Insights into Hospital Discharge
A study of patient, carer and staff experience in Essex

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### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BRH</td>
<td>Broomfield Hospital</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>CGH</td>
<td>Colchester General Hospital</td>
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<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
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<tr>
<td>DST</td>
<td>Decision Support Tool</td>
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<tr>
<td>EoL</td>
<td>End of Life Care</td>
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<td>HWE</td>
<td>Healthwatch Essex</td>
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<tr>
<td>MECCG</td>
<td>Mid Essex Clinical Commissioning Group</td>
</tr>
<tr>
<td>NEECCG</td>
<td>North East Essex Clinical Commissioning Group</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NRES</td>
<td>National Research Ethics Services</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PAH</td>
<td>Princess Alexandra Hospital</td>
</tr>
<tr>
<td>PALS</td>
<td>Patient Advice and Liaison Service</td>
</tr>
<tr>
<td>SW</td>
<td>Social Worker</td>
</tr>
<tr>
<td>TTA</td>
<td>To Take Away (referring to medicinal tablets)</td>
</tr>
<tr>
<td>TTO</td>
<td>To Take Out (referring to medicinal tablets)</td>
</tr>
<tr>
<td>WECCG</td>
<td>West Essex Clinical Commissioning Group</td>
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</tbody>
</table>
Contents

Key Messages 4
  Recommendations 6

1. Introduction 9

2. Healthwatch Essex 10

3. Background 11
  3.1 An issue of public concern 11
  3.2 A growing, elderly, frail population 12
  3.3 Hospital admissions and acute care 14
  3.4 Discharge planning and care continuity 14
  3.5 The Study Locality 17
    Colchester General Hospital 17
    Broomfield Hospital 18
    Princess Alexandra Hospital 18
  3.6 Existing Literature 19
  3.7 Study aims 19
  3.8 Study Design and Methods 19
  3.9 Study Sample 20
  3.10 Data Collected 21

4. Findings 22
  4.1 Participant characteristics 22
  4.2 Early discharge (and the consequent possibility of re-admission) 25
  4.3 Delayed discharge 26
    Delays on the day of Discharge 26
    Delays at weekends 28
    Delays in transfer of care 28
  4.4 Continuity and coordination of care 30
    Limited Resources 30
    End of life and Fast Track 33
    A lack of care pathways 34
    Problems after leaving the hospital 35
  4.5 Information and communication ruptures 37
    Poorly involved and informed patients 37
    Family/carer involvement 37
    Staff perceptions of and communication with patients’ families 40
    Poor communication between staff and organisations 41
    Systems of communication 45
    A lack of integration: Tensions between and within teams 46

5. Concluding Discussion 49
  5.1 Concluding discussion 49
  5.2 The importance of In-depth and narrative data 50
  5.3 Patient and family carer information and involvement 50
  5.4 Care continuity and integrated care 52
  5.5 End of life 52
  5.6 Local issues and solutions 53
  5.7 A Healthwatch Essex Perspective 54

6. Recommendations 56
  6.1 The provision of information and communication systems 56
  6.2 Integration and continuity of care 58
  6.3 Raising awareness and planning ahead 58

7. Bibliography 60

Appendix i: Literature review 64
Appendix ii: Methods 79
Appendix iii: Samantha and Fiona’s story 83
Acknowledgements 88
List of tables
Table 1: Common key elements when planning for discharge 15
Table 2: Total number of delayed days per hospital, during June to September 2015 16
Table 3: Total number of delayed days by patient, during June to September 2015 16
Table 4: Total delayed days by responsible organisation (June - September 2015) 16
Table 5: Cost per patient (calculated according to the average number of days a delayed patient remained at each hospital from June through to September) 17
Table 6: Overall cost of delays (calculated according to the total number of delayed days in each hospital over the four-month period) 17
Table 7: Patient profiles for CGH 23
Table 8: Patient profiles for BRH 24
Table 9: Patient profiles for PAH 24

List of figures
Figure 1: Common key elements when planning for discharge 15
Figure 2: The three lenses approach & associated methods for studying hospital discharge 20
Figure 3: Average age of survey participants by decade (Lens 1) 23
Figure 4: Reasons given by survey participants for their delay on the day of discharge (Lens 1) 27
Figure 5: Whether survey participants felt confident they knew who to contact if they had any post-discharge worries (Lens 1) 36
This study was designed to identify people’s lived experiences of hospital discharge in three hospitals in Essex. Our hope was that analysis of the data gathered would provide new insight and potential solutions to the increasing problems that patients and their family carers encounter. We recognise that while Broomfield Hospital in Mid Essex, Colchester Hospital in North East Essex and Princess Alexandra Hospital in West Essex and the associated health and social care services, face enormous challenges as a result of rising demand, budget deficits, fiscal constraints, and a growing ageing population, this is a problem that faces all parts of the country. Indeed, many of the problems we report in this study have been persistently identified in areas of the UK. However, despite previous research recommendations, many of which are embedded within national guidelines and initiatives, these problems have not only persisted, but they have increased dramatically in scale in recent years.

In this report, we report on our combined findings at all three hospitals, having previously published individual reports for each of the three participating hospitals (Healthwatch Essex, 2016a; 2016b; 2016c). We triangulated the data comprising of the following:

- Survey interviews with 201 patients (including some accompanying family care givers) who had just been discharged from hospital beds and were waiting in the discharge lounge on the day of their discharge just prior to their departure.
- 18 in-depth interviews with patients (including some accompanying family care givers) recruited soon after admission, 13 of whom provided patient diary recordings during and following their hospital stay.
• 38 in-depth interviews with clinical staff involved in discharge planning activities (24 staff from the discharge teams and 14 ward staff).
• 195+ hours of ethnographic observation involving the shadowing of discharge team staff.

Most patients who participated were elderly and had come into hospital as an emergency/unplanned admission. While we found some cases where care provided was patient-centred, timely, and overall of high quality and satisfactory to patients, this was not a consistent finding. In at least half of the cases we studied, some aspects of discharge care were less than satisfactory. Our analysis of patient, family care giver and staff experience portrays a worrying picture of hospital discharge processes. As we describe more fully in the report, these are characterised by the following:

I. A lack of person-centred care
a. Many patients reported that they were not involved in the planning of their discharge from hospital and their follow-up support care after leaving hospital.
b. Family care givers play an important role in supporting their relatives in preparations for leaving hospital and in supporting them once home and yet there was little evidence of their involvement by hospital staff in discharge planning.
c. A lack of information regarding diagnosis and management of patients' conditions and post-discharge care, including follow-up appointments, caused patients to experience anxiety and confusion. This contributed to a lack of care continuity and on occasions, patients being readmitted.

II. Being discharged too soon
a. Patients sometimes felt under pressure to leave hospital before feeling ready to be discharged, which was also reported by family care givers. This was particularly the case for some elderly patients and those who had care responsibilities or little family or other support once home.
b. Some patients felt guilty and stigmatised by the label ‘bed blocker’.
c. A number of patients had to be readmitted soon after leaving hospital.

III. Delayed discharge
a. Delays on day of discharge were commonplace due to hold-ups in the delivery of take home medication, hospital transportation and/or discharge related information such as letters for GPs and discharge or care plans.
b. Longer delays occurred in patients with more complex care needs and were due to delays in assessments for care packages, exacerbated by a lack of coordination and integration between health and social care resources and shared working.
c. Relatedly, delays for patients needing Continuing Health Care packages who were considered to be ‘End of life’ also occurred resulting in patients dying while in hospital. This caused considerable distress to patients, families and staff involved in arranging the care required.
d. Delays were also due to the shortage of care places in the community, care homes, nursing homes and re-ablement services, as well as staff shortages in the hospital.
e. In some cases, delays were due to a lack of care pathways. For example, there were no pathways for patients experiencing delirium.
IV. Poor communication

a. Deficits in communication within and across different levels of care, negatively affect the hospital discharge experience of patients, and their family caregivers.

b. Our observational research of discharge teams revealed that they often had poor internal methods of communication and that they frequently failed to update each other sufficiently as to patients’ progress during the handover of medical notes. These notes were often badly written and not concise enough. This meant that, despite being present at board rounds,¹ staff often did not have the right information regarding a patient’s readiness and needs for discharge. Patients were often told different things by different members of staff regarding the timing of their discharge which led to further delays, confusion and frustration for patients and their family care givers.

V. Lack of coordination and integration of care

a. A lack of structural integration between health and social care manifested in a number of different ways leading to delays in patients being discharged, a lack of care continuity and patient care, as well as, tensions between health and social care staff.

We make a number of recommendations for hospital managers, policy makers and care providers to follow:

Recommendations

I. The provision of information and communication systems

- First, we strongly recommend that all hospitals instigate systems to improve communication with patients and their families, which will involve them in discharge planning and will ensure that they are provided with the correct information about any medication, follow-up care and appointments required. It is essential that open communication and open discussion with the patient and family should take place from the point of hospitalisation, regarding their options and preferences for discharge.

- We also recommend that improvement be made to communication between staff within the hospital, and between hospital staff and other health and social care organisations and providers. Rigorous systems need to be put in place to gather, store, retain and share information within the hospital and between key organisations and providers. We suggest that digital technology such as iPads/tablets could be used to replace outmoded fax machines and other unsystematic means of conveying information, such as writing notes relevant to discharge on scraps of paper.

II. Training

- We contend that all frontline hospital staff, and in particular staff working in wards with a high turn-over of older patients, should receive mandatory training in hospital discharge planning. Currently, new ward staff and discharge nurses learn discharge related work by experience and not through training, thus increasing the pressure to care professionals. We recommend that local CCGs, medical schools, and training organisations work together and incorporate discharge related care planning at the curriculum of all trainee health professionals.

¹ A Board Round is a multi-disciplinary meeting held away from the patient’s bed. The pooling of information means that everyone is aware where any patient stands from the perspective of all the different departments and specialties involved in the discharge process. In doing this, there is a focus on discharge planning and any potential issues can be identified and resolved early on. [http://www.chshealthcare.co.uk/2015/02/our-new-role-in-the-board-round-the-principle-of-discharge-planning-from-earliest-opportunity/](http://www.chshealthcare.co.uk/2015/02/our-new-role-in-the-board-round-the-principle-of-discharge-planning-from-earliest-opportunity/)
III. Integration and continuity of care

- We recommend that local health and social care commissioners identify a shared vision of care, and find ways to bring the health and social care sectors under a unifying vision of care. Developing new integrated care pathways, could lead to quality improvements that will make care safer and more patient-centred.

- We suggest that the work already begun to integrate services in North East Essex, Mid Essex, and West Essex and East Herts continues. There is no doubt from the documentation we have seen and the planning meetings we have attended, that there is a great impetus, and enthusiasm among associated local organisations to do so.

IV. Raising awareness and planning ahead.

- We suggest that citizens should be made more aware about the kinds of care provided in the local community, and how they should respond to health matters either in an acute or non-acute form. It may be that the increasing pressure to acute hospitals is the result of a struggling primary and community care sector. Nonetheless, our research shows that in many cases patients present in hospitals with non-acute conditions or with problems that could have been resolved with better planning and information, on behalf of the patient and the family. Health and social care services should work together and find new ways of informing the public about the care services offered in their locality, and how and when to access them.

- Citizens need to be aware that, even though the acute sector is ‘open for business’ 24/7, it is a place of caring for acute medical emergencies.

- Raising awareness of advanced planning, including advanced directives, such as DNR (Do Not Resuscitate) orders, living wills and nominating a family carer to act as power of attorney (for health) could help ensure better care provision and lived experience for people.

We are pleased to report that initiatives designed to improve the problems and issues we identified in our research and are underway. However, we strongly recommend that such interventions are evaluated using qualitative methods that focus on following the course of a patient’s journey and gathering their stories, and where possible those of any family care givers involved in a patient’s discharge.

The extent and seriousness of the problem surrounding hospital discharge should not be underestimated. There still remains a lack of capacity in particular, including temporary or permanent residential care and it is not clear how those with more complex care needs can be met in the community without an increase in the services of professionals such as GPs, nurses and health visitors.

In our research we came across enthusiastic professionals who want to take advantage of this opportunity and address long lasting gaps, resolve difficult problems, and provide bridges to bring together separate world views in service delivery and provision. We also came across patients and service users who acknowledge and appreciate the efforts of frontline care staff to deliver good quality care; they also want their views to be heard and incorporated into service design and delivery. It is within this context that we remain optimistic for the future of our local health and social care services and enthusiastic for the work that we carry out.
In this report we present our findings from data derived from our multi-method and multi-dimensional study into hospital discharge in Essex. Whereas we previously presented data for each hospital in separate reports, here we present the main themes that have emerged following our triangulation analysis of the entire dataset.

Our study, which was conducted between May and December 2015, was carried out in Colchester General Hospital (CGH), Broomfield Hospital (BRH) in Chelmsford, and Princess Alexandra Hospital (PAH) in Harlow. Our aims were two-fold: first we wanted to discover how patients and family care-givers experience the discharge planning process and care post-discharge, and secondly we intended to identify the barriers and facilitators for a safe and timely discharge for patients. We also felt it was important to understand the process of discharge from the perspective of key hospital staff involved.
This research has been conducted by Healthwatch Essex (HWE), an independent organisation with responsibilities under the Health and Social Care Act (2012) to provide a voice for the people of Essex with regard to health and social care services. Our research team conducts high quality research on the ‘lived experience’ of patients, citizens and social-care users to inform improvements in local health and social care provision.

Studying the ‘lived experience’ involves the detailed examination of participants’ ‘lifeworlds’, their experiences of a particular phenomenon, how they make sense of these experiences and the meanings they attach to them. It is premised on a philosophical understanding that a proper scientific analysis of the social world cannot be undertaken by merely collecting ‘objective facts’, but that research needs to engage in a deep and empathetic way with those involved in an attempt to get as close as possible to the everyday world as experienced by those individuals. It is the ‘lived experience’ that reflects and determines people’s confidence and trust (Brennan et al, 2013) in the healthcare system and undoubtedly contributes to their overall physical health and emotional well-being, and to their assessment of how the NHS and social care function in meeting their needs.

2. Healthwatch Essex

The ‘lived experience’ is a concept that originates from the work of the German philosopher Edmund Husserl. He proposed that a proper scientific understanding of the social world could not be undertaken by collecting facts about an event, but rather the researcher needs to engage in an empathetic way with those they are studying in an attempt to get as close as possible to the world as experienced by those individuals. (Husserl, E. 1970 [1901]. Logical investigation. New York: Humanities Press.)
3. Background

3.1 An issue of public concern

Patients’ experiences prior to and following their discharge from hospital are often reported to be unsatisfactory. Following a number of high profile national reports and widespread media coverage about instances of unsafe discharge, including cases where patients had received poor care relating to hospital discharge practices (Francis, 2013), there is growing concern among the public about hospital discharge. A recent inquiry of people’s experiences of hospital discharge conducted by Healthwatch England reported that many were experiencing delays and a lack of co-ordination between services and that patients were not sufficiently involved in, or informed about, decisions involving their care (Healthwatch England, 2015).

In Essex, policy advisers and members of the public have highlighted hospital discharge as an issue of great concern. In 2013, an independent commission lead report identified it as an issue requiring urgent attention by commissioners, providers and other statutory organisations (Hughes-Hallett and Probert, 2013). Experience of hospital discharge has also been one of the prominent issues reported to the Information Service provided by HWE.4 The service has received a large number of calls from relatives of elderly patients in particular, who wished to complain about the discharge process and/or to request information to support and care for an elderly relative following their discharge from hospital. Some callers gave detailed and distressing accounts of what they had experienced, reporting cases in which their

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4 Healthwatch Essex provides an information and signposting service, which members of the public can contact in order to better access, understand and navigate health and social services in Essex. Further information can be found at http://www.healthwatchessex.org.uk/find-information/
elderly relatives were discharged prematurely, with little or no explanation about their condition, and little or no support or follow-up care. A number reported their loved ones being subjected to undignified care and dying in distressing circumstances in a hospital ward rather than in their preferred place of choice.

Problems relating to hospital discharge are not new, but growing unplanned/emergency hospital admissions combined with an increasing ageing population (often with accompanying complex patient discharge needs), a reduction in social care expenditure, and rising hospital deficits have all contributed to the challenges in achieving a timely, safe and satisfactory discharge for patients.

3.2 A growing, elderly, frail population

The UK’s elderly population has been rising since the 1970s, with the population aged 65 and over now making up nearly 18% of the general population. Of the 16 million adults admitted to hospital in the UK during 2015 almost 8 million (47%) were aged over 65 years (Hospital Episode Statistics, 2015). As 36% of people aged 65–74, and 47% of those aged 75 and over have a limiting longstanding illness (Age UK, 2016a), it is unsurprising that we have an accompanying rise in the number of elderly people being admitted to hospital. According to the Alzheimer’s Society, two thirds of medical beds in general hospitals are occupied by people over the age of 65 and around 30% of these will have dementia (Lakey, 2009).

