why this discharge pathway would be the most appropriate, based on the skills of staff at that location. They had pre-empted concerns about wanting to be discharged to a hospital closer to the patient’s husband and re-assured their relative they had already spoken with the husband, who was happy to travel, given the circumstances.

- While good practice clearly exists, expectations could be better managed by ensuring we:
 - help patients and families to make informed choices
 - involve them early
 - are clear that a hospital setting is for (more) urgent care
 - are clear that choice and preferences are more appropriate to long-term care settings

The roll out of one such approach is commencing in Cornwall, through NHS England and NHS Improvement. While trying to make discharge processes more transparent for patients, families and staff, Diana Porter (NHSE/NHSI) developed an easily understood strapline:

“You do not have to move anywhere permanently that you do not wish, but, you may not wait here while waiting for your service of choice”.

(can be used in any health setting)

- Whether through conversations with staff or with patients and those close to them, we were aware that the ability to meet people’s needs or preferences for onward care was not always possible for a number of reasons. These included:
 - Difficulty in accessing the onward care of their choice whether a care/nursing home or community hospital bed

² Newton Europe Embrace Care Presentation, Thursday 6 Aug, 2019

- Some people had turned down a specific community hospital or care home and were delayed due to waiting for a preferred choice (most often closer to home), or were concerned about its suitability
- It was particularly challenging for more complex patients to access care and onward care of their choice

“No option of where to be transferred (Bodmin would have been more appropriate as home is nearby). I’m frustrated with being told one thing yet another being done... No discharge discussed from Liskeard to home but there has been talk of rehab/physio at Bodmin hospital.”

“Our [relative] is very confused ... the nursing home said they would accept them but we [family] were not impressed.”

Staff commenting on a patient who, along with their family, were keen to be discharged:

“The patient is awaiting a package of care and it could be some time. Yesterday the social worker offered them a step-down bed. The family is supportive but the patient declined. The patient has been medically fit for some time.”

- A relative praised the onward care team who they were seeing regularly, who they felt were working hard. However, they felt the hospital does not listen. They were clear that the ward environment and hospital bed was not the best place for their loved one but despite this had refused a number of residential settings due to their not being close to home. The family member was informed their relative could go to an interim placement to conduct a CHC assessment, but for a variety of reasons they awaited a permanent setting closer to home.

“I want a placement close to home but they keep bringing unsuitable placements far away.”

- Both staff and those close to patients made comments related to length of stay having an impact on loss of mobility and independence, increased risk of fall-related injuries, as well as a decline in mood. Deconditioning is a well-recognised concern for lengthy inpatient stays. Delays to discharge caused patients to deteriorate while waiting, who then become medically unfit again. This was clearly evidenced in some patients’ journeys contained in this report. HC witnessed this when visiting one patient, on three separate occasions, for whom family choice was a factor in their discharge.

Complex care needs means accessing appropriate onward care is challenging with concerns about activities and stimulation:

- Challenges in accessing the right care setting or package of care for residents with complex needs or dementia was difficult and causing extended lengths of stay and delayed discharges. These patients could be subject to numerous changes of care settings, and experience incidents which resulted in them quickly being brought back to the acute/community hospital. Examples included patients experiencing falls, or demonstrating challenging behaviour. We were told patients were then prevented from returning to their care setting, with those waiting to access to new placements experiencing delays. In some examples, the offer of a placement was agreed and then subsequently withdrawn. Increased staffing needs or concerns about managing the patients’ safety or risk, were some examples given as to why this was occurring. One relative told us there was a paucity of care homes who would accept their relative which meant their choice of location was greatly reduced. This resulted in patients waiting longer in the hospital setting, an environment that not necessarily suitable for their loved ones needs, despite care being praised.

“I am frustrated my [relative] isn’t discharged yet and how slow the process is... other patients can be loud and violent and this makes my [relative] frightened and emotional.”

- Some staff at RCHT raised concerns about the experiences of complex dementia patients on wards that were not specifically deemed dementia friendly. They felt there was little space for activities

and ward environments were not conducive to positive patient experiences due to lighting, noise, a lack of stimulation or normal daily routines, for example.