Healthwatch England’s Special Inquiry into what happens to patients once they’ve been discharged identified that elderly patients in particular experience problems in accessing continuing healthcare, and in waiting for assessment before being discharged (Healthwatch England, 2015). Many elderly patients are particularly frail and vulnerable and as such have greater care needs while in hospital. A two-year analysis of hospital episode statistics data found that dementia patients were 10% to 20% more likely to die in hospital than other comparable patient groups and that their lengths of hospital stay are, on average, a quarter longer than for those without dementia (Robinson and Tyndale-Biscoe, 2014). While the number of patients with dementia is rising, an increasing number of elderly patients in hospital will experience delirium during their stay. A recent study confirmed that about 1 in 5 of general hospital inpatients, and particularly those with prior cognitive impairment, will present with delirium (Ryan et al., 2013). Delirium is a common and serious illness for people admitted to hospital and is often very distressing for patients and their families. It also increases the chances of developing other complications in hospital, being admitted to a care home or dying in hospital (Siddiqi, Harrison and Clegg et al., 2016). Such patients tend to have basic care needs requiring assistance with toileting, washing and feeding. There are currently many more people now than in the past with dementia and co-morbidities who are being cared for at home (rather than in care homes or nursing homes), which means that family members are often already involved in supporting frail elderly relatives and those with dementia living at home. Many cases of dementia go undiagnosed; the Alzheimer’s Society (2014) report that less than half of those living with dementia in England have received a formal diagnosis. Furthermore, only some of those with...
a diagnosis are known to the local authorities, as GPs do not automatically inform social or other services once someone has received a dementia diagnosis. In Essex there are 3,381 individuals known by the local authority and who are in receipt of a dementia service and of these 60% are in residential care while 40% live in the community. This combined with the fact that, nationally, two thirds of people with dementia live in the community while one third live in a care home (Alzheimer’s Society, 2014), means the true number of those living with dementia or those caring for a family member in the community in Essex is likely much greater. In Essex, we find that ‘despite the significant increase in older people with care needs ... this has not been matched by increased use of registered care, as people are being cared for via alternatives in the community’ (Essex Joint Strategic Needs Assessment - Countywide Report, 2013).

Many family carers are under considerable stress and pressure and an emergency admission to hospital often represents a crisis moment for patients and their families who no longer feel able to cope. Over half of all new admissions to care homes in the UK are of people transferred from general hospitals (Office of Fair Trading, 2005). For such patients, and their family members, being discharged from hospital often presents life-changing, unique and emotionally difficult decisions. This may also present accompanying financial challenges, insofar as most people being transferred to a care home will often be classified as having ‘social care’ needs rather than healthcare needs and as such will be means-tested and will likely have to pay for all or some of their care.

Nevertheless, it should be noted that while the growing elderly population, particularly those with comorbidities and complex care needs, has resulted in an increasing number of hospital admissions and an increase in demand for hospital resources, as government policy encourages shorter hospital stays, the ‘total number of acute bed days following emergency admissions of people aged 65 and over has fallen’ (Wittenberg et al, 2014). It might seem contradictory to reduce hospital bed availability given the increase in demand, but this is in line with various policy initiatives to improve community health and social care provision. However, as we shall discuss further, this provision has largely failed to materialise.

Many family carers are under considerable stress and pressure and an emergency admission to hospital often represents a crisis moment for patients and their families who no longer feel able to cope.

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7 All Services (Orbit) 2015/16 as at end March 2016.
8 A further Healthwatch Essex report titled ‘Negotiating the Care Maze’ explores the experiences of family and carers in more depth; it can be found at [http://www.healthwatchessex.org.uk/what-we-do/our-reports/](http://www.healthwatchessex.org.uk/what-we-do/our-reports/)
3.3 Hospital admissions and acute care

The number of hospital admissions has risen sharply in recent years. There were 15.892m total hospital admissions in 2014/15, 31% more than a decade earlier (NHS Confederation, 2016). Between 2006/7 and 2012/13 the number of hospital admissions nationally has risen by 16% (Smith et al., 2014). In addition, most patients’ admissions to hospital have followed their attendance at a hospital’s accident and emergency (A&E) department. During the years 2013/14 and 2014/15, emergency admissions rose in each of the three hospitals we reviewed; CGH showed an increase of 1,378 more emergency admissions in 2014/15 than the previous year (total emergency admissions for 2014/15 were 36,161), BRH showed an increase of 1,198 (the total for 2014/15 being 33,708) and PAH increased by 2,643 (making their 2014/15 emergency intake 29,679). During the year 2014/15, emergency admissions alone formed over a third of overall admissions in each hospital; in CGH and BRH it was 38%, while in PAH it was 41% (HSCIC, 2016). Whereas planned admissions for elective procedures were once the norm, this is now no longer the case. In order to deal with the rising number of admissions, the NHS has developed policies and initiatives to reduce the length of duration a patient will occupy a hospital bed and to ensure that patients are discharged as quickly as possible. Indeed, hospital beds are in short supply and the number of beds per capita has fallen dramatically in the past ten years; the recent OECD Health at Glance 2015 report tells us that the UK now only has 2.8 beds per 1000 people (OEDC Indicators, 2015) and the Kings Fund reported recently that over the past 26 years the number of available beds has more than halved (The King’s Fund, 2015). Unplanned admissions make it very challenging for hospitals to plan and prepare for patient flow (movement of patients between wards and in and out of hospital). It also creates problems for families, who are not able to make advanced plans to put in place informal post-care support. Indeed, the emergency/unplanned status of such admissions can make this a particularly stressful situation for all involved. Given this situation, it may not be surprising to find that delayed discharge (commonly referred to as a ‘delayed transfer of care’) and readmissions are commonly occurring problems.

3.4 Discharge planning and care continuity

Effective discharge planning is crucial to care continuity. The extent to which, over time, people experience care as connected, both within a hospital setting and during the transfer of their care into the community, is an essential component of care quality (Allen et al., 2014). For people leaving hospital, the discharge planning process plays a significant role in achieving a safe and timely discharge. Hospital discharge policies vary between hospitals, and may also vary between wards within a given hospital. At the time this study was initiated, NHS England had provided some guidance for discharge planning, a modified extract of which is presented below, in Table 1 and Figure 19 (NHS Institute for Innovation and Improvement, 2016). The guidance also suggests that a treatment plan, including details for discharge or transfer to another care organisation, should be developed.

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9 In preparation for this study, one of our research team wrote to the National Institute of Clinical Excellence (NICE) to enquire whether they had produced any guidelines on hospital discharge. At this stage they had not, but since then NICE have drafted guidance and we have submitted evidence based on our study findings into the consultation process preceding the final guidelines.
Table 1 and Figure 1:

**Common key elements when planning for discharge**

- Specify a date and/or time of discharge as early as possible
- Identifying whether a patient has simple (80 per cent of all patients) or complex discharge planning needs
- Identify what these needs are and how they will be met
- Decide the identifiable clinical criteria that the patient must meet for discharge

and discussed with the patient and this plan should begin soon after admission. It further advises that a discharge assessment be made to determine whether care for the patient is required after he or she leaves hospital and that this may require detailed assessments, planning and delivery by multi-agency working or multi-disciplinary teams. Finally, it states that the patient should be fully involved in the assessment process and that family or carers should also be kept informed and given the opportunity to contribute to discharge plans.

It is common practice for there to be a dedicated team of discharge nurses and social workers within the hospital to manage the process of assessments and arrangements for patients with complex discharge needs. These teams are made up of both health and social care professionals and although they do not oversee all patients being discharged, they deal with cases where patients care needs or circumstances are complex. Much of their time is spent arranging and carrying out assessments and liaising with health and social care service organisations both within the hospital and in the community. Patients with complex discharge needs are more likely to experience delayed transfers of care and many of these will be elderly patients requiring one or more of the following: specialist equipment, beds in residential/nursing homes, funding to be arranged for residential care, transport, and social care or other assessments. These are the issues that contribute to delayed transfer of care. Indeed, 80% of all delayed discharges or transfers of care are experienced by people over the age of 70 (Royal Voluntary Service, 2013).

On the following page we present NHS statistics for delayed transfers of care (DTOCs) in each of the three hospitals which coincided with the period in which our research was conducted. They show that, a large number of delayed days can be attributed to a very small number of patients who experienced long periods of delay each. During this four-month period in 2015, a patient experiencing delayed discharge in CGH waited on average 24 days; in BRH this was 30 days and in PAH the average wait was 26 days. During the same four-month period in 2015 there were a total of 7,141 delayed days of transfer at all three hospitals affecting 268 patients. As the breakdown of these figures demonstrate (Table 2), PAH had considerable more delays than BRH and CGH.

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**Table 1**

<table>
<thead>
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<th></th>
<th>Emergency</th>
<th>Elective</th>
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<tr>
<td></td>
<td>Expected date of discharge based on anticipated length of stay</td>
<td>Patient meets clinical criteria for discharge</td>
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<tr>
<td>Simple discharge</td>
<td>Patient meets clinical criteria for discharge</td>
<td>Patient meets clinical criteria for discharge</td>
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<tr>
<td>Complex discharge</td>
<td>Patient meets clinical criteria for discharge</td>
<td>Patient meets clinical criteria for discharge</td>
</tr>
</tbody>
</table>

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10 [https://www.england.nhs.uk/statistics/statistical-work-areas/delayed-transfers-of-care/]
The cost of a hospital bed per day varies but a recent Freedom of Information request estimates the cost to be £400 per day: [https://data.gov.uk/data-request/nhs-hospital-stay](https://data.gov.uk/data-request/nhs-hospital-stay).

Table 2:
**Total number of delayed days in 2015**

<table>
<thead>
<tr>
<th></th>
<th>June</th>
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<th>August</th>
<th>September</th>
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<tr>
<td>CGH</td>
<td>352</td>
<td>288</td>
<td>511</td>
<td>536</td>
<td>1,687</td>
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<tr>
<td>BRH</td>
<td>452</td>
<td>391</td>
<td>417</td>
<td>578</td>
<td>1,838</td>
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<tr>
<td>PAH</td>
<td>780</td>
<td>756</td>
<td>964</td>
<td>1,166</td>
<td>3,616</td>
</tr>
</tbody>
</table>

Table 3:
**Total number of delayed patients in 2015**

<table>
<thead>
<tr>
<th></th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGH</td>
<td>11</td>
<td>17</td>
<td>25</td>
<td>17</td>
<td>70</td>
</tr>
<tr>
<td>BRH</td>
<td>14</td>
<td>7</td>
<td>22</td>
<td>18</td>
<td>61</td>
</tr>
<tr>
<td>PAH</td>
<td>30</td>
<td>28</td>
<td>28</td>
<td>51</td>
<td>137</td>
</tr>
</tbody>
</table>

Within the three Trusts the majority of these delays were attributed to the NHS rather than social care (Table 4).

Table 4:
**Total delayed days by responsible organisation (June - September 2015)**

<table>
<thead>
<tr>
<th></th>
<th>NHS</th>
<th>Social Care</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGH</td>
<td>1590</td>
<td>97</td>
<td>0</td>
</tr>
<tr>
<td>BRH</td>
<td>1308</td>
<td>530</td>
<td>0</td>
</tr>
<tr>
<td>PAH</td>
<td>3276</td>
<td>390</td>
<td>0</td>
</tr>
</tbody>
</table>

Given that the estimated cost of a bed in an acute hospital is somewhere between £260 and £400 per day, the combined cost of delayed discharge over this four month period for all three hospitals would be somewhere between £1,856,660 - £2,856,400. The below tables set out the cost per delayed patient according to the average number of days spent at each hospital, and the total costs of delays per hospital during the months of July to September.
**Table 5:**

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Cost per patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGH</td>
<td>Between £6,240 - £9,600</td>
</tr>
<tr>
<td>BRH</td>
<td>Between £7,800 - £12,000</td>
</tr>
<tr>
<td>PAH</td>
<td>Between £6,760 - £10,400</td>
</tr>
</tbody>
</table>

**Table 6:**

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Overall cost of delays</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGH</td>
<td>Between £438,620 - £674,800</td>
</tr>
<tr>
<td>BRH</td>
<td>Between £477,880 - £735,200</td>
</tr>
<tr>
<td>PAH</td>
<td>Between £940,160 - £1,446,400</td>
</tr>
<tr>
<td>Total</td>
<td>Between £1,856,660 - £2,856,400</td>
</tr>
</tbody>
</table>

### 3.5 The Study Locality

Essex has a population of 1.4 million and is located immediately north-east of London bordering the counties of Suffolk and Cambridgeshire to the north, Hertfordshire to the west, Kent across the estuary of the River Thames to the south and London to the south-west. The county town is Chelmsford, which is the only city in the county. The health of the people in Essex is generally significantly better than the average of the general population of England, although there are some areas of economic deprivation such as Harlow and the Colchester/Tendering area.

Twenty-five per cent of the total population live in a rural part of the country. A recent report claims that the many of the older population living in rural areas have growing health and social care needs and limited access to local services, with problems relating to transport availability often leading to social isolation and consequently a profound impact on the quality of life of local residents (Essex Community Foundation, 2015). Many of the county’s towns have been experiencing a population growth, with Colchester in particular being one of the fastest growing towns in the region. The population is expected to rise to 207,000 by 2018 an increase of 20% over a ten year period (Office of National Statistics, 2010).

The three hospitals were selected on the basis that they are all acute hospitals, and provide accident and emergency, medical care, surgery, critical care and other core services. Their catchment areas cover West Essex (PAH), Mid Essex (BRH) and North East Essex (CGH) and as such cover much of the county of Essex.

#### Colchester General Hospital

Colchester General Hospital, situated in North East Essex, is the main hospital within the wider Hospital Trust and provides healthcare services to around 370,000 people from Colchester and the surrounding area of north east Essex and south Suffolk. Colchester is the largest town in north east Essex and one of the fastest growing; it is a largely affluent area with relatively low unemployment and above average life...
expectancy. The Tendring peninsula is more rural and has a much higher concentration of elderly and economically less well-off people.

There are 562 inpatient beds within the Trust (general and anesthetic). In 2014/15 the Trust reported a deficit of £22.3m compared to a deficit of £2.4m for 2013/14. Colchester General Hospital is currently rated as ‘inadequate’ by the Care Quality Commission (CQC), and the Trust has spent considerable time in special measures. Earlier this year, a long-term partnership between Colchester Hospital University NHS Foundation Trust and the Ipswich Hospital NHS Trust was recommended jointly by the CQC and NHS Improvement as the only way of securing sustainable services for patients.

**Broomfield Hospital**

Broomfield Hospital is situated in Mid Essex, and Mid Essex Hospital Services NHS Trust provides local elective and emergency services to 380,000 people living in and around the districts of Chelmsford, Maldon and Braintree. The main site is Broomfield, which has been redeveloped as part of a private finance initiative (PFI). The Trust has begun to centralise the majority of its services at Broomfield Hospital, including urgent and emergency services. In 2014/15 the Trust reported a deficit of £22.3m compared to £19.5m for 2013/14. Broomfield Hospital is currently rated as ‘requires improvement’ by the CQC.

According to the Mid Essex CCG, the population in this area is expected to grow to more than 400,000 by 2020, with consequent higher demand on local services, and the area has been recognised as one of the 11 most challenged health economies nationally. There is already a growing number of frail elderly and chronically ill people living in this area, and this coupled with a sustained slowdown in spending growth in recent years, along with local government cuts, is expected to place unprecedented pressure on services (Care Quality Commission, 2015).

**Princess Alexandra Hospital**

Princess Alexandra Hospital NHS Trust (West Essex) is located in Harlow, Essex and is a 480 bed hospital (general and acute) excluding maternity and children’s services and escalation areas. The hospital provides a comprehensive range of acute and specialist services. In 2014/15 the Trust reported a deficit of £22.3m compared to £16.5m in 2013/14. After a CQC inspection in June 2016, PAH was rated as ‘inadequate’ overall the CQC inspectors found that the Trust had significant capacity issues and staff shortages.

The health of people in Harlow is varied compared with the England average, and about 21% children live in poverty. Life expectancy for men is lower than the England average. The hospital provides largely a local service for the people of West Essex and East Hertfordshire including Harlow, Epping, Uttlesford, Bishops Stortford and Loughton, serving a population of circa 285,000 people. While areas in East Herts are relatively affluent, Harlow ranks in the bottom third of the most socially and economically deprived areas in England. West Essex is less populated by the elderly than the areas surrounding Colchester General and Broomfield hospitals, however, the elderly population is set to grow significantly over the next decade in Uttlesford and Epping in particular (West Essex CCG JSNA, 2014).
3.6 Existing Literature

In preparing for this study, we conducted a 'narrative review' of empirical research and other published reports about patients' and family caregivers' experiences of discharge planning and care post-discharge, published from 2005 to 2016 (see appendix i). These studies indicate that patients' and family caregivers' interactions with healthcare professionals play a vital role in hospital discharge planning and care post-discharge. Poor communication between patients, family caregivers and healthcare staff, patients' limited involvement in hospital discharge planning as well as poor information sharing between patients, family caregivers and healthcare staff, are all common findings (see appendix i).

3.7 Study aims

The issues experienced by elderly people and their families in particular, and the complexity and scope of the discharge process, are reflected in our study's aims:

• To develop insight into the 'lived experience' of those involved with or experiencing the hospital discharge process and subsequent post-discharge care, which includes: patients, carers, family & friends, ward staff and discharge team staff (health and social care).
• To identify both the challenges and positive attributes that facilitate, or inhibit, an effective and safe discharge from hospital for patients.
• To engage with stakeholders throughout to maximise the impact of the research study to improve patient and carer experiences of discharge.

3.8 Study Design and Methods

To best understand the complex factors involved in participant experiences of discharge, we adopted a mixed-methods approach (Creswell, 2003; Morgan, 2007). While largely qualitatively driven, we drew on both qualitative and quantitative research methods. This approach was designed to produce: in-depth accounts of patients' and carers' lived experiences; a rich description of both cultural practices and processes surrounding discharge; and an analysis based on statistical survey methods to identify factors that influence patient and carer experiences of discharge.