- Staff told us they felt many patients would benefit from more interaction and time spent with volunteers. Other focussed on admission avoidance, feeling patients should not have been admitted in the first place.
- One patient required one to one care due to being at high risk of falls with behaviour that challenged, that could be difficult to manage. A nursing home visited and had provided a considerably high quote which would not be covered by CHC funding. An alternative home was discussed with family who had concerns about how the home would meet the patient's needs. Staff were in the process of considering using the Reluctant Discharge policy, sometimes known in trusts as a Choice Policy. As a further point for future consideration, this policy had been mentioned several times by staff. However, we did not specifically illicit how staff felt about the policy or what training or support they received in implementing it.

One relative described accessing the right onward care as:

"It's like 'blowing' into a thunderstorm" [actual word replaced]

Example:

Patient A was extremely cognitively impaired and staff told us they had been medically fit for two and a half months. They had a care home in place but contracted an infection which was dealt with swiftly, but because they were readmitted, they then had to go through the discharge process again and lost their placement. The patient had a CHC assessment and qualifies for help, but requires one to one care, "...so most care homes are not willing to take them." The patient was recently been offered a care home but based on a regulatory inspection (Care Quality Commission) the family had declined it.

- There was a call for more education in the care sector relating to managing patient risk, with particular reference to complex care needs and managing challenging behaviour. There was a clear need for more placements to be made available, especially for patients living with complex dementia.
- The brokerage system for purchasing care makes accessing onward care more challenging for patients with complex care needs, or in rural and certain locations. Solutions to make this more equitable could be explored. The costs of providing care for patients living with complex dementia meant that quotes returning from the brokerage system often come in above the threshold. As such, staff confirmed it was acutely more difficult to access onward care for these patients. Whether for nursing or residential care, or in accessing a package of care, patients requiring complex care were more commonly experiencing delayed discharge.

Staff: "The patient was admitted inappropriately as they didn't have any medical needs, it was due to behavioural issues at the home. He is mobile, is always wandering and gets bored easily. There is not enough entertainment or stimulation on the ward. We are not sure why discharge is taking so long. It may be because they are looking for long term care for him and so cost is a barrier. Who will accept him? There is little choice for a placement".

HC: We observed this patient for some time. He wandered endlessly throughout the ward with staff continuously having to watch and supervise the gentleman.

"[relative] I think the cost of services is the main reason a suitable placement hasn't yet been found."

Patients approaching the end of life

- Patients approaching the end of life also experienced increasing challenges in leaving hospital. Staff told us, for those eligible for funded care through the NHS CHC fast-track system, even if the fast-track form had been accepted it did not necessarily lead to patients accessing a package of care more quickly. The same challenges with accessing care existed for the dying patient, with reports that access could not always be prioritised. It is widely acknowledged that improvements need to be made to ensure dying patients are identified earlier, which could further support a prompt discharge where appropriate. However, while we did not speak to any patients at the end of their life, staff confirmed their concerns about this increasing trend at RCHT in particular (no specific comments from CFT included). This was corroborated through the following: HC's work with the Cornwall and Isles of Scilly End of Life Strategy Board, our research into public experiences at end of life in April 2018 'My Life My Death'³, our role within the Sweeney county-wide end of life quality improvement project currently, and via the July 2019 RCHT EOL Care Group. RCHT reported there were 50 patients who had applications initially declined during April to June this year. Of these, 36 patients were known to have died. They reported three incidents logged by staff in the last three months for whom they believe fast track deferrals impacted on the ability of a patient in their care to achieve their preferred place of death. Furthermore, we were informed there have been complaints from relatives that family members have been unable to return home for end of life care. The impact on staff was also clear. The following comments from a member of staff was shared with us:

“I really feel personally that too many fast tracks are being deferred....Fast Tracks are written by professional nurses in good faith and we enter as much information as humanly possible, yet still our work on behalf of our patients are being ignored seemingly.”

Several other examples staff shared during this research included:

“Patient is very confused and has cancer. Has had several fast tracks - six of them rejected or deferred.”

“A patient last week wanted to go home to die but it was virtually impossible to due to living in [rural location]. This was not their preferred place of dying.”

“We have had some very complex cases. They [care funded through CHC] do try and make them a priority, but discharge can be easier if there is family support.”

Another example included an elderly patient with dementia and a metastatic lung tumour. This patient had four forms rejected in total and died 11 weeks from the initial deferral, having spent many weeks in hospital.

Homeless patients and those facing housing issues:

- There were clear challenges faced by homeless patients and those with housing issues, resulting in delayed discharges. A consultant raised their concerns regarding the discharge of homeless people. There were particular concerns about high likelihood of being readmitted when a good level of personal care or attending aftercare appointments cannot be sustained due to their living circumstances. With no known fixed address or contact details it can be challenging to follow-up with these patients unless they are readmitted, and it becomes a difficult cycle to break.
- One homeless person we spoke with experiencing delays who told us about the very distressing experience of trying to access the benefit system: Universal Credit, which they were repeatedly told was an online service despite the person having no means of accessing this, nor a mobile phone number (a supposed requirement). They were clearly distressed and reluctant to leave the safety of the ward to go to unknown accommodation without any means of supporting themselves financially.

³ <https://www.healthwatchcornwall.co.uk/report/2018-05-13/end-life-care-report>

Public Information

- Staff in particular expressed concerns whereby those close to patients glean information online and believe that a diagnosis of dementia can mean their loved one is entitled to NHS CHC funded care. They said patients made comments such as “How bad do they need to be?”, reiterating how ineligibility for CHC funding can leave families feeling shocked and distressed, with the potential for further delays. Two social work staff mentioned the confusion often caused in respect of this and of the guidelines for where CHC assessments can or should take place. Perhaps having more information at hand or anticipating these challenges with reliable/NHS approved information would help people to make more informed choices and support staff with their discussions.

Review of complaints (RCHT only)