Our design was premised on our initial understanding that hospital discharge is a fluid process that begins once a patient is admitted to hospital, and carries on throughout their stay in hospital and beyond. It is a dynamic negotiated process involving a number of key people - patients, doctors, other members of the clinical and social care teams along with patients' family members and/or carers (formal and informal). We applied academic rigour with a degree of pragmatism (what is achievable, practical and ethical), thinking carefully about how best to capture the dynamic discharge process (movement over time) from the perspective of the patients, their family members (carers) and key staff involved in the process. To this end we designed a three lens framework (see Figure 2) to capture experiences of hospital discharge from different perspectives in anticipation that these perspectives, when analysed, would help present an overall picture, capturing the dynamic nature of hospital discharge, in order to inform a broad understanding of the issues.
### 3.9 Study Sample

Given that we knew that hospital discharge for elderly people in particular is often more challenging, we worked closely with the hospitals involved to secure a large number of elderly patients' participation. We carried out the survey component of the study (Lens 1) in each hospital's discharge lounge. Discharge lounges are used by all three hospitals as places for patients and carers to wait after being discharged from a hospital bed, and while waiting for medication, transportation and/or a discharge letter before being formally discharged from hospital. Carrying out the survey allowed us to capture the experiences of a large number of older people (such patients are more likely to be there awaiting transport home) and to inquire about their experiences up to the day of their discharge. When recruiting patients from wards (Lens 2), we were able to gather the experiences of patients from admission to a week or so after their discharge, and here we focused on wards for care of the elderly (though not exclusively so). We also included carers and family members' experiences as part of our study to try and ensure that we captured the experiences of those patients who were less able to participate (due to the severity of illness and/or cognitive problems such as dementia) and also to understand the role of the carer in the discharge process. While our study sample has a slight purposive bias overall towards the experiences of elderly patients, unfortunately the experiences of those with dementia were largely absent because of the difficulty we experienced in recruiting their family and carers, and also because those with
dementia were rarely sent to the discharge lounge before being discharged. However, our researchers observed first-hand both formally, through staff interviews and ethnographic observations of the discharge teams’ work (Lens 3), and informally, in our observations of wards during the recruitment of patients to the study, some of the challenges posed by the care of those with dementia and delirium in hospital wards.

Furthermore, by conducting the study across three Essex hospitals (BRH in Chelmsford, CGH in Colchester and PAH in Harlow) we were able to pool and triangulate the data and identify good and less good practice, as well as wider regional difference that played into validation in experiences. We have published individual reports on each of these hospitals, and in this report we present our analysis of the triangulated data for all three hospitals.

3.10 Data Collected

Data collection was challenging, particularly during the recruitment of patients and their family care givers. It presented both emotional and practical challenges for our researchers. Recruitment in the discharge lounges was more time consuming than anticipated as there were periods during the day when the lounges were not well occupied. As will be demonstrated, while we achieved or were close to achieving our target of recruiting 100 survey patients for PAH and CGH, we fell well short of this figure for BRH. Furthermore, although our Research Ambassadors were all trained and supported throughout the survey administration period, listening to patients’ stories was often emotionally draining and distressing. Our experienced researchers (one of whom was a former nurse) who recruited and interviewed patients from the wards also found this an emotional and practical challenge, especially when recruiting and listening to patients who died soon after they had given consent, but before they had participated. Attempts to recruit carers of patients with dementia failed, because often the families were too fraught and did not wish to participate. However, nurses responsible for discharging patients on wards who had participated in patient recruitment, were keen to participate and, although we had not originally intended to interview ward staff, we interviewed a number of them in addition to discharge team staff, and in doing so gained additional perspectives.

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**Lens 1**
Survey interviews with 201 patients (plus some family care-givers) in the discharge lounge.

**Lens 2**
18 in-depth interviews with patients and 13 patient diary recordings.

**Lens 3**
38 in-depth interviews with clinical staff involved in discharge planning activities (24 staff from the discharge teams and 14 ward staff) Plus 195 hours of observation shadowing the discharge teams.

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16 These can be found at [http://www.healthwatchsex.org.uk/what-we-do/topics/hospital-discharge-in-essex/](http://www.healthwatchsex.org.uk/what-we-do/topics/hospital-discharge-in-essex/)
Participants reported mixed experiences of hospital discharge and post-discharge care over the duration of this study and this variation is in itself an important finding. Many who participated did tell us of a positive experience; however, a large proportion of respondents/interviewees also reported considerable difficulties, and these have been the focus of the individual written reports for each hospital, the survey report and this substantive report – which is consistent with the overall aim being to aid further improvement of the hospital discharge process. In this report we bring together our analysis of our multi-site and multi-method study. All participant patients and staff members have been given pseudonyms to protect their identities.

4.1 Participant characteristics
The vast majority of patients who participated in our study overall were aged 60 years and older. The median age of our survey participants was 78.5 years. Below are the demographics for the participants in Lenses 1 & 2 of the study, for further analysis of the demographic see appendix ii.
Figure 3: Percentage of participants by age decade

![Bar chart showing the percentage of participants by age decade.](chart)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Home town and living situation</th>
<th>Condition</th>
<th>Ward recruited</th>
<th>Length of stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>David (male)</td>
<td>70s</td>
<td>Lives with wife</td>
<td>Urinary tract infection</td>
<td>EAU</td>
<td>2 days</td>
</tr>
<tr>
<td>Eric (male)</td>
<td>70s</td>
<td>Lives with wife</td>
<td>Chest infection and shortness of breath</td>
<td>EAU, Layer Marney and Dedham</td>
<td>27 days</td>
</tr>
<tr>
<td>Hilary (female)</td>
<td>60s</td>
<td>Lives alone, in town</td>
<td>Fell - broken ankle and damaged hip</td>
<td>Aldham Ward</td>
<td>7 days</td>
</tr>
<tr>
<td>John (male)</td>
<td>50s</td>
<td>Lives alone</td>
<td>Knee - thought it was a dvt, actually cysts</td>
<td>Aldam Ward</td>
<td>5 days</td>
</tr>
<tr>
<td>Kathleen (female)</td>
<td>90s</td>
<td>Lives alone</td>
<td>Fell - banged her head</td>
<td>DArcy Ward</td>
<td>7 days</td>
</tr>
<tr>
<td>Anastasia (female)</td>
<td>80s</td>
<td>Lives alone</td>
<td>Obstructed bowel following dramatic weight loss</td>
<td>DArcy Ward</td>
<td>6 days</td>
</tr>
</tbody>
</table>
Table 8: Patient profiles for BRH

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Home town and living situation</th>
<th>Condition</th>
<th>Ward recruited</th>
<th>Length of stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angie</td>
<td>80s</td>
<td>Lives alone, sheltered housing 26 miles south east of hospital</td>
<td>Blockage in lower digestion, pain, unable to eat</td>
<td>Rayne</td>
<td>5 days</td>
</tr>
<tr>
<td>Bob</td>
<td>40s</td>
<td>Lives alone, 10 miles from hospital</td>
<td>Suspected DVT, ongoing health condition causing falls</td>
<td>Rayne</td>
<td>6 days</td>
</tr>
<tr>
<td>Samantha</td>
<td>90s</td>
<td>Lives alone, in town 15 miles from hospital</td>
<td>Liver cyst</td>
<td>Danbury</td>
<td>17 days</td>
</tr>
<tr>
<td>Tom</td>
<td>60s</td>
<td>Lives with wife, 10 miles from hospital</td>
<td>Gallstones</td>
<td>Rayne</td>
<td>7 days</td>
</tr>
<tr>
<td>Richard</td>
<td>20s</td>
<td>Lives with family, local village</td>
<td>Emergent surgery on an old injury</td>
<td>Rayne</td>
<td>1 day</td>
</tr>
<tr>
<td>Ian</td>
<td>Late 60s</td>
<td>Lives alone, Chelmsford</td>
<td>Bone marrow aplasia/ aplastic Anaemia</td>
<td>Danbury</td>
<td>5 days</td>
</tr>
</tbody>
</table>

Table 9: Patient profiles for PAH

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Home town and living situation</th>
<th>Condition</th>
<th>Ward recruited</th>
<th>Length of stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joe</td>
<td>60s</td>
<td>Lives alone</td>
<td>Urinary tract infection and MS</td>
<td>Lister</td>
<td>4 days</td>
</tr>
<tr>
<td>Kate</td>
<td>60s</td>
<td>Lives alone in static home</td>
<td>Infection in hip</td>
<td>Penn</td>
<td>17 days</td>
</tr>
<tr>
<td>Jim</td>
<td>60s</td>
<td>Lives with adult disabled daughter</td>
<td>Collapsed lung and infection</td>
<td>Ray</td>
<td>12 days</td>
</tr>
<tr>
<td>Brenda</td>
<td>60s</td>
<td>Lives with her husband</td>
<td>Infected toe</td>
<td>Penn</td>
<td>12 days</td>
</tr>
<tr>
<td>Linda</td>
<td>50s</td>
<td>Lives with partner and daughter</td>
<td>Kidney stone</td>
<td>Penn</td>
<td>4 days</td>
</tr>
<tr>
<td>Daniel</td>
<td>50s</td>
<td>Lives with his mother</td>
<td>Infected toe and diabetes</td>
<td>Kingsmoor</td>
<td>6 days</td>
</tr>
</tbody>
</table>
4.2 Early discharge (and the consequent possibility of re-admission)

Most of the patients who participated in our study were elderly and had experienced an unplanned, emergency admission. Some felt that their discharge had been rushed and would have preferred to have remained in hospital a little longer before being discharged. Our survey data (Lens 1) for BRH shows that 8% of those interviewed reported that they did not feel confident in their ability to look after themselves when discharged from hospital. Whereas at CGH, 1% of survey respondents reported not feeling confident in their ability to look after themselves post-discharge, and and in PAH this was 5%.

Some felt that they were being discharged from hospital too early and that this negatively affected their care transition; for example, one elderly survey participant at BRH said she felt she was ‘bed-blocking’ but that she would ‘really like another day’. In-depth interviews at all three hospitals with patients reveal greater percentage of those patients reported that their discharge was premature. Jim, a patient interviewed at PAH who was himself a carer for his disabled daughter, told staff he did not feel ready to leave, and managed to persuade them that ‘there is no way I am going to be able to go home and look after myself’; however this caused him considerable anxiety and stress, and he reported feeling like a ‘burden’. John (CGH), in his 50s and living alone, had been admitted to hospital for a problem with his knee, which turned out to be a cyst. He knew that he would have to walk up a number of stairs to get home and didn’t have anyone to assist him once he was back. He told our researcher that he felt was being discharged prematurely, regardless of him having told the staff he did not feel fit enough to resume living at home. John needed to be readmitted soon after his discharge, and commented:

*Then to come back in again... something's not getting done right. I don't think I should have been in twice within the same couple of days, you know?*

Others, like Angie, a BRH patient in her 80s, were informed that ‘we want the bed, so you've got to go home,’ a decision which she said ‘shocked’ her, as she also felt her health was not yet improved enough. Early discharge can endanger patients, something that was noted by the GP of another patient, Samantha, who thought it was ‘outrageous’ that she had been discharged so early. Samantha, whose story is related in more detail in appendix iii, was a 91-year-old woman who lived alone and was also readmitted soon after being discharged.

Staff from each hospital (Lens 3) confirmed that the pressure for beds was so great that some patients were, against their own wishes and the wishes of staff, discharged too early. Francis (ward staff, CGH) said:

> ‘There are some patients who I think are just being discharged quite unsafely, it happens far too quick... And I think it's because of bed pressures.’

A staff member at BRH voiced similar opinions:

> *There is a difference between somebody sitting here and not needing to be here and somebody they're trying to push out before they're ready. That is a huge problem here. A huge problem.*

(Adam, social care)

In PAH ward staff reported feeling this pressure to discharge from management, which was challenging when trying to advocate for the patient and work towards improving their health. Jenny (ward staff, PAH) pointed out that their patients are usually:

> *Very vulnerable, mostly elderly, some very elderly and confused... it's all about getting them out and we get them out and they just trundle back through the door again.*
This simply contributes to a long-term increased pressure on resources (where re-admittance could be avoided), when bowing to the short-term pressure for beds. It also puts hospital staff in an impossible situation, in which they cannot advocate fully for the health of the patient due to bed pressures. A number of staff pointed out that new government performance targets were also preventing them from giving patients adequate care specific to their illness. Staff felt that these targets just added pressure; Taylor (healthcare team, CGH) told our researcher:

You are trying to do what is best for the patient... but always at the back of it is government targets... whether it is good for the patient or not.

This can mean that patients are sent home early, or with inadequate care packages. At BRH, social care staff reported that sometimes patients were discharged before being assessed for their care needs. They said that this was often because the healthcare staff on the team spent so much of their time focusing on administering the actual process of discharge, they did not have enough time to assess the patients and talk to them and their carers. Our HWE researcher who carried out the observation of the discharge team staff (Lens 3) at one point accompanied Hannah, a BRH nurse (social care), when she went to assess a patient for whom she had received a Section 5, and noted that:

One of the nurses told us that the patient was discharged last night because they needed the bed. The patient left Friday night without any care plan in place.

While it is clear that discharge was rushed or premature for some patients, we also found that for other patients there were delays in being discharged. As we shall outline in the following section delays on the ‘day of discharge’ were commonplace, ‘delayed transitions of care’ often caused patients who were otherwise deemed to be ‘medically fit’ to remain in hospital bed for an extended period of time.

4.3 Delayed discharge

Delays in discharging patients who were assessed as medically fit were reported to be symptomatic of additional problems, such as: short staffing; lack of appropriate or available transitionary care; and a lack of pre-planning for patients’ discharge needs prior to the point of discharge. This lead to delays on the day of discharge, whereby patients had to wait a number of hours for paperwork, medication or hospital transport. However, the lack of an appropriate place to transfer a patient could also lead to much longer delays, in which patients remained in hospital for an extended number of days, often for several weeks. Indeed, the average number of days (for CGH, BRH and PAH) a patient whose discharge was delayed spent waiting was 27. This is extended delay is known as a DTOC, or ‘delayed transfer of care’.

4.3.1 Delays on the day of Discharge

Overall, 29.7% of survey participants (Lens 1 results for all three hospitals) reported their discharge as being delayed. However, respondents were approached to fill out the surveys on their arrival to the lounge and it is possible that, had they filled out the survey midway through their time in the lounge, or as they were leaving, the results would have been different. At BRH, just under half of the survey...
participants questioned (Lens 1) reported their discharge was delayed. This was slightly lower at CGH, where 79% reported it as ‘going well’. In PAH, 35% of participants recorded their discharge as delayed, and of the 87% of participants who had been given medicine to take home, 30% reported its delivery as delayed. In CGH, 26% of those who reported their discharge as delayed recorded the reason as being ‘waiting for medication and/or discharge letter’.

The most prominent hospital-wide reason for discharge delay was waiting for medication. The wife of one patient at BRH who had been waiting 3.5 hours for medication said that this aspect was ‘totally letting the hospital down.’ Eric, a CGH patient in his 70s, who had been admitted to hospital with a chest infection, had to wait for over 8 hours for medication in the discharge lounge, because the pharmacy was initially not informed of his discharge needs, and then mixed up his medication.

One reason given by staff from all three hospitals (Lens 3) for delays in waiting for medication is that doctors needed to return after assessments were carried out to sign off the (TTA/TTO)18 prescriptions but as they were often pressed for time this did not usually happen promptly. In BRH the wards did have allocated ‘ward pharmacists’ – however ward staff still considered delays in receiving medicines to be the norm.

**Figure 4:**

**The reasons for delay given by patients in the discharge lounges of all three hospitals, who recorded that they were experiencing delays on the day of discharge**

<table>
<thead>
<tr>
<th>Reason for Delay</th>
<th>Number of Mentions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicines only</td>
<td>29</td>
</tr>
<tr>
<td>Hospital transport only</td>
<td>24</td>
</tr>
<tr>
<td>Medicines and test results</td>
<td>17</td>
</tr>
<tr>
<td>Something else only</td>
<td>16</td>
</tr>
<tr>
<td>Discharge letter only</td>
<td>5</td>
</tr>
<tr>
<td>Medicines and discharge letter</td>
<td>5</td>
</tr>
<tr>
<td>Hospital transport and discharge letter</td>
<td>3</td>
</tr>
<tr>
<td>Test results only</td>
<td>3</td>
</tr>
<tr>
<td>Hospital transport and something else</td>
<td>2</td>
</tr>
<tr>
<td>Medicines and something else</td>
<td>2</td>
</tr>
<tr>
<td>Test results, hospital transport and something else</td>
<td>1</td>
</tr>
<tr>
<td>Doctor and discharge letter</td>
<td>1</td>
</tr>
<tr>
<td>Doctor only</td>
<td>1</td>
</tr>
<tr>
<td>Medicines, hospital transport and discharge letter</td>
<td>1</td>
</tr>
<tr>
<td>Medicines and see doctor</td>
<td>1</td>
</tr>
</tbody>
</table>

18 To take out (TTO) and to take away (TTA) are abbreviations used to refer to take out medicines given to patients on discharge from hospital.
PAH ward staff felt that the transport links were also a cause of delays; sometimes inappropriate transportation would be sent for patients with special requirements, or transportation would be delayed (particularly on weekends/evenings). They reported that there had been one central contact for transport for both Essex and Herts, but since then the system had been changed so that transporting a patient back to Hertfordshire had become much more complex. They proposed reintegrating this service to speed up discharge transport services. It was apparent that transport was also a cause of delays at CGH and BRH. In the CGH survey (Lens 1), just under half of participants recorded reasons for a delay on the day of discharge, and of these, a quarter recorded their delay was due to ‘waiting for hospital transport’. An additional two people recorded that they were waiting for ‘transport and something else’, and one more for ‘medicines, hospital transport and a discharge letter’.

When BRH ward staff raised the issue of transport they reported that it often arrived late, which meant if a patient had a home care package, and a carer waiting at their home to assist them, the carer had often had to leave by the time they were dropped home. Emily, a BRH ward nurse, told us that: ‘at the moment, if you book for a certain time they are allowed two hours… so that’s difficult,’ as you do not know when they will arrive or whether the time will be appropriate for the patient’s carers. Fast Track patients were also prioritised with transport which, while beneficial to the Fast Track scheme, was thought to delay everyone else’s discharge. Furthermore, the transport service, run by a private company, employed its drivers for a certain number of hours, and if the time it took to get to a patient’s destination went over these hours they would not be given transport. Delays also had a knock-on effect for those patients who rely on others to take them home from hospital, and family members/friends are recorded as often waiting a number of hours to be able to take the patient home, beginning their transition of care in a negative way.

4.3.2 Delays at weekends

Ward staff at all three hospitals reported that patients with complex care needs could not be discharged during weekends because of the lack of availability of GPs and district nurses during those hours, causing medically fit patients to stay in hospital over the weekend. It was also pointed out that access to the pharmacy at the weekend was limited, and in general the dispensing process from the pharmacy was problematic. Additionally, care staff were pressured to discharge as many patients as possible on Friday in order to empty beds for the weekend and also to avoid letting medically fit patients to stay in the hospital during the weekend.

4.3.3 Delays in transfer of care

Staff interviews and observational data (Lens 3) further revealed that exceedingly long delays in patients being discharged (as opposed to delays on the day of discharge) were commonplace. Ward staff at CGH pointed out that delays in discharge can cause patients to stay in hospital for an unnecessarily long period, especially when elderly, to pick up new infections, institutionalise them, and negatively affect their mental health. Francis (ward staff, CGH) told our researcher about one patient, for whom:

*It’s taken so long for their [patient] care to be organised, they’ve developed another acute condition while they’ve been here… and they’ve stayed in.*
Re-ablement refers to services funded by social care to work with individuals who have support needs to rebuild their confidence, and to support the development of daily living skills.

The service is time-limited and the overall goal is to help people back into their own home or community.

It’s taken so long for their [patient] care to be organised, they’ve developed another acute condition while they’ve been here... and they’ve stayed in.

By the time they do the checklist, they’re either not going to make it out of hospital, or they don’t get here in time, and they’ve already died.

(Francis, ward staff CGH)

These problems were particularly acute at CGH but staff at all three hospitals found it extremely distressing when patients died on the ward while awaiting a care package which would have enabled them to have died in their place of choice.

Staff also often attributed the delays of transfer to short-staffing. Patients who are medically fit to be discharged must be checked over by a doctor and/or therapist, who staff told us (and who we observed) were often overstretched and not readily available. Bill (consultant, CGH) claimed that:

At any one time on any ward there are... up to 50% or more patients who may be medically fit for discharge.

He argued that things would be significantly improved ‘if we had more resources to get these patients seen and get them out’. Similarly, our in-depth interviews with patients (Lens 2) reveal that disorganisation, symptomatic of a shortage of resources, contributed to delayed discharge; Kate a PAH patient who lived in Hertfordshire, told us how she had to stay in hospital a week longer than necessary because Essex and Hertfordshire CCGs could not agree as to who would pay for the dressing for her hip infection which was required following her discharge. Given this expensive treatment and the fiscal constraints facing both parties, neither CCG was willing to take responsibility for the cost. We suggest that the delays were increased further by the fact that PAH resides over two different counties and these led to inconsistencies and confusion surrounding discharging patients from Essex and Herts. As we shall later see, the problem of internally-caused delay was compounded when nursing homes or re-ablement services did not have the capacity to take on patients when they were finally able to be discharged. Furthermore, as PAH was in the unique position of caring for a large number of patients who lived in Hertfordshire as well as Essex, it experienced problems when reinstating care packages, because patients from East Hertfordshire could only have a ward-led restart of care after one week of hospitalisation (whereas in Essex it is after 3 weeks). In other words, if a patient’s stay in hospital was more than one week any pre-existing care package had to be reinstated and the assessments sent to the relevant CCG in Herts, after which the care companies required at least 48 hours to reinstate the care package. This delayed discharge and meant a medically fit patient remained in a bed for several more days than would otherwise have been the case.
4.4 Continuity and coordination of care

Continuity of care is concerned with the quality of care over time. Promoting continuity of care includes fostering continuous, caring relationships between patients, and healthcare providers. It concerns the processes involved in co-ordinating, integrating and personalising care in order to deliver a high quality service (Freeman and Hughes, 2010).

The General Medical Council state in their ‘good medical practice advice’ that doctors must contribute to the safe transfer of patients, between healthcare providers and between health and social care providers. This requires them to share all relevant information with colleagues involved in a patient’s care within and outside the team to include the delegation of care or the referral of a patient to other health or social care providers. Furthermore, the doctor, in this case the hospital doctor, needs to make sure that a patient’s care is handed over to another named doctor.

[Doctors must] check, where practical, that a named clinician or team has taken over responsibility when … [the doctor’s] role in providing a patient’s care has ended. This may be particularly important for patients with impaired capacity or who are vulnerable for other reasons (General Medical Council, 2013)

In order for a patient to be discharged successfully, it is necessary for hospital staff (the ward staff and discharge team) to work together as well as involve the patient's family or carer (if they have one) to assess an appropriate level of post-discharge care for the patient. Patients' may need to be transferred to a care or nursing home; or need re-ablement services; or they may need care within their own home. Staff and services in and out of hospital play an important role in ensuring that patients experience a seamless transition when they move across different care settings or levels of care.

Our study reveals a number of problems relating to patients’ experiences of care continuity and the management and coordination of care. We found that the general limitation on hospital resources hampers the entire discharge process, causing delays because there were not enough staff to process care transitions promptly and because, like acute hospitals, the various locations for care in the community do not have the capacity to care for the number of patients who require them. Furthermore, as we will discuss, for those patients receiving Fast Track because they require EoL care, delays in carrying out assessments meant patients often stayed in hospital for protracted periods of time, and did not end up dying in their place of choice. The final problem for care continuity which we will discuss is the lack of appropriate pathways of care for patients who did not fit the eligibility criteria, as these patients often end of spending more time than necessary in hospital, and are unable to receive appropriate transitional care.

4.4.1 Limited Resources

In this study, various issues surrounding limited resources were raised by staff and patients alike. Limited resources extend to staff shortages, the limited number of care/nursing home placements available and the underfunding of the transport system, communication systems and staff training. Staff (Lens 3) frequently complained that there were insufficient care homes and/or re-ablement services, and lack of equipment to facilitate a smooth transition of care. BRH staff made in-depth complaints to HWE researchers about the transport service, and this extended to transporting equipment for patients to their
homes, which the transport service often did days later than required (particularly over weekends). Complaints regarding the transport service were also made by staff at CGH and PAH, but it was at BRH where the transportation of equipment was mentioned specifically.

4.4.1.1 Residential care

When it comes to ensuring a smooth transition of care, it is important to make sure that each patient is provided with the right care options for their specific situation. However, staff at all three hospitals noted that there were a limited number of available nursing homes in the locality and this number was further reduced when it came to accepting patients with dementia. Staff told us that this made it incredibly difficult to find an appropriate place for the transfer of these patients. Speaking about capacity problems, Amanda (healthcare, PAH) told us:

We have one nursing home, and no nursing homes that deal with dementia nursing care. The home that did is under embargo. It's got safeguarding against it.

BRH staff also had the view that there was simply not enough capacity to house patients appropriately, meaning patients stayed in hospital until a place became vacant:

There is a lot of social needs on this ward, and trying to co-ordinate the person being medically fit, with their care or residential home placement, or whatever it may be, they don't always coordinate. (Emily, ward staff).

This point was also made by several members of staff at PAH and CGH. Sarah, (ward staff, PAH) told our researcher that ‘people may have to stay in hospital for an extended an extended two, or three days because there is no capacity in the community for them.’ Alex (ward staff, CGH) told us that this problem of capacity came about because nursing and care homes, like acute hospitals, did not have the number of beds required, saying: ‘you can’t push a person out of a residential home.’ He also pointed out that re-ablement services, though useful, had a similar problem of capacity, and therefore not all those who required the service received it.

It was also mentioned that care in the community, from district nurses to social care, had diminished, as budget cuts lessened resources. Francis (ward staff, CGH) said:

They were [in the past] a lot more supportive, I think, when we had patients going home who were struggling a bit.

This contributed to delays, as patients had to wait until they were assessed by the nursing or residential care assessor. It also contributed to double assessments as patients were assessed by both the hospital social care team and the nursing/residential care assessor.

BRH staff reported that communicating with privately run social care providers/care homes was difficult, and that they did not take in a very diverse group of patients in terms of their needs levels/financial capacity. This meant some patients could not leave hospital despite being fit to go; Jack (healthcare, BRH) told us:

I've had one patient stay in hospital for probably two months longer than they should have, because you can't find a placement for them, because they are declined, there is no extra support from social care or health. They are stuck on the battle lines and that's it.

In many cases, discharge facilitators had found a care home for the patient, but the patient did then not receive funding, and thus lost their place. This can have particularly distressing consequences for patients who have a terminal illness and who do not want to die in hospital.
4.4.1.2 Staff shortages

Staff shortages were reported at all three hospitals, and were considered by staff to have a very negative impact on the discharge process. The pressure on discharge team staff meant that they were not always able to attend board rounds, and that they often felt overburdened with casework, particularly those in social care. The social care team were perceived by others to be too busy trying to manage existing cases to attend the board meetings, which could then result in communication failure between departments. Francis (ward staff, CGH) added that this situation was the same in the re-ablement team; staff could not manage their caseload, resulting in a backlog of paperwork, and this was causing patients to stay in hospital for longer than necessary. Staff pointed out that no one was actually applying to fill the vacancies available, and Alex (ward staff, CGH) reported that:

*We, as of last month, were running on about 33% of vacancies, with three people off long term sick.*

Similarly, Sarah (ward staff, PAH) reported that they had so many unfilled vacancies that the ward nurses often also assumed care for patients in the discharge lounge, or when their patients moved to another ward, meaning ‘we could, in effect, end up with 32 or 33 patients’ (to 3 nurses per ward). At CGH staff also spoke of a shortage of therapists and doctors, who were needed to look over patients before their assessments could be completed and they could be discharged, causing more unnecessary delay. Doctors were often too overloaded with other duties to perform this assessment and had to be sought out by ward staff.

At BRH, staff also identified the lack of discharge team staff as a key issue; our researcher noted that for a period of several days only one healthcare worker was in charge of complex discharge. At PAH, the discharge team similarly reported they did not have a permanent manager, and the HWE researcher present noted that:

*[Name of discharge facilitator] told me that she has been called to resolve other discharges in the wards and hence she has not managed to finish writing up her assessment, which causes further delays to the patient that the assessment has been done for.*

(Researcher field notes)

Staff at BRH felt that those in managerial positions in the hospital were letting them down, adding to the view espoused by staff from the other hospitals, which was that there was a lack of guidance and overall understanding of their long-term goals and workload. Instead, staff were hopping from case to case trying to deal with whatever came their way first, rather than a planned schedule.

Ward staff in CGH were critical of the employment of agency/bank nurses, which staff shortages led to, as they felt that these nurses made frequent mistakes and did not know the patients well enough to successfully discharge them. At PAH this sentiment was shared, and ward staff reported that the presence of agency nurses only added pressure as they made frequent mistakes and did not know patients’ needs, meaning the ward nurses had to keep an eye on them while carrying out their own duties.

Low resources contributed to an all-round feeling of low morale among staff, in all hospitals. In BRH, staff reported feeling unsupported by hospital management and various teams felt unsupported by their colleagues. This was contributing to the short-staffing problem too; Jack (healthcare, BRH) told us:

*The group is dedicated, there is no doubt about it they are dedicated. Unfortunately... they lose members of staff because it's just not being supported well enough.*
4.4.2  End of life and Fast Track

For patients needing an urgent package of care due to a rapidly deteriorating condition which may be entering a terminal phase, then the Fast Track Tool may be used instead of the Decision Support Tool to confirm eligibility for NHS Continuing Healthcare funding:

*If this is the case, an appropriate clinician will complete the Fast Track Tool and send it directly to the CCG which will arrange for care to be provided as quickly as possible. Occasionally, a CCG may arrange for a review of your needs and arrange a Decision Support Tool to be completed after immediate support has been provided following the completion of a Fast Track Tool. (Department of Health, 2013).*

Staff reported that fewer and fewer people were receiving NHS funded care packages, and as a result of this patients in the terminal phase were sometimes not able to die in the right environment and with the right care. This caused staff considerable distress and was very upsetting for patients and families. Staff at CGH were particularly frustrated by the fact that the North East Essex CCG had recently ‘adjusted criteria’ meaning that there are ‘an increasing number of patients whose CHC [Continuing Health Care] applications are rejected.’ Our researcher noted significantly that:

*One nurse commented that she is unable to predict any more if an application is going to be accepted or not as there are massive variations [in who is accepted]. (Researcher field notes).*

During the study our researchers witnessed a number of cases where patients died while waiting for decisions regarding EoL (End of Life) to be agreed upon and implemented. The inability to change the CCG’s decisions, while seeing first-hand how it affects patients, caused ‘moral distress’ among staff and contributed to low morale among all those involved in discharge process. A staff member at CGH suggested this may be due to budget cuts, which they felt also increased the pressure to provide post-discharge care on social care workers within the discharge team, who were already under pressure:

*I think the biggest reason for those tensions is that the social workers work to the new Care Act that was introduced this year in April, and it clearly says in the Care Act that if somebody should be entitled to continuing healthcare, by law they shouldn’t be providing the social care.*

(Sophie, Healthcare CGH)

Our researcher observed, and staff told us, that because of these reasons discharge was disorganised and delayed. Access to EoL care was an issue for both PAH and BRH as well. PAH ward staff made the point that Fast Track continuing care assessments would often take weeks to come through - despite being designed to prevent EoL patients dying in hospital, because their assessments are stuck behind a mass of paperwork. Annie, a ward nurse, said ‘we have some [patients] for whom Fast Track has been weeks.’ This issue was also raised extensively by staff in BRH. Emily, a ward staff member, explained that Fast Track was not able to perform its function because it was often the case that one staff member was responsible for assessing and Fast Tracking a list of ‘four to five’ patients.

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By the time they come to do the assessment, [the patients] are too unwell to be discharged from the hospital... you have patients who would like to go to the hospice but they can't... So it's really tricky. So very sad.

Angeline,21 another member of the ward staff at PAH, informed us that the previous week an elderly lady had waited for four weeks to receive End of Life fast track. Although she was already in a home, [the] nursing home came to review her and [they] agreed to take her back 'but what they wanted was continuing healthcare because you get more funding.'

4.4.3 A lack of care pathways

Across all three hospitals we observed that some patients had become stuck in a system of continuous assessment because they did not necessarily fit into the criteria for the available pathways of care. In some cases, CGH staff pointed out, there did not seem to be an appropriate track for some patients (such as those with delirium) and these patients either remained in hospital beds unnecessarily, or went down a different track which did not provide adequate care. This point was raised in BRH – Emily (ward staff) gave the example of an elderly lady who was medically fit but had delirium as a result of her medication:

The only resolution was the lady remained in an acute bed for four weeks while her delirium resolved. The delirium did resolve, she regained capacity, she returned home to independent living. That to me is not the ideal use of acute hospital beds.

Some staff at CGH suggested that hospitals were not the appropriate places to make assessments for continuing care needs, especially for patients with diminished cognitive abilities, and that seeing the patient in their own home would give a better idea of their post-discharge care needs. Staff in BRH agreed, and suggested that if a patient was assessed at home a lesser care package would be required because they would be in a more familiar environment. Staff believed it would be better for the patient to be assessed at home, but also acknowledged because of their delirium and or dementia, there was not an effective track to get them home and care for them there safely. These patients ended up staying in hospital because this type of discharge pathway was not available.

This issue was also raised by a BRH social worker, Hannah, who told us that there were no longer any opportunities to create new pathways of care, as there had been previously. She said:

That's what we need to do with the Delirium Pathway, and I've been trying to do that for years, but haven't been able to get any interest whatsoever in anybody doing it, because nobody has got any money.

Staff at BRH also reported that there was extra difficulty when trying to find a care/nursing home for patients with dementia, or patients who were showing signs of delirium which could not be predicted to be either permanent or temporary. In some cases, patients who were admitted to hospital from a care home, and then diagnosed with dementia in hospital, were not allowed to return to the care home. This delayed discharge and could be distressing for the patient. Patients who needed a mental health assessment were delayed even more by the long waiting lists for those who needed to be seen by the mental health team, who carried out these tests. Re-ablement services, though considered generally a positive approach to getting patients home, disallowed patients with delirium/dementia through the assessment.