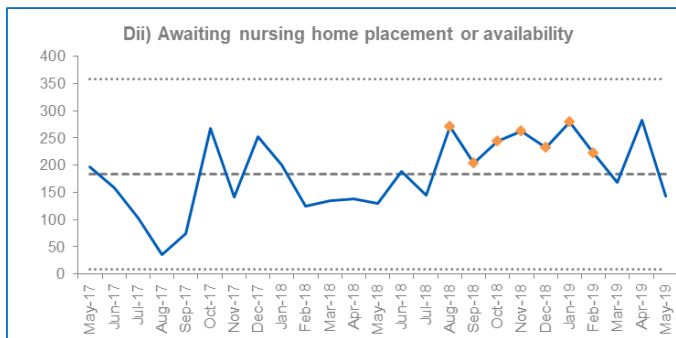
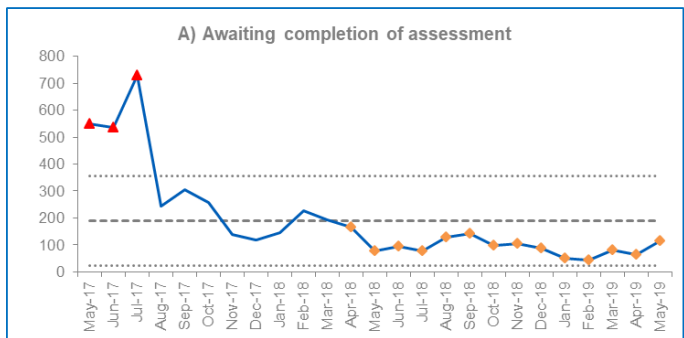
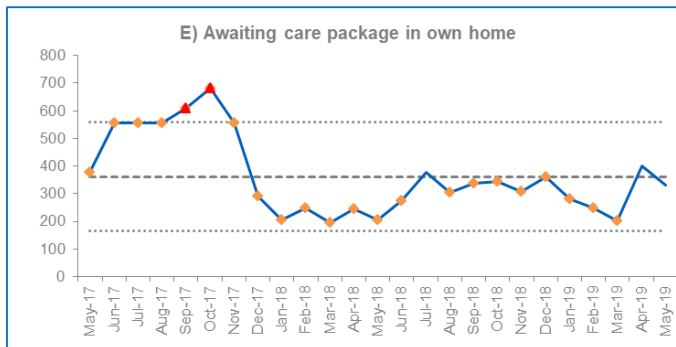
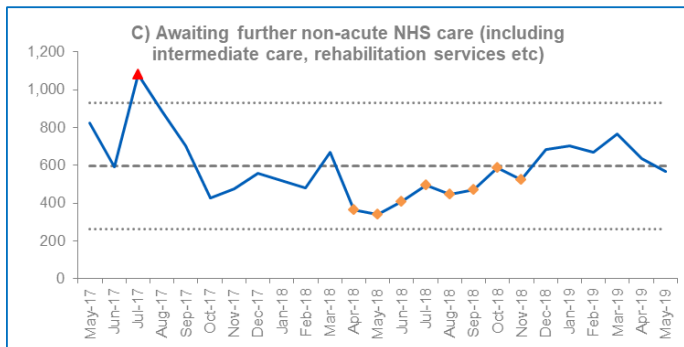
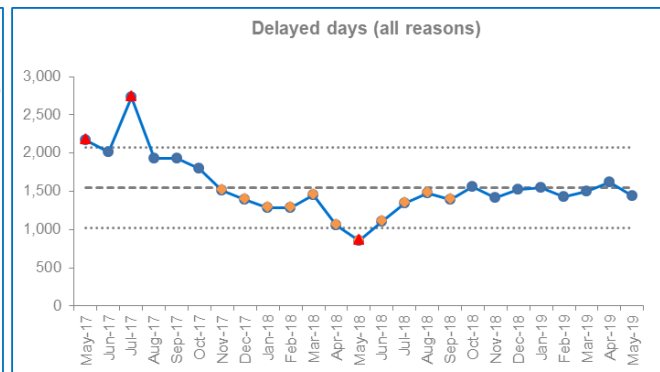
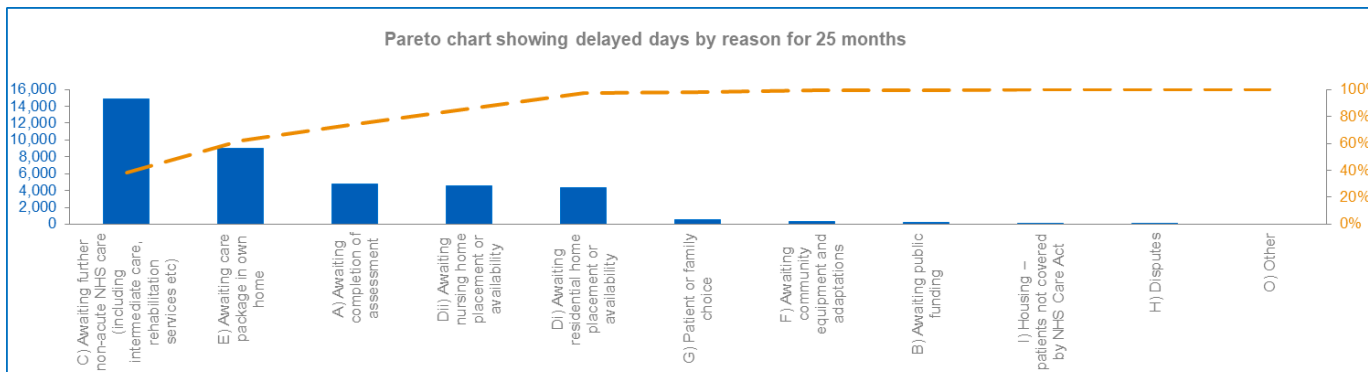
- In liaising with patient experience teams in our research for this report, we conducted a review of 56 informal and formal complaints related to discharges between 01/06/18 - 03/05/19 at RCHT. The two most common themes running throughout cases were communication and involvement of the patient and those close to them in the discharge process (39%); along with issues related to patient/family choice (32%); followed by (<18%): discharge planning, inappropriate discharges, lack of care plans, medication issues etc. (NB at the time of writing the report, we were awaiting similar complaints data from CPFT).