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21 Angeline is a pseudonym for the staff member who in the PAH report is known as 'Angela'.
4.4.4 Problems after leaving the hospital

Our interviews with patients and family/carers (Lens 2) reveal in more depth the problems faced when it comes to post-discharge care, particularly regarding the organising of follow-up care such as physiotherapy or check-ups. Jim, a patient at PAH, was given minimal information regarding follow-ups, and had been promised physiotherapy, but hadn’t seen or heard from anyone when we interviewed him two months following his discharge. He did not know if the doctors had organised it for him, or if in fact he was meant to organise it himself:

_I was expecting them to pop in maybe once a day or do they write to the doctor and he organises it?_

Jim had also not been contacted by a respiratory consultant for a separate follow-up appointment. He argued that the confusing process post-discharge, where he (like many other participants) had to organise going ‘back to the doctor, back to hospital’ for medical health assessments and medicines, was indicative of disorganisation, and was an illogical way to organise transition of care, creating ‘such a waste of resources and money’.

Kate, a patient in her 50s at PAH, and who lived alone in Herts, had a similar experience when discharged; she was given no follow-up appointments, despite being told she would be contacted about one at some point after her discharge. ‘Seven or eight weeks’ later she had received nothing and had to try and make contact herself, eventually leaving an answerphone message at the clinic, which was never replied to. Kate, who was a recovering alcoholic, reported how her negative discharge had made her worried for her mental health:

_I said, ‘I don’t want this to make me go back on the drink again because I have done so well for seven to eight years,’... I haven’t had any thoughts of doing it but because of everything that is going on….Now I have got answers and I am alright, but it still left me traumatised._

Kate’s experience chimes with the experience of many others, and it is evident that a negative discharge experience can lead to feelings of anxiety, stress and depression, in which people, who are already worried about their illness, feel unheard by health and social care services.

It is crucial to a smooth transition of care that carers be treated as partners in care; if they are not communicated with properly regarding care needs, the discharge process can be uncoordinated and stressful. Annie, the wife and main carer of an elderly patient (Eric) at CGH, certainly felt this way:

_They sent the medication and the bag that was for a rescue pack, but didn’t explain to me... they didn’t explain to me how to use it. They did [to my husband], but he wasn’t very well._

This comment bears similarity to a carer remarking in the PAH survey that you cannot necessarily assume that the patients themselves, if they are ill or suffering from dementia, should be the only recipients of their care instructions, as if their carers are not fully informed there will be a breakdown in the transition of care. Similarly to Kate and John, Eric and his wife had been told he had appointments with primary and secondary care services planned as visits in the home, but had heard nothing since leaving hospital.

Such disjointed accounts of discharge situations even extended to some participants leaving hospital without their healthcare needs being assessed, and in the case of one interviewee
who had been admitted with knee problems, John (CGH), being discharged at 10.30pm, with 36 stairs to climb in his flat. John already felt he had been discharged prematurely, and had not been offered a physiotherapy appointment or asked if anyone was at home to look after him. He was readmitted a few days later. This reflects the view of other patients we spoke to, who felt staff were not approaching their illness and its impact with sensitivity, and did not consider how it would affect their ability to continue with their daily lives (and likewise for their carers). In a small number of cases, when interviews were carried out in people’s homes following their discharge (Lens 2), we witnessed first-hand that some people who were deemed as having no need for support were struggling, often with basic tasks. Many did not feel well/fit enough to go out to get grocery shopping. In a number of instances, we referred cases to Community Agents Essex.22

4.4.4.1 Lack of information regarding post-discharge care

A lack of continuity in post-discharge care was reported by patients we interviewed from all three hospitals. At BRH, the majority of our survey participants (Lens 1) were discharged with no further formal support, and said they would look to a family member/friend for support – while at the same time 8% reported they did not feel confident about looking after themselves once home. This was compounded by factors mentioned previously, for example, not being provided with a formal discharge plan, and two separate elderly individuals at BRH whose regular medicines had been changed without explanation or warning. Others also reported feelings of anxiety surrounding the transition out of hospital as they were unsure about what follow-up care they would receive and how, and when, hospital and other appointments would occur post-discharge.

Figure 5:
The graph below tells us how many survey participants (Lens 1) in each hospital knew, by the time they had reached the discharge lounge, who to contact if they had any worries or questions regarding their discharge

[Figure showing the percentage of survey participants who knew who to contact in each hospital]

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22 Community Agents Essex provide a service delivered through a community and voluntary sector partnership to support older people and informal carers to find and develop independent living solutions from within their local community.
At PAH, though 61% of survey participants rated the arrangements made for their leaving as excellent or good, 39% rated it as fair/poor/very poor (10%). One specific example of this was a delay caused because a care package had not been organised in time, though the patient had been fit to leave the day before; this example emphasises how disorganisation surrounding transition of care can cause delays which take up beds with otherwise healthy patients. The problem of not being accurately informed regarding post-discharge care is most often caused by a breakdown of communication, either between staff members/different teams, or between patient/carers and staff. This is discussed in further detail in the section below.

### 4.5 Information and communication ruptures

It is vital that the individuals and groups involved in facilitating a positive hospital discharge communicate clearly and share information throughout the entirety of the process; however, this involves regular communication between families, carers, patients the various different hospital teams involved. This means that without the right systems for communication in place, and with hospitals and their discharge teams already under-staffed and under pressure, it is easy for a breakdown in communication to occur - and this was reported to be the case by both staff and patients at CGH, BRH and PAH.

#### 4.5.1 Poorly involved and informed patients

Understanding how and why miscommunication occurs is key to assessing why patients and/or carers may have felt uninvolved in the discharge process. Our research tells us that the better communication and involvement is, the better the overall experience is for the patient and/or carer. For instance, Claire, talked about the good quality information she received upon discharge:

> A thorough consultation took place prior to discharge regarding medication, all of which was listed and administered for use at home, i.e. existing pills that I'd taken in and am on... I was encouraged to ask questions, given details of follow-up visits and general idea of length of treatment. You weren't kept in the dark.

However, our participants often complained that they were not communicated with properly, and that this led to numerous further problems; for example, if a patient's post-discharge care was inappropriate, if they were discharged before fully recovering, or if their medicines were not explained, there was a likelihood they would be re-admitted.

The initial survey (Lens 1) identified a lack of information as a key issue affecting discharge experience at all three hospitals. As we have already shown, patients often felt 'out of the loop' as to their own progress, often up to the point when a member of staff would tell them, without warning, that they were going to be discharged. At PAH, of the 80% of participants who had been given medication, 29% did not understand the side effects, 14% did not understand its purpose, and 13% did not understand how and when to take the medicine. One BRH survey respondent echoed the feelings of many who partook, saying:

> it was nothing to do with me - they were arranging my discharge.

I was encouraged to ask questions, given details of follow-up visits and general idea of length of treatment.
Almost half of the BRH discharge lounge participants reported that they did not think they had been given a formal discharge plan. Likewise, 37% of the PAH sample reported they were unsure as to whether they had received one. In PAH, 48% reported not being told who to contact if worried, and 43% said they had not been warned about danger signs to watch out for. At CGH, 23% of participants reported they did not know who to contact if worried and 30% did not know what danger signs to watch out for.

Jim (PAH), who we have discussed previously and who was the main carer for his disabled daughter, reported expressing worries to hospital staff regarding his discharge which were not listened to; about both not being able to cope in his home situation, and not feeling himself physically fit to be discharged. He said:

*I am single with my daughter, but they don’t know the set-up. They are not really interested; as long as you are medically well, they don’t want to know.*

He was not asked about his living arrangements, and was unable to communicate his fears about whether he would still be able to look after his daughter. However, if the healthcare team had discussed how his care needs might be met in the community, Jim may have been able to keep caring for his daughter, while receiving support himself. A similar experience was reported by David, a CGH patient in his 70s who lived with his wife. David reported that:

*The doctor said, ‘oh, you can go home,’ [but] never really gave me any clue as to what I had to do, whether I had to go back to my doctor, whether I just carry on taking the tablets which they gave me.*

David reports a similar experience of being told he could leave without having been told how to care for himself post-discharge, though he had been given the medication, he did not know how to use it, or whether he had to make arrangements himself for seeing a doctor.

Kate (PAH), as previously discussed, required a special dressing for her hip wound that the local CCGs did not want to pay for and, as a result of this, she stayed in hospital for an extra week. She told us that if she had been communicated with properly and updated on her situation, she would have been able to leave much earlier. She remembers saying to a nurse: ‘Do you mean to say I have been in here for a week because if it had to be I would have paid for it [the dressing]’! Kate also felt uninvolved in her own discharge process as she felt she should have been discharged to a specialist centre before going home, where she could be given all the information that she needed regarding caring for her illness. However, despite her wishes, she was eventually discharged without any information regarding the cause of her illness, and with no follow-ups planned for her in the community. She suggested how an improvement of communication channels might have had a positive impact on her experience:

*‘What they could have done was given me more answers or helped me to go and see somebody who I needed to go and see. That is what they should have done, given me a referral letter’.*

Further, it is not always the patient who should be the sole recipient of information. The story presented in appendix iii of this report, of Samantha and her daughter/carer Fiona, exemplifies the fact that if a patient’s carer is not also fully informed, their discharge can be severely disrupted.
4.5.2 Family/carer involvement

Staff failing to communicate vital discharge information extended to carers and/or family members not being informed on how to care for patients once home: being given no information on how to administer medicine; how to watch out for side effects; or who to contact if they felt worried. This is pertinent not least because the vast majority of elderly patients in each hospital were being discharged home, and reported they would look to family and/or friends for support (for example, in Colchester, 70% of survey respondents were being discharged home with no further formal support, and 70% of respondents also said they would look to friend/family for support). Not having the correct information is thus a great cause of anxiety, especially for those living with comorbidities and existing health conditions.

Less than half of the participants in CGH reported that their friends and/or family had been given appropriate information to care for them. In particular, the carer of an 80-year-old patient wrote in the survey that they had not been informed of the purpose of his medication or when it should be taken. These results reflect the fact that staff were often not treating carers as partners in care who also need the relevant information for post-discharge care. Twenty-four percent of the sample at PAH reported staff had not given their family and/or friends the appropriate information, with one carer making the point that patients with dementia must be communicated with differently, staff ‘must liaise with the carers much more closely and listen to what they say’.

Our in-depth interviews with patients and family carers (Lens 2) reveal that being involved in the planning process was inextricably linked to a positive experience. Where patients and/or carers felt they were not involved they felt a loss of control, and their not knowing created unforeseen obstacles for planning ahead and life in general post-discharge. For example, when patients were not informed of their discharge date, their family and/or carers could not make arrangements for caring for them at home, or even know when to pick them up. Fiona spoke of a similar experience when visiting her mother Samantha in hospital (BRH):

*When I turned up on Wednesday, mum was sitting there ready to come home… they hadn’t telephoned me like they said they would, so I wasn’t prepared to take mum home.*

Eric (CGH), a patient in his 70s, told us he was given no warning of his impending discharge until the day when a staff member told him ‘you’re going home today’. This caused distress to both Eric and his elderly wife (who was his main carer), as they had been provided with little to no information regarding his care.

*They are not really interested; as long as you are medically well, they don’t want to know.*
4.5.3 Staff perceptions of and communication with patients’ families

Although our Lens 2 interviews provided the perspective of patients and carers, when staff were interviewed (Lens 3) about their experience of working with families, they often provided contrasting perspectives on the problems they faced when communicating with a patient’s family and/or carers. Another issue staff raised, when questioned about their interactions with patients’ families, was that often family dynamics were played out during a patient’s hospitalisation and that this could disrupt the smooth running of the discharge process. Staff at CGH reported some families were ‘difficult’ and disrupted discharge by raising unnecessary concerns about the patient’s living situation and described many of them as ‘overprotective’. PAH ward staff agreed claiming that families often complicated the discharge process, particularly after a decision had been made regarding a patient’s discharge. Families’ refusal to take a patient relative home or to sign the discharge form until they approved of its content, was reported to be frustrating for nurses who felt they were following protocol that the family didn’t understand. Helen told us:

*It’s not their decision to make, unfortunately. We can’t always put people in a care home, especially if they’ve never had a care package before.*

This chimed with reports from BRH staff of patients’ families demanding the impossible, exceeding the limits of the kind of care that staff could lawfully provide. Abi, from their social care team, told us:

*It is quite challenging when you speak with a family that is very over-protective and they demand miracles. They demand that we put something in place that is completely unrealistic and would, I’d say, would disable that person who may be, after a few weeks with re-ablement, become independent again.*

At BRH, staff noted that some families did not seem to have organised anything for the patient prior to the time of discharge, and it was often only at this point that they raised concerns. One nurse mentioned that discharge, especially of the elderly, can often cause undisputed family issues to come to the fore, for example, disputes regarding who would be looking after the patient. Some families refused to take their relatives home, insisting on a care home, and this is simply left to the staff to organise. Staff also mentioned that they relied on families for practical discharge assistance, such as picking up the patient or bringing them house keys, and if a family was hard to communicate with, these small issues prevented or delayed discharge. BRH staff also pointed out that if the wishes of the patient and the family clashed, they had to follow the wishes of the patient although this could anger the family; for example, if an elderly patient wants to return to living at home.

Julia (ward staff, PAH) also noted that it is difficult to know who the best person is to communicate with, who exactly should be treated as the partner in care? She told our researcher:

*Sometimes it is hard to work out who is who and what place they have in the family... sometimes it’s a friend that’s got more significance to a person in their family perhaps, as you have to get to know them.*

I think there needs to be more clarity. I think the process needs to be explained earlier...
BRH staff did point out that trying to communicate with families could be further complicated when communication between staff failed, and families were provided with the wrong or misleading information. The most common example of this is when ward staff told patients and/or families that they would be entitled to a form of continuing healthcare they may not in fact qualify for. Hannah (healthcare, BRH) reported that:

_Doctors tell the family well they should get the funding but it’s not based on their diagnosis, it’s on their needs. Doctors automatically think they should get it. Until you’re sat in the meeting hearing the evidence, you can’t say whether they’re eligible or not._

Another staff member at BRH suggested the best way to deal with families was managing expectations and this was only possible with clear communication, which took into account the families’ feelings too. Jack, (healthcare, BRH) told us:

_It is always about expectations… they’ve got their own thing in mind and they want to have a conversation about that._

Other staff members suggested the best way to communicate with patients and their families would be to introduce them to the workings of the process much earlier on, so conflict and protracted discussion was avoided when it came to the point of discharge:

_I think there needs to be more clarity. I think the process needs to be explained earlier of how it’s going to work, and maybe even with a letter saying how it works, exactly what it means, what is expected of them, what we are going to do, when they can appeal, and what we’re asking for when we ask them to sign a document. (Amelia, discharge team, PAH)_

Staff perceptions about patients’ families contrasted with what family members told us. Samantha’s daughter Fiona (BRH), for example, told us how she repeatedly asked to be kept informed about her mother and to be notified when she might be discharged and yet on both occasions, during her mother’s initial and subsequent hospital stay, she was not kept informed and was unable to prepare for her mother’s discharge. Also in our observational research of the discharge teams, we witnessed variation in whether there was direct communication and contact taking place between patient family members and the staff arranging discharge. Systems and means of communication were also very poor. For example, discharge team staff did not make good use of mobile phones or other devices to keep in touch with family members by phone or text.

### 4.5.4 Poor communication between staff and organisations

During this study, it became evident that channels of communication between the different teams involved in discharge planning regularly broke down. From our observational and interview research data, we discovered communication deficits across the hospitals with regards to their communication practices on discharge planning. We identified these deficits in a range of activities, including lack of collaborative work on patient updates, misplaced focus on board rounds, problematic hand-overs, ineffective write up of medical notes, and problematic information sharing within and between hospital staff and external organisations (i.e. CCGs). Communication deficits in these activities led and contributed to premature and delayed discharges, as well as affected clinician job satisfaction.
At BRH hospital staff (complex discharge team) provided mixed accounts regarding their communication with each other. Some participants described their communication with their health or social care colleagues as particularly problematic whereas others described it as at least functional. The participants that described communication as problematic, and particularly the social care workers, linked it with the presence of a blame culture within the discharge team, whereas the rest of participants did not make this association. Participants reported that poor communication spanned through the hierarchy of the discharge team, from the management to the frontline staff. In regards to management, participants mainly talked about the complex structure of the social care team, as it prevented them from establishing clear communication channels for exchanging and acting upon the information they received from each other. For example, Maria, a member of the BRH health care team, talked about the challenges that her team faced when they needed to communicate and organise discharges with the managers of the social care team:

> So since I have been here social care have gone through a restructure; so that has caused a lot of angst because there have been a lot of unhappy people not happy with what they have got out of that restructure. Plus also they have put in two managers now where we only had one. So at least you knew where to go... So that wasn’t resolved for a while about who was dealing with the Acute and who was doing Community. There is that real disconnect between the teams; so [name of SW] for instance, very good, chases, tracks, comes down to the eleven o’clock, comes back at half past three, gives us updates. Is on everybody’s case. Does what you want her to do and keeps you in the loop for all of that. The other managers don’t do that and they don’t take that, they kind of think, ‘Well we’re social care and we’re over here and we do our bit and you do yours.’

Participants from both the health and social care teams talked about the unwillingness of each side to exchange and share information, create partnerships and collaborate on discharging patients:

> They do make it sometimes feel like it’s us personally. Sometimes communication between us isn’t very good. We can be waiting days for updates. Then sometimes they come and update one person but that information might not get communicated through. Sometimes the band sixes feel like we don’t know what’s going on because the social care aren’t communicating it to us. (Sophie, healthcare, BRH)

Similarly, social care staff described the communication with their health colleagues as inconsistent; they reported that they did not receive regular updates about patients’ discharge status and that they were frequently blamed about delayed discharges.
I always put on them, ‘Please advise of the outcome,’ but they never do that, so sometimes, we don’t have that audit trail. I know everybody is really busy and it’s a very hectic environment to work in. (Hannah, social care, BRH)

Participants that worked in the social care team, reported that they were unduly blamed for delaying and causing problems in the discharge process. These participants talked about an emerging blame culture that appeared to prevent them from creating stronger partnerships and collaborative work with their health care colleagues. For instance, a social worker talked about his experience working within the social care team and his interactions with his healthcare colleagues:

Generally, it’s not too bad, but I think it’s very much a case that they try and blame each other a lot. The discharge team will try and blame us, and in turn, we’ll try and blame other things. (Adam, social care, BRH)

A main component of the blame culture was the lack of trust between the teams. We noted that many times the social care team requested further assessments in order to make sure that their health care colleagues did not refer a patient whose care needs could have been met by the NHS. This resulted in an increasing number of redundant assessments (as in the majority of occasions the patients did not qualify for NHS funded care) that further delayed the discharge process, added further pressure to the health care team, and influenced negatively patients and their families discharge experience. Similarly though, we observed that the health care team criticised their social care colleagues for not attending the board rounds – whilst they also did the same thing – and for not providing accurate information on discharge planning.

Poor communication between the discharge team and ward staff was also present at CGH. Processes that had been established to facilitate knowledge sharing did not or partially worked and communication on discharge planning processes was frequently ruptured. Both issues had direct and indirect impact to patients and their families’ experience of discharge. For instance, despite the fact that a proportion of participants described the ward board rounds as a good opportunity to exchange and share information (which indeed it was), our researchers noted variations between wards on how well focused their board rounds were on discharge planning. Whereas some wards used the board round as an opportunity to share knowledge and facilitate discharge planning, other wards did not appear so much involved in the process. Instead these wards used the board round primarily as an opportunity to exchange information on patients’ health needs and not planning ahead for their care needs upon discharge. In these wards our researchers noted that the discharge facilitator was an observer of the process and not an active participant of the board round.

Further, knowledge sharing and communication between the discharge team and ward staff were also variable. Whereas some ward staff were aware of discharge planning processes and facilitated the discharge team, in the majority of wards the staff were rarely willing to get involved, and when they did, their involvement had frequently adverse effects in discharge planning. Sending inappropriate discharge notifications and providing patients and their families with incorrect information about discharge planning were examples that participants used to illustrate communication ruptures and problems with knowledge sharing between the discharge team
and ward staff. For instance, many participants highlighted the fact that patients usually received contradictory information on their discharge planning from a range of different sources. Doctors frequently said to patients that they qualified for a particular care package whereas (specialist) nurses said that they qualified for another one. Despite the fact that ward staff had met with the discharge facilitator in the board round, our researchers noted that ward staff provided information to patients without any prior consultation with the members of the discharge team (either health or social care):

**Doctors will say one thing. We went through a spate where all the doctors were going, “This person’s palliative, this person’s for fast track, this person” and they were telling families and telling the patients that they would get full funding, but then the fast track was getting rejected and they were going via social care. That was causing a few complaints and a few problems from our point of view because we’re the discharge team, we’re the ones that make that recommendation, not the consultants. (Sally, healthcare, CGH)**

Similar problems were also reported by hospital staff in PAH. Here, the lack of effective communication practices between hospital staff led and contributed to inter-professional conflicts. Many participants reported that their professional judgement was de-valued and replaced by the opinion of the ward staff, which set up an expectation for patients and their families that the discharge team had to meet:

**I think, personally, and I think a lot of my colleagues would agree, that we get sent referrals with all the information on it and then it gets documented that the person needs residential placement. It seems like they’ve done the assessment before us going in and actually assessing people. (Ariana, social care, PAH)**

A small proportion of participants, and in particular the social workers, reported that the de-valuation of their professional judgement coupled with the difficulties in collaborating with the ward staff contributed to feeling as an outsider and unwelcome in the hospital wards:

**A massive challenge is it’s not easy to work together with other different professionals. There are so many things that affect multi-discipline, working in some of the things include power. Other professionals will feel they’re more powerful. There is a lot of dominance as well. When you walk into the ward there’s a ward manager, there are nurses, there are doctors, and you are like an outsider because you’re coming from the outside. (May, socialcare, PAH)**

The absence of clear and genuine communication between hospital staff led and contributed to premature and delayed discharges. Additionally, poor communication between the hospital and local CCGs further complicated discharge planning for both the patients and the care staff. This was particularly the case for CGH, where such communication deficits contributed to poor patient experience and affected clinician job satisfaction. For example, during the study, many NHS continuing healthcare fast tracked applications were rejected, causing much distress to patients, families, and care staff. Many participants from the complex discharge team reported that they were uncertain for the sudden increase of deferred patients, and therefore, they had asked to meet with the panel to rectify the problem:

**When you walk into the ward there’s a ward manager, there are nurses, there are doctors, and you are like an outsider because you’re coming from the outside.**
We have asked them to have a meeting and to look at some case scenarios and to say, 'Why did you accept that one and not that one?' And we were promised that about six months ago and we still haven't had it. So that is what I went back to last week and said, 'Look you promised this six months ago, we've still not had it. We need to understand'.

(Taylor, healthcare, CGH)

Owing to poor communication between the CCG and the complex discharge team, who was responsible for the assessments, several patients, against their wishes, died in the hospital. Many participants reported that they were particularly upset about this issue; they also described it as unfair towards the families and the patients:

I've had two people recently die after being rejected for fast-track in hospital, and it's not particularly fair on them or the family, especially if their wish has been to die at home. (Suzanne, social care, CGH)

Poor communication between hospital staff as well as between departments in the wider health system, has negative effects on discharge planning and can affect clinician job satisfaction.

4.5.5 Systems of communication

We also observed some technical problems which either caused communication breakdowns, or considerably slowed down means of communication. For example, staff at all three hospitals used faxes to arrange aspects of discharge, and staff at CGH in particular criticised this system as 'old-fashioned' and 'unreliable'. At PAH there were also problems with the IT system (JONAH); namely, not everyone knew how to use it, which could potentially have a serious impact on a patient’s care if the wrong information was entered. Bella (healthcare staff, PAH) said of the IT system:

Sometimes it's accurate, sometimes it's not accurate. It's that you can't rely on it. It's only as good as the information that's put on it by the person who's putting it on.

Because staff did not trust the information on it, the computer system had very little effect whatsoever - arguably, though, if used appropriately, it could be very useful in speeding up the discharge process by centring all information about a patient, along with their assessments, in one easily accessible place. Instead, to understand a patient's medical notes, staff had to look for the paper version or find the relevant member of staff, which slowed the process considerably. Some nurses suggested that proper training in the use of the IT system and how it could be used to aid the discharge process, was needed for less experienced members of staff - however, they felt they simply wouldn't have the time to do this training until the wards were better staffed.

Other staff at BRH complained that there was a lack of administrative process regarding discharge. Our researcher observed information being written by discharge team staff on scraps of paper and then placed in pockets, which were forgotten about till later on. Like at CGH, staff here also complained about the faxing system and that they often had to repeat the same information on to paper, on to computer records, via fax and telephone, and then also face-to-face. These complaints at BRH and CGH were replicated at PAH, where all staff pointed out that the time spent chasing up communication meant time lost for communicating with patients. Some staff members suggested a standardised approach to discharge was needed, and that the creation of simpler paperwork for needs assessments, incorporating both ward and discharge staff in the same document, would help to avoid delay and mistrust of each other's assessments.
Patients too felt that while staff were willing to help, they were working to a chaotic system and did not always have the right information to hand. Tom, at BRH, suggested that though staff were busy and hard to locate, it was not their fault as they were clearly working under pressure. He said:

*This suggests a sense of patient agreement that, with systematic improvement and reform of communication channels, the process would be a more positive experience for both patients and staff.*

4.5.6 A lack of integration: Tensions between and within teams

Tensions arose for several reasons across hospitals: firstly, because teams were short-staffed and burdened with high caseloads (particularly social care); secondly, as a result of the problematic communication between staff and departments; and lastly, because there was a lack of meaningful integration (different teams did not understand each other’s needs and lack of pooled budgets). It was observed that there was some causal attribution contained within hospital DTOC (Delayed Transfers of Care) reports, in which responsibility for issues associated with the delays are classified as either ‘health’, ‘social care’ or ‘both’. This, along with difficulties in differentiating and assessing whether a patient was eligible for health or social care support following discharge, resulted in at the very least tension and at worse an emergent blame culture.

4.5.6.1 Tension between the health team and social care team (within the discharge team)

While in some hospitals the discharge team members worked in a more integrated way, tensions arose between health and social care teams to some extent at all three hospitals. Staff at CGH reported that their relocation to joint offices was positive in facilitating knowledge-sharing and collaboration on discharge cases, but pointed out that they still worked to different rules and regulations. Judy (social care, CGH) spoke of the difference it made to work in an integrated office:

*We are integrated in a sense of in the office and there is a lot of joint work going on, but we are still very fragmented.*

This demonstrates that though personal relations might have improved while the teams shared the same office space, without jointly funded care pathways, and without sharing assessments or the same electronic files for patients, ‘integration’ did not necessarily mean successful collaboration. At PAH, health and social care staff both reported this lack of collaborative work was the cause of some tension between the two teams; they both felt pressure from the other side to do more than they reasonably could, and yet did not appear to recognise the type of pressure the other team was also experiencing. Pressures from the health team, who were in need of beds, only added to this feeling of overload. May, (social care PAH), told us:

*I really appreciate they need the beds...but sometimes the pressure we get is very insensitive.*

Healthcare staff reported in turn that social care often didn’t trust their assessment of patients, and asked them to carry out further checklists to make sure they didn’t need to be referred to social care when they could receive continuing care from the NHS.

In CGH tensions between the health and social care teams were mainly due to the increasing caseload of the social care team because of the high numbers of people who were rejected for fast-track NHS Continuing healthcare package.

*We are integrated in a sense of in the office and there is a lot of joint work going on, but we are still very fragmented.*
I think the biggest reason for those tensions is that the social workers work to the new Care Act that was introduced this year in April, and it clearly says in the Care Act that if somebody should be entitled to continuing healthcare, by law they shouldn’t be providing the social care. (Sophie, healthcare, CGH)

Our findings indicate the unintended consequences of decisions taken at a managerial level on frontline healthcare staff’s ability to work collaboratively.

4.5.6.2 Problems between the discharge team and the ward staff (and wider hospital staff)

Further tensions regarding internal communication arose between the discharge team and ward staff. Here, our findings indicate that tensions arose because the ward staff were not aware of the role of the complex discharge team within the hospital. Across the hospitals, we noted that, whereas in some wards the ward staff welcomed the members of the complex discharge team and viewed them as an essential ‘tool’ for the smooth running of the ward, in other wards, staff were apprehensive to collaborate and work with the discharge facilitators. Through our interview data we gained further insights on how ward staff and discharge facilitators viewed each other.

At PAH ward staff told our researchers that they felt the discharge team were removed from the reality of the patients’ illnesses and, unlike ward staff who cared for them day-to-day, were unable to identify their correct care needs. Jenny (ward staff, PAH) reported that:

They go along their set criteria as opposed to treating them [patients] as individuals.

This, in Jenny’s eyes, meant that patients were often given inadequate or inappropriate care, and she added that she was ‘not convinced we’re working seamlessly with social care.’ These tensions surrounding non-collaboration of teams at PAH were reported to sometimes cause interpersonal conflicts and power struggles. This was mainly due to the different teams’ separate ways of viewing patient needs post-discharge. Ward staff and the healthcare teams tended to see them in terms of their medical needs, whereas discharge staff, especially social care, saw their needs in a more holistic model (promoting autonomy and choice of the patient). These different ways of seeing the patient were often communicated to the family by one team, giving them expectations that the other team had to disappoint. Sometimes doctors told patients/carers they were eligible for something they were not and social care staff had to tell them this wasn’t in fact possible. Bella (healthcare, PAH) told us:

Every day is a challenge if you’re planning a discharge because how you may see it might not be the same as how your consultant or your ward doctor see it.

Both teams agreed that good communication was key, and providing patients with clear information should be the aim. However, researchers at PAH reported that the arising tensions led some staff, particularly social workers, to feel like outsiders whose professional judgement was undervalued, and this feeling of being unwelcome in the wards further drove a wedge between the teams and prevented necessary integration. May, a member of the discharge team responsible for social care at PAH, told us:
It’s not easy to work together with other different professionals. There are so many things that affect multi-discipline… There is a lot of dominance as well. When you walk into the ward there’s a ward manager, there are nurses, there are doctors, and you are like an outsider because you’re coming from the outside. There are a lot of problems with the other professionals. They sometimes make their own decisions based on their own perspective, their professional values, professional judgements, and when we walk in they’ve already made decisions. They’ve told the families that, ‘Oh your father is going to a care home.’ Something like that. So when you sit down and see that this person can go home... it will be so difficult to tell the families.

At BRH, staff reported feeling like various different teams (discharge team, ward staff, managers) were not aware of the correct delegation of responsibilities, such as who should send notifications of discharge, arrange assessments, and time the overall structure of discharge events. This was a common theme in all of the hospitals, indicative of a lack of direction and/or structure. The discharge team felt that the ward staff were inhibiting the discharge process at some points because they had no or limited understanding of the process, meaning they sent referrals too early and/or did not update the discharge team about the patient’s progress. The HWE researcher who was present, while shadowing a discharge team member at BRH, witnessed first-hand how fraught the relationship could be at times:

I visited (the ward) today with Jack. It was the first time that I had seen a nurse talking so abruptly and disrespectfully to another member of staff. Clearly that nurse did not want to share information and work collaboratively with Jack. (Researcher field notes)

Like at PAH, there existed an antagonistic relationship between ward staff and the social care team at BRH; so much so, that some social care staff claimed that on occasions the ward staff had been told to delay giving them information about patients as an act of sabotage, so that they took the blame for the delayed discharges. Adam (social care, BRH) told us:

They were told not to. The discharge coordinators told them not to... the nurses would say to me, I can’t do it. I’ve been told I can’t.

Our researcher additionally noted that ward staff at BRH had poor internal methods of communication and that they did not update each other properly as to the patients’ progress during handovers of medical notes. The notes were often badly written and not concise enough. This meant that, despite being present at board rounds, they often hadn’t got the right information. It also meant that discharge staff had to search for ward staff. Similar problems of incorrect information on medical notes leading to delays were also reported at CGH and PAH.

They sometimes make their own decisions based on their own perspective, their professional values, professional judgements, and when we walk in they’ve already made decisions.
5. Concluding Discussion

5.1 Concluding discussion

The issues we discuss in this report present a worrying picture of how hospital discharge is experienced by patients and family care givers. However, previous research (see appendix i) shows that these are not uncommon research findings. Our findings largely chime with national research on patient and carer experience of hospital discharge carried out over the previous ten years. However, despite this and the recommendations made as a result, many of which have been embedded within national guidelines and initiatives, these problems have not only persisted but have increased dramatically in scale in recent years. A recent report by the National Audit Office (2016), which examines how effectively the health and social care system is managing the discharge of older patients from hospital, highlights the rapidly increasing economic and social cost of increasing hospital admissions and delayed transfers of care. During a four-month period in 2015, that coincided with the time our study was carried out, we estimate the total cost of providing acute hospital beds for patients who are formally classified as ‘delayed transfers of care’ to be between £1,856,660 to £2,856,400 (for CGH, BRH and PAH combined). Nationally, the number of delayed transfers of care has increased dramatically and January 2016 saw the largest number of “snapshot” patients reported in any month since monthly data collection began in August 2010 (NHS England, 2016). Delays where the patient was awaiting further non-acute NHS care made up the largest number of delays in 2015/16, with 18.3% of all delays being mainly due to that reason. However, delays due to social care have risen during 2016 reflecting pressures faced by local councils, which have seen significant
cuts to their budgets in recent years (Ibid). As such, addressing these problems is now high on the policy agenda for national and local government, and providers of health and social care.

While our findings on patient and carer experience chime with previous research, our ethnographic observation of the complex discharge teams at all three hospitals, interviews with discharge team and ward staff (Lens 3), and the triangulation of this data with our patient survey (Lens 1) and patient and family care giver interview data (Lens 2) provides new insight into the complexity of the issues involved. This points not only to problems with particular systems and practices in individual hospitals, relevant local authorities and CCGs, but to wider structural problems in health and social care provision and in the contemporary demographic and societal landscape.

This study reveals persistent problems with the hospital discharge processes at all three hospital locations. Nevertheless, it has to be borne in mind that for this report we have focused on the problems experienced by participants. At least half of the patients who participated in our study reported some aspects of their discharge related care that were positive. Nursing staff in particular, at all three hospitals were highly praised, although it was perceived by many that wards were short staffed and that agency nurses were less attentive and caring.

5.2 The importance of In-depth and narrative data

As with previous research we have undertaken, we found that when people are asked to rate their experiences overall, as we did with our Lens 1 survey, then there’s a tendency for between two thirds and three quarter of all respondents to give an overall positive score. However, when we probe with more precise questions, that involve ‘free text’ answers, and carry out in-depth narrative style interviews, we gain a more nuanced and credible insight. It is important to bear this in mind when using patient feedback or surveys to evaluate services and we would strongly suggest that any evaluation of services should include a qualitative element focusing on the lived experience and patient narratives.