Other feedback raised by staff:

- Staff were clearly experiencing pressures, particularly during times of high demand, during out of hours and at weekends. We were told this placed considerable pressure on staff in managing effective and timely discharges and had caused considerable distress for some staff. While we did not explicitly ask staff, there could be an opportunity to explore how trained and supported by line management staff feel in managing discharge and in implementing the reluctant discharge/no choice policies. We only heard of this policy potentially being used with a small number of patients and their families, but were not clear how staff felt about implementing this. Managing patient expectations effectively early on in the patient journey has the potential to ease some of this pressure.
- We heard Best Interest Meetings could take a while to arrange. One member of staff told us three patients died recently while waiting to access onward care. A member of staff commented, it might be better if they could let families know they are needed for BIMs and if there could be greater flexibility in the times available to meet with family, making meetings more flexible to them.
- While care is 24/7 staff told us there is a skeletal crew on the weekends and bank holidays, particularly in respect of occupational therapists and physiotherapists, who were deemed as critical in making decisions about people’s onward care. A new system at RCH was being piloted to move such roles to the ‘front door’, which it was hoped would reduce the numbers of patients being admitted. However, some staff felt this had the potential to impact upon discharge, and is a concern that could be explored.

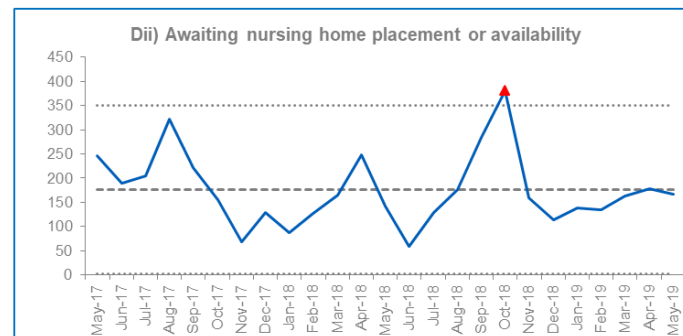
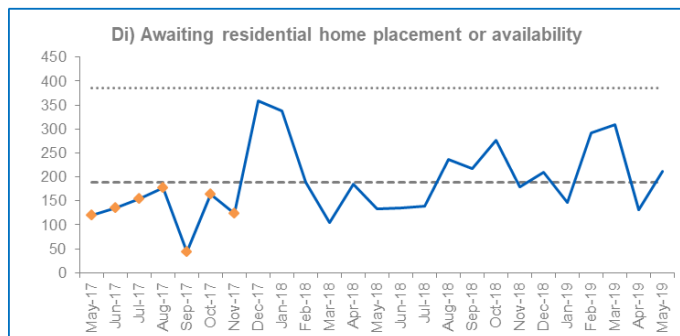
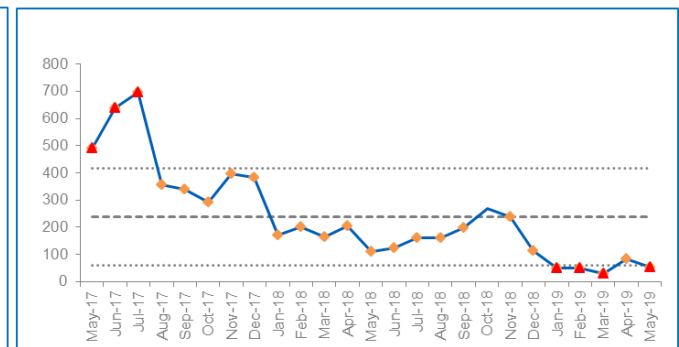
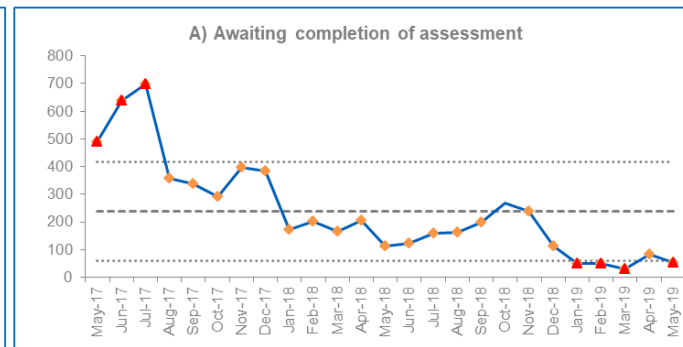
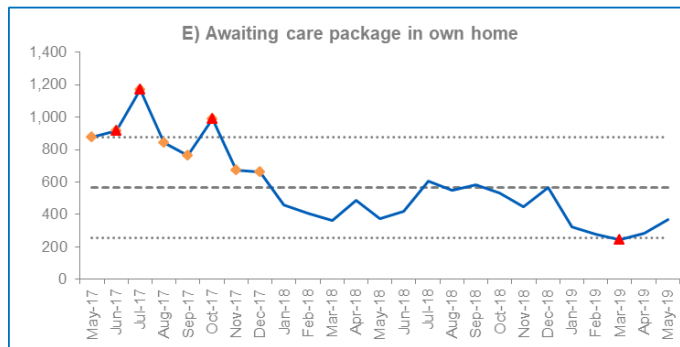
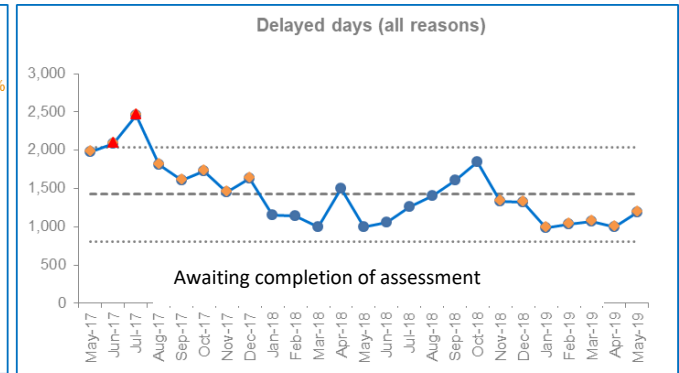
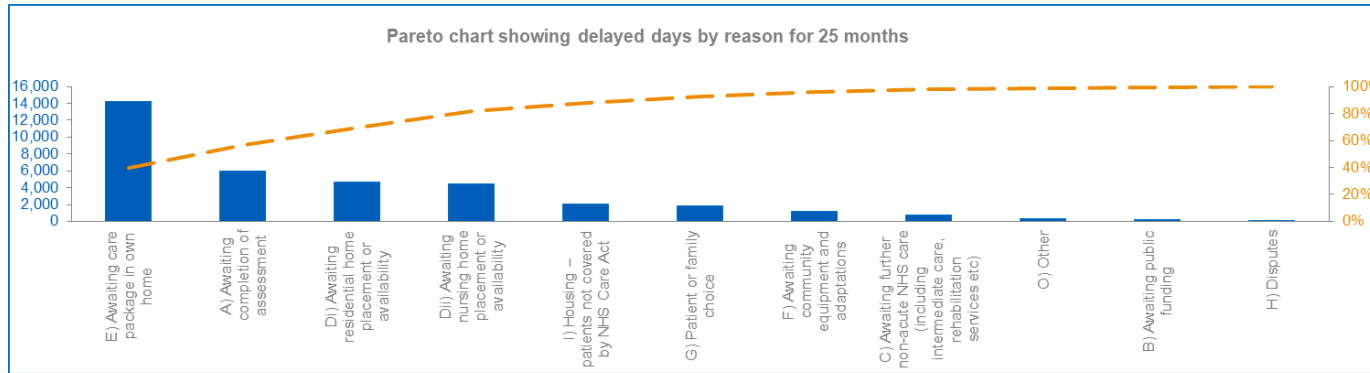
Appendix 1: Delayed Transfers of Care May 2017 - May 2019 by Acute and Non-Acute

Cornwall, Acute Hospitals May 2017- May 2019



<https://improvement.nhs.uk/resources/delayed-transfer-care-dtoc-improvement-tool/>

Cornwall, Non-Acute May 2017-May 2019



<https://improvement.nhs.uk/resources/delayed-transfer-care-dtoc-improvement-tool/>