5.3 Patient and family carer information and involvement

In this report we identify a range of problems resulting in some patients experiencing a premature discharge, and others’ delayed discharge, often while awaiting appropriate care packages. This led many to have anxieties and concerns regarding their continued health and social care needs. Further frustrations were experienced by patients due to delays and a lack of information about their ongoing care needs and follow-up appointments. Many of the patients who participated in the study looked to family members for support, however, the family care-givers who participated in our study conveyed their frustration and distress at their lack of involvement in discharge planning and the

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24 Credibility involves establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research. See Guba and Lincoln, 1994.
Effective communication is vital to the quality and safety of healthcare, including hospital discharge. Good communication between patients and care professionals is particularly important at the discharge planning stage, where patients need to receive quality information on how to manage their medication and symptoms post-discharge, and to be notified about any follow-up appointments they may have with primary care services or outpatient clinics. Similarly, good communication between hospital-based and primary care doctors and services, particularly during the early post-discharge period, is vital in ensuring continuity of care, and patient safety.

By contrast, as our study shows, deficits in communication within and across different levels of care, negatively affect the hospital discharge experience of patients, and their family caregivers.

Our observational research of discharge teams, revealed that they often had poor internal methods of communication and that they frequently failed to update each other sufficiently as to the patients' progress during the handover of medical notes. These notes were often badly-written and not concise enough. This meant that, despite being present at board rounds, staff often did not have the right information regarding a patient's readiness and needs for discharge. Patients were often told different things by different members of staff regarding the timing of their discharge which led to further delays, confusion and frustration for patients and their family caregivers.

This study reveals the important role played by family members in providing support for patients to assist with their discharge on the day and in the provision of support following discharge. This is of particular importance for elderly and frail patients. We believe that the inclusion of family carers is particularly important, given the increasing number of elderly patients currently being admitted to hospital. However, we found staff to be less enthusiastic about this prospect, with some seeing patients' families as 'overprotective', risk-averse or obstructive. Families often want to be involved, despite coping with existing pressures, dealing with the emergency/unplanned admission of their relative; possibly living some distance away; working full time or having pre-existing care commitments.

This is not to undermine the autonomy of elderly patients, and consent from patients who have the capacity to give it should be obtained, but as our research and other research has shown, some older people may only want ‘limited involvement and participation in decision making, preferring their families to make discharge decisions due to their physical frailty and fatigue, psychological dependence on their carers, and cultural factors’ (Graham et al., 2009; Huby et al., 2007; McWilliam, 1992). Indeed, as many families will be involved in providing support and care immediately post-discharge, they will need to be part of the decision-making process.

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25 The so-called ‘sandwich generation’ who have care commitments for children, grandchildren and elderly parents (Carers UK, 2014).
5.4 Care continuity and integrated care

Continuity of care is another problem area we identify. Some patients reported leaving hospital without having a care plan and a clear understanding of their condition and whether, when and by whom they would be followed up. When interviewed at home several weeks after being discharged some patients reported that they were both anxious and unsure about their follow up care. As reported by Age UK, a lack of follow up support following early discharge inhibits people’s independence during discharge and care transition, and limits their ability to have their questions about self-care and independence addressed (Age UK, 2016b).

Furthermore, our Lens 3 data also revealed problems faced by the complex discharge team and ward staff in facilitating a safe, seamless and timely discharge for patients with more complex needs. Resource problems featured large at all three hospitals including a lack of suitable residential care or re-ablement services. Care continuity was often effected by a lack of integration. Structural issues, namely that healthcare and social care are funded and largely administered separately, resulted in a lack of integrated work on the ground. Delayed Transfers of Care reports, which are mandatory requirements for hospitals to collect and relate the number of patients delayed each month and the total delayed days during the month, classifies such delays due to either ‘health’ or ‘social care’ factors. This, along with difficulties in differentiating and assessing whether a patient was eligible for health or social care support following discharge, resulted in at the very least tension, and at worst, an emergent blame culture between health and social care staff within the discharge team. This sometimes caused interpersonal conflicts and power struggle due to the different teams’ separate ways of viewing patient needs post-discharge.

5.5 End of life

Staff reported that fewer and fewer people were receiving NHS funded care packages for those patients who were thought to be relatively close to the end of life; consequently, many patients, even though their illness had reached a terminal phase were sometimes unable to die in the right environment (their preferred place of choice) and with the right care. This caused staff considerable distress and was very upsetting for patients, families and nurses. During the study our researchers witnessed a number of cases where patients died while waiting for decisions regarding EoL (End of Life) care to be agreed upon and implemented. This was a particular problem at CGH where discharge staff disagreed in cases where the CCG refused EoL CHC on the grounds of illegibility and they were unable to change the CCG’s decisions. Because staff were unable to act, and at the same time witnessed first-hand how this affected patients, they experienced ‘moral distress’ (Georgiadis, Corrigan and Speed, 2016) and low morale was experienced by among those involved in such cases. While we have since been reliably informed, during our stakeholder meetings with the hospital and North East Essex CCG, that this particular issue regarding EoL care criteria has since been addressed, we saw some examples at all three hospitals where decisions about EoL care were delayed. We observed cases where continuing care assessments and approval for ‘Fast Track’, a pathway designed to prevent EoL patients dying in hospital, would often take weeks to materialise.
By the time they come to do the assessment, [the patients] are too unwell to be discharged from the hospital... you have patients who would like to go to the hospice but they can’t... So it’s really tricky. So very sad.

5.6 Local issues and solutions

In our individual reports for each of the participating hospitals26 we have made a number of recommendations based on our findings both before and after the publication of our reports. Many of the hospitals and associated CCGs have reported that they had already begun to address problems associated with delayed discharge in particular, including issues associated with delays in pharmacy and transport before our findings were revealed.

The NHS have in their Five Year Forward View (NHS England, 2014) encouraged efforts to increase the delivery of healthcare away from acute hospitals and closer to home, ‘with the aim of providing better care for patients, cutting the number of unplanned bed days in hospitals and reducing net costs’ (REF). In Colchester, North East Essex CCG has commissioned a local enterprise organisation to deliver such services to ensure that ‘people with long term conditions and their family/carers are supported to be independent in their own homes, avoiding hospital admissions and to make a good recovery from episodes of ill-health’ (Anglian Community Enterprise, 2016). This involves the formation of multi-professional teams planning and working together including the patient and their family/carer, neighbourhood teams and professionals working alongside GPs and practice nurses to support patients.

PAH have provided a detailed written account of a number of initiatives they have undertaken to improve patient experience, many of which have already begun. These include involving patients and carers in discharge processes, collaborative initiatives with the CCGs to improve patient pathways, and helping to identify suitable placements for patients being discharged through the CHC pathway. Other initiatives include those aimed at achieving a better integration of services with the CCGs. In particular, the PAH Chief Nurse has met with the West Essex CCG Director of Nursing to work on bridging and resolving the concerns of the hospital discharge team and have enabled the Integrated Discharge Team at the hospital to work with both commissioners (Herts and Essex) to overcome the difficulties of different processes and documentation in relation to CHC assessment. This should avoid duplication of processes as they have developed one set of documentation and are further working to align all related processes.

At mid Essex, BRH, local CCGs, care provider organisations, and ECC are working together to implement an integrated discharge plan. This will include the commissioning of services to support a ‘home to assess’ model of care where a team of assessors will arrive within hours of a patient being discharged to make an assessment of the person’s needs taking into account their home environment.

26 To access these reports, see our website: www.healthwatchessex.org.uk/what-we-do/our-reports/
In addition, HWE have agreed to provide support for the integrated discharge team plan by working with the hospital to initiate a new discharge patient and family care giver information sharing platform and to improve discharge planning and post discharge support. See recommendation 1 below for further details.

In theory, we welcome all these initiatives as they would seem to have the capacity to deliver patient-centred care and should address at least some of people’s care needs in the immediate and in the longer term. In some instances, just having some initial assistance, and support such as food shopping, would greatly assist many elderly, and frail patients in particular.

This research has fed directly into new government guidance on ‘discharge to assess’ (NHS England, 2016). Locally, members of HWE research team have also been involved in meeting with commissioners at ECC about the ‘home to assess’ initiative provision which would be provided by a third sector agency. It will be a challenge to ensure that the right contracts are drawn up with enough flexibility to ensure that people’s needs are properly assessed and catered for. However, we strongly recommend that such interventions are evaluated using qualitative methods that focus on following the course of a patient’s journey and gathering their stories and where possible those of any family care givers involved in a patient’s discharge.

The extent and seriousness of the problem surrounding hospital discharge should not be underestimated. There still remains a lack of capacity in particular, including temporary or permanent residential care and it is not clear how those with more complex care needs can be met in the community without an increase in the services of professionals such as GPs, nurses and health visitors.

5.7 A Healthwatch Essex Perspective

Most would agree that acute hospitals are not the most appropriate place to attend to the care needs of many elderly frail people. However, with less provision in community hospitals, fewer care homes and a shortage of GPs in Essex in particular, questions remain about how the care needs of the frail elderly are to be adequately met. The community, including spouses, adult children, friends and family care givers are already supporting family members living with dementia and ageing related health conditions to live at home. As we have reported elsewhere this often creates an enormous strain on those carrying out this care as they frequently do so with little or no support for their own needs. Furthermore, we have, as a society, built a highly specialised acute healthcare system that utilizes state of the art MRI scanners and other tests and health technology while ignoring the more everyday growing healthcare needs of the elderly. We believe that the provision of person centred care, that provides those in their latter years of life in particular, with high quality healthcare (including non-acute care) and social care, must be placed at the top of reform agenda. All too often we have witnessed a target driven managerial focus that works in opposition to the provision of person centred care. This is exemplified by the use of the term ‘bed blocker’ that as we have seen, is sometimes internalised by patients and their carers who are left feeling guilty and stigmatised by this label. It is sad too that what is forcing the attention now of local and national government, policy makers and health and social care commissioners and providers to the issue of hospital discharge, is the cost of delayed transfers of care and rising hospital admissions rather than the experiences and needs of those who rely on the services.
We believe though that savings can be made as care is relatively cheap compared to the cost of acute hospital care. However, we do want to ensure that people receive high quality care and that care should not be considered too cheap and somehow less important than tests and treatment. In the short term, investment must be made in such a provision and those carrying out such care should be highly valued.

The extent and seriousness of the problem surrounding hospital discharge should not be underestimated...

...we believe that the provision of person centred care, that provides those in their latter years of life in particular, with high quality healthcare (including non-acute care) and social care, must be placed at the top of reform agenda.
6. Recommendations

6.1 The provision of information and communication systems

- First, we strongly recommend that all hospitals instigate systems to improve communication with patients and their families, which will involve them in discharge planning and ensure that they are provided with the correct information about any medication, follow-up care and appointments that the patient requires. It is essential that open communication and open discussion with the patient and family should take place from the point of hospitalisation regarding their options and preferences for discharge.

- This implies that an improved understanding among staff on how to communicate with family members; and staff must be able to identify the family members who are willing to be involved with discharge; listen to their insights on the patient involved; and recognise that with some families it may difficult to do this. From the point of view of the family, it seems there is some work to be done on alerting the public to the importance of acute beds and short stays at hospital, and showing them that their family members will, post-procedure, need to recuperate for some time at home, rather than just hospital. At HWE, we acknowledge the role we can play in drawing attention to these matters for those with family members in hospital, by informing the public on what the discharge process requires of family members and carers.

- We suggest that to help achieve this, systems of information gathering and sharing should be instigated as soon as patients have been admitted to hospital. This recommendation is in alignment with new NICE (2016) pathway guidelines on transition between inpatient
hospital settings and community or care home settings; indeed, our research contributed to the NICE guidance that preceded this consultation.  

To facilitate this, we have recommended that hospitals establish rigorous systems whereby relevant information about a patient’s social circumstances/needs, including names and availability of family carers, can be gathered and exchanged between hospital staff, patient and family carers. HWE have offered to work with hospitals to implement this, which has been accepted at BRH as part of joint initiatives with Essex County Council to improve hospital discharge process. This recommendation has been set out more fully in our individual hospital reports (Healthwatch Essex 2016a; 2016b; 2016c)

• We also recommend that improvement be made to communication between staff within the hospital, and between hospital staff and other health and social care organisations and providers. Again, this would involve ensuring that systems are put in place to support this. We found it incredulous to discover the lack of rigour in gathering, storing, retaining and sharing information of information in the hospital and between key organisations and providers. The lack of established information sharing systems led and contributed to disruptions to collaborative work between hospital departments. Disjointed work coupled with staff shortages led to pressures at all hospital levels, impacting negatively the morale of the hospital staff.

• We contend that all frontline hospital staff, and in particular staff working in wards with high turn-over of older patients, should receive mandatory training, in hospital discharge planning. Currently, new ward staff and discharge nurses learn discharge related work by experience and not through training, increasing the pressure to care professionals. We recommend to local CCGs, medical schools, and training organisation to work together and incorporate discharge related care planning at the curriculum of all trainee health professionals.

• We also suggest that digital technology such as iPads/tablets could be used to replace outmoded fax machines and other unsystematic means of conveying information, such as writing notes relevant to discharge on scraps of paper.

In all three hospitals nurses were often highly praised by patients and were reported to be kind and caring, and yet it is clear that with the current pace of movement/patient flow in and out of hospital, combined with staff shortages and the increasing numbers of elderly patients with higher level of care requirements in hospital, interpersonal communication is challenging and therefore new systems could be extremely useful in assisting this process.

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27 In preparation for this study, one of our research team wrote to the National Institute of Clinical Excellence (NICE) to enquire whether they had produced any guidelines on hospital discharge. At this stage they had not, but since then NICE have drafted guidance and we have submitted evidence based on our study findings into the consultation process preceding the final guidelines.
6.2 Integration and continuity of care

Integrated care is a long-lasting aspiration in the NHS. Although there have been improvements in the local level (e.g. joint commissioning of services), deeper and more collaborative work needs to be done. Health and social care professionals are trained and practice care under different assumptions with regards to people’s care needs. Our research illustrates that people do not make a clear distinction between health and social care needs. Instead, they want to receive care that’s holistic and focused on their personal circumstances and needs.

- We recommend that local health and social care commissioners identify a shared vision of care, and find ways to bring the health and social care sectors under a unifying vision of care. Developing new integrated care pathways, could lead to quality improvements that will make care safer and more patient centred.
- We suggest that the work already begun to integrate services in North East Essex, Mid Essex, and West Essex and East Herts continues. There is no doubt from the documentation we have seen and the planning meetings we have attended, that there is a great impetus, and enthusiasm among associated local organisations to do so. These are new initiatives and we strongly recommend that these are externally evaluated using robust qualitative methods to ensure that they are achieving better continuity of care and improved experiences for patients and their family carers.

6.3 Raising awareness and planning ahead

- We suggest that citizens should be made more aware about the kinds of care provided in the local community, and how they should respond to health matters either in an acute or non-acute form. It may be that the increasing pressure to acute hospitals is the result of a struggling primary and community care sector. Nonetheless, our research showed that in many cases patients present in hospitals with non-acute conditions or with problems that could have been resolved with better planning and information, on behalf of the patient and the family. Health and social care services should work together and find new ways of informing the public about the care services offered in their locality, and how and when to access them. Citizens need to be aware that, even though the acute sector is ‘open for business’ 24/7, it is a place of caring for acute medical emergencies.
- We also suggest that, owing to the increased pressure that acute hospital settings are experiencing, patients are more likely to experience a short hospital stay. Therefore, they should be better prepared for a hospital stay and subsequent discharge. This would be particularly important for elderly frail patients living with deteriorating health conditions. Raising awareness of advanced planning, including advanced directives, such as DNR (Do Not Resuscitate) orders, living wills and nominating a family carer to act as power of attorney (for health) could help ensure better care provision and lived experience for people.
Nationally the health and social care sectors face significant challenges, both in terms of financing and in terms of the quality of care they can deliver. Since 2010, both sectors have been experiencing radical changes which have created some turbulence with regards to the quality of care they deliver and the job satisfaction they offer to staff. Therefore, it is unsurprising that the local health and social care sectors are experiencing challenges that test the limits of their staff and confuse patients and service users. Yet, it is important to note that these turbulences offer the rare opportunity to both the funders and deliverers of care to reflect what type of care they want to deliver, and what are the best ways to achieve this. In our research we came across enthusiastic professionals who want to take advantage of this opportunity and address long-lasting gaps, resolve difficult problems, and build bridges to bring together separate world views in service delivery and provision. We also came across patients and service users who acknowledge and appreciate the efforts of frontline care staff to deliver good quality care; they also want their views to be heard and incorporated into service design and delivery. It is within this context that we remain optimistic for the future of our local health and social care services and enthusiastic for the work that we carry out.
7. Bibliography


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Essex County Council (personal communication, 2016) All Services (Orbit) 2015/16 as at end March 2016.


Healthwatch Essex (2016e) ‘Negotiating the Care Maze: the process of decision-making when a family member or friend needs full time social care’, http://www.healthwatchessex.org.uk/what-we-do/topics/negotiating-the-care-maze/


Appendix ii: Methods References


Appendix i: Literature review

Aims of the review
We undertook a narrative review of the literature patients and family caregivers’ experiences of hospital discharge in order to illuminate current knowledge on the subject, to inform our research project and to explore how our findings relate with the wider literature.

Method
The research question that this narrative literature review sought to answer was “How do patients and family caregivers experience the discharge planning process and care post-discharge?” Before considering how the current research relates to patient and family caregivers’ experiences of discharge planning and care post-discharge, we first had to ensure that we were using appropriate and precise definitions of the concepts we were investigating. The review aimed to retrieve empirical qualitative studies, including adult patients with a diverse range of medical or surgical conditions and their family caregivers, to investigate their experiences of discharge planning and care post-discharge. Table 1 presents the inclusion and exclusion criteria. To ensure that the retrieved literature was current and relevant, the search was limited to the years 2005-2016, using four electronic databases: one medical (PubMed), one nursing (CINAHL), one sociological (SocINDEX), and one interdisciplinary (Web of Science). Retrieving published peer-reviewed articles from 2005 and onwards was also supported by the publication of an extensive literature review on patients’ experiences of discharge planning by Coffey (2006). Therefore, we drew upon the literature on patients and family caregivers of discharge planning and care post-discharge published from 2005 and onwards.
Table 1: Inclusion and exclusion criteria for literature review

<table>
<thead>
<tr>
<th>Category</th>
<th>Inclusion</th>
<th>Exclusion</th>
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<tbody>
<tr>
<td>1. Participants</td>
<td>Adult patients and family caregivers</td>
<td>Children and patients below the age of 18</td>
</tr>
<tr>
<td>2. Focus of the paper</td>
<td>To explore patients and family caregivers perspectives on discharge planning and care post-discharge</td>
<td>To explore issues relevant to patients and family caregivers who are being discharged from mental health settings. To explore issues relevant to discharge planning and care post-discharge from health and social care professionals’ perspective.</td>
</tr>
<tr>
<td>3. Methodology</td>
<td>Qualitative and primary research</td>
<td>Quantitative/RCTs/ Secondary/Audit or service evaluation</td>
</tr>
<tr>
<td>4. Location of the studies</td>
<td>UK and international studies</td>
<td>n/a</td>
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Table 2 presents the strategy we employed to retrieve the current literature. The combined search produced 362 hits, which were initially downloaded as titles and abstracts. All titles and abstracts of articles published in the English language were read and their relevance to the subject of this review assessed. From 362 hits, 103 papers met the inclusion criteria (after their titles and abstracts had been read). Most studies were service evaluations, RCTs or studies participants were not recruited on the basis of being discharged from a hospital setting. Of these 103 papers, only 20 referred directly to the topic under investigation. In order to better understand the discharge planning process from the patients’ and caregivers’ perspectives we also searched for grey literature. We used snowballing methods and google scholar to retrieve such publications. The search resulted in retrieving 6 UK-based reports on patients and family caregivers’ experiences of discharge planning and care post-discharge.

Table 2: Keywords and combination strategy

<table>
<thead>
<tr>
<th>“hospital discharge”</th>
<th>“qualitative research”</th>
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<tr>
<td>OR</td>
<td>AND</td>
</tr>
<tr>
<td>“discharge planning”</td>
<td>perception*</td>
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<td>OR</td>
<td>experience*</td>
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<td>OR</td>
<td>interview*</td>
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65
Results

Of the 19 studies that met the inclusion criteria (we could not locate the full-texts of one article), 9 were from the UK, 3 from Australia, 3 from the USA, 1 from the Netherlands, 1 from Norway, and 1 from Brazil.

Across the literature we identified a range of factors, which permeated all levels of care to influence patients and family caregivers’ experience of hospital discharge planning and care post-discharge.

Interacting with care professionals in the hospital

The retrieved studies indicate that patients and family caregivers’ interactions with healthcare professionals play a vital role in their experience of hospital discharge planning and care post-discharge. Poor communication between patients, family caregivers and healthcare staff; patients’ limited involvement in hospital discharge planning as well as poor information sharing between patients, family caregivers and healthcare staff, were the key issues mentioned in the retrieved literature (Huby et al. 2007; McMurray et al. 2007; Fitzgerald et al. 2011; Brown, 2012; Baillie et al. 2014; Bragstad et al. 2014; Doos et al. 2014; Bauer et al. 2015; Healthwatch England, 2015; Healthwatch Gloucestershire, 2015). A study by Doos et al. (2014) into the experiences of heart failure and chronic obstructive pulmonary disease multi-morbid patients and their carers found that communication problems within the hospital between professionals, patients and carers had a negative impact on patients’ and carers’ experience of hospital discharge. Participants reported that they received limited or mixed information with regards to their discharge date or procedures for discharge from the hospital. Additionally, participants reported that, upon discharge, they had received very little information about their diagnosis or any changes to their medication regime. Such practices had a negative effect on their safety and well-being post-discharge, as they were uncertain what their symptoms meant, which medicines were linked to which symptoms, and how to respond to symptoms in order to avoid rehospitalisation. A study by Benzar et al. (2011) into palliative care patients’ experiences of discharge planning reported similar findings. Participants commented that, upon discharge, they had received limited information over the prognosis of their illness and what the caregiver should expect. The authors report that the provision of such information is particularly important for these patients and their family caregivers, as it allows them to prepare themselves emotionally and logistically for one’s death. Similarly, a study by Henratty et al (2012) into older adults’ end-of-life transitions in the UK reported similar findings. Participants reported that they often felt that healthcare professionals did not listen to their concerns and that they were unwilling to respond to their queries about their health and care. For example, participants reported that communication problems with staff created barriers in understanding their illness, its prognosis and the rationale behind their therapies. A study by McMurray et al. (2007) into general surgical patients’ perspectives on discharge planning reports similar findings. Participants described communication problems with healthcare professionals as the major issue affecting their hospital discharge experience. In addition to the limited information they had received from healthcare professionals, participants also commented on the negative impact of receiving conflicting or inconsistent
information from healthcare professionals involved in their care on their hospital discharge experience. Problematic information sharing between healthcare professionals contributed to patients’ receiving mixed information about their illness, its prognosis and care post-discharge.

The retrieved literature also suggests that patients and family carers’ experience of hospital discharge planning is inextricably linked with the extent to which they feel involved in discharge care preparations (Huby et al. 2007; Fitzgerald et al. 2011; Ellins et al. 2012; Brown, 2012; Healthwatch England, 2015). A study by Huby et al. (2007) into older adults’ participation in decision-making regarding discharge after acute hospitalisation found involvement in discharge-care preparations was a core element in a positive hospital discharge experience. However the authors report that, owing to the declining physical and cognitive abilities of older adults, participation and involvement in decision making becomes more difficult for this patient group. As a result, participants reported that they relied more on family caregivers to make decisions regarding their discharge planning and care post-discharge.

Family caregivers’ active role in supporting and advocating for patients was also reported by Bragstad et al. (2014). Their study on informal caregivers’ experiences of achieving influence at the point of and after hospital discharge found that, owing to older adults’ declining function and increased frailty, family caregivers were forced to take over tasks and responsibilities that were previously managed by the patients. Difficulties surrounding the patients’ involvement in decision-making around discharge planning and care exacerbated participants’ feelings of worry and uncertainty about the quality of care that older adults received at and after hospital discharge. Participants commented that, despite explicitly stating that they wanted to be involved in patients’ hospital discharge planning, they often struggled to have their opinions heard and acknowledged by health care and social care professionals.

Similarly, a study by Ellins et al (2012) found that often patients and their family caregivers felt uninvolved in the decisions surrounding their discharge and care post-discharge. Participants reported that they did not receive clear explanations of the things happening to them, and that they were never asked questions about their health and care while being hospitalised. Other participants reported that they received limited information about the services they could turn to for their care after they had left the hospital. According to the authors, anxiety and uncertainty were feelings that characterised participants’ emotional state at discharge. Moreover, participants reported that doctors were not eager to provide much information about their health and care; they reported that they had to turn to the nurses to retrieve more information about their needs. The vital role of nurses in providing information about patients’ health and care needs was also mentioned in Pompeo et al. (2007). Participants reported that nurses were often more familiar with their health and care needs and, therefore, they were in a better position to provide information to patients and involve them in discharge planning and care post-discharge.

Delayed or premature discharge was another issue reported in the retrieved literature. Brown et al.’s (2012) study into medical patients’ experiences of in-reach occupational therapy found that often patients were not informed about their discharge until the day before they
were discharged. Further, other participants reported that they had to wait for several days until there was an available bed in the community. Both practices resulted in patients and family caregivers experiencing anxiety and uncertainty over the practical and logistical preparations for their transfer in the community. However, patients’ and family caregivers’ interactions with healthcare professionals were not the only issue affecting their experiences of hospital discharge planning and care post-discharge. The weak primary and secondary care interface contributed to negative patient experience and poor clinical outcomes.

A weak service interface

Another central theme in the retrieved literature was the weak service interface between the primary and secondary care services. In many studies care post-discharge was described as a struggle, owing to the poor follow-up care that participants received in terms of continuity, coordination, and communication with community-based services (McMurray et al. 2007; Bauer et al. 2011; Ellins et al. 2012; Foust et al., 2012; Fujii et al. 2013; Knight et al. 2013; Healthwatch England, 2015; Healthwatch Gloucestershire, 2015; Healthwatch Suffolk, 2015). By contrast, participants valued continuity of care, and good communication and information exchange across care professionals and services (Hanratty et al. 2012).

Continuity of care was often described as problematic in the retrieved literature. A study by Hesselink et al. (2013) into patients, relatives and care providers’ experiences of quality and safety during hospital discharge, found that continuity of care after hospital discharge is often not guaranteed. Barriers in continuity of care include the quality of information exchange (between patients and care providers as well as across providers), the coordination of care and communication between hospital and community care providers. The authors argue that hospital staff are unacquainted with care offered in the community and that they do not take into account the needs of the community care services after patients have been discharged from the hospital.

A study by Dickson et al. (2011) into patients’ difficulties in adjusting to post-discharge life following a spinal cord injury found that the lack of post-discharge support had a negative impact on patient experience and clinical outcomes. Participants reported that the poor follow-up care and support from community-based services contributed to their physical and psychological deterioration post-discharge. Although participants reported great recovery improvements while hospitalised, they also reported that they quickly lost all the progress they had made due to the limited support they received post-discharge. Participants also reported psychological difficulties due to the limited support they had received, coupled with the deteriorating recovery progress. Similarly, Doos et al (2014) report that, despite their expectations, many participants were not followed up by their GPs post-discharge. The authors report that poor follow-up care resulted in many participants feeling concerned about how to manage their symptoms, or what they should do if their symptoms worsened. Many participants reported that if their symptoms worsened, they had developed contingency plans, based on prior experience and not with the support of healthcare professionals, which increased their risk of rehospitalisation.
These findings are echoed by the study of Ellins et al (2012), where participants described their care post-discharge as uncoordinated and fragmented. For instance, participants reported that they had to chase up healthcare professionals and be very persistent in order to access services post-discharge. On many occasions participants described their interactions with services as ‘doing battle’, as often they had difficulty accessing them, or when they had accessed them they were seen by a different clinician each time. Personal continuity was vital for both the patients and the family caregivers as they could retrieve important information about services from people who were familiar with their cases. Personal continuity was also reported in Brown et al’s (2012) study. Having an accurate knowledge of people’s medical hospital and personal information was described as a key factor in building a trusting relationship with care professionals post-discharge. Difficulties with accessing services post-discharge were also reported by Christie et al. In their study on people’s experiences of seeking support after hospitalisation for injury, they found that participants had often difficulties with receiving support from GPs and, in particular, with accessing physiotherapists in the community. Participants reported that they felt neglected by services after they had been discharged, as the responsibility to contact and access primary care services and subsequent care coordination were left up to them. Participants reported that such practices fuelled feelings of uncertainty and caused them to worry about their recovery. Feelings of abandonment caused by poor follow-up care from community health services were also reported by the participants in Brown et al. (2012). Participants commented that the limited information they had received with regards to their care post-discharge (i.e. appointments with GPs and community based physiotherapists) created feelings of uncertainty and worry about their recovery.

Problems with medication management post-discharge was another issue reported in the retrieved literature (CQC, 2009; Knight et al. 2013). A study by Knight et al. (2013) into the experience of older people and their carers’ with regard to support with medication on discharge, found that participants received limited information about medicines at discharge. Problems with medication resulted in omission of medicines, incorrect dosages, anxiety and confusion. Poor communication between the hospital and general practitioners or community pharmacists further exacerbated participants’ problems with medication post-discharge.

Similar findings are reported in the retrieved grey literature on patients’ experiences of care post-discharge. A national study on people’s experience of hospital discharge by Healthwatch England found that often people are left without the services and support they need after discharge. This was particularly problematic for older adults who, after being discharged, did not know which services to turn to for support. Many participants reported that they had been left to arrange their own aftercare. This was particularly problematic for this frail and vulnerable group, as they often experienced adverse events (i.e. falls in home, feeling abandoned), which increased their risk of rehospitalisation. A report issued by the Commission for Social Care Inspection (2005) reports similar findings. The authors report that poor coordination of care post-discharge increases readmission rates. This was particularly relevant for individuals at risk of emergency admissions as, in the absence of good follow-up
Discussion - conclusion

The aim of this narrative review was to examine the available literature on patients’ and family caregivers’ experiences of hospital discharge planning and care post-discharge. The retrieved UK and international literature demonstrates that hospital discharge planning is a complex issue which, if it is not well planned and executed, can contribute to poor patient experience and clinical outcomes. The retrieved literature demonstrates that patients and family caregivers often face several obstacles in their discharge from hospital and in planning their care post-discharge. Problematic interactions with hospital staff and the weak service interface between primary and secondary care services resulted in negative patient experience and, often, poor clinical outcomes. Communication problems, limited information sharing between patients and the hospital staff, and patients’ and family caregivers’ limited involvement in decision-making around hospital discharge had a negative impact on patients’ and family caregivers’ experience of hospital discharge planning. Similarly, poor follow-up care and communication problems between primary and secondary care services resulted in patient and family caregivers experiencing difficulties in accessing community-based services and receiving good quality and appropriate information about their care needs post-discharge.
<table>
<thead>
<tr>
<th>Study</th>
<th>Subject of study</th>
<th>Location/setting</th>
<th>Research aims</th>
<th>Key findings in relation to present study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bragstad et al., 2014</td>
<td>Informal caregivers</td>
<td>Norway</td>
<td>To describe the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-bound older relatives</td>
<td>The take of informal caregivers on comprehensive all-consuming roles as intermediaries between the care recipient and the health care services. In essence, the informal caregivers take the role of the active participant on behalf of their older relative. They describe extensive efforts struggling to establish dialogues with the ‘gatekeepers’ of the health care services. Achieving the goal of the best possible care for the care recipient seems to depend on the informal caregivers having the resources to choose appropriate strategies for gaining influence over decisions.</td>
</tr>
<tr>
<td>Bauer et al. 2011</td>
<td>Family carers of patients with dementia</td>
<td>Australia</td>
<td>To explore whether hospital discharge practices meet the needs of the family carer of a person with dementia.</td>
<td>Key issues that families found problematic included: coordination of discharge planning, the ability of the staff to address family members' needs, poor engagement with family, and perceived lapses in care delivery.</td>
</tr>
<tr>
<td>Benzlar et al. 2011</td>
<td>Family caregivers and patients</td>
<td>USA</td>
<td>To identify the range of health care experiences of family caregivers and patients who received palliative care consultations after they left the hospital, and to understand how PCTs might best prepare patients and caregivers for the post-hospital experience.</td>
<td>Key issues that the study identified were: prognosis, symptom management, and knowing whom to call when problems arose. Deficits in these areas are potentially preventable and can be addressed before a patient leaves the hospital. However, they require complex interdisciplinary participation, so responsibility for addressing them is often ambiguous.</td>
</tr>
<tr>
<td>Baillie et al., 2014</td>
<td>Frail older people</td>
<td>England</td>
<td>To investigate the care transitions of frail older people from acute to primary care.</td>
<td>Involvement of patients and families in care transitions is important. Quick discharge can result in patients feeling worried, dissatisfied and distrusting. Nurses could be in a good position to empower patients with regards to their care setting transition. However, staff often lack control regarding transition and so they are disempowered, preventing them from empowering patients. Care transitions of frail older people from acute to primary care.</td>
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<tr>
<td>Study</td>
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<tr>
<td>Brown et al., 2012</td>
<td>Older people, OT</td>
<td>England</td>
<td>Understand medical patients’ experiences of in-reach occupational therapy.</td>
<td>That it was important to patients that they had knowledge of their treatment and plans to discharge them. Patients desired autonomy and control and valued continuity between care settings. Patients felt confident when staff appeared to know their personal information and medical history.</td>
</tr>
<tr>
<td>Christie et al., 2016</td>
<td>Injured patients</td>
<td>England</td>
<td>To identify good practice and unmet needs in respect of post-discharge support for injured patients.</td>
<td>Patient associated a positive experience with pro-active responses from GPs. Community physiotherapy offered important support, providing information and context about their injury and often taking the role of a councillor to help them 'gauge' their recovery. Many patients felt they were not provided with the information they needed concerning their injury, prognosis, pain control, return to work, psychological problems, or services to help meet their needs.</td>
</tr>
<tr>
<td>Dickson et al., 2011</td>
<td>Spinal cord injury</td>
<td>Scotland</td>
<td>To capture the lived experience of individuals who had suffered spinal cord injuries.</td>
<td>Patients reported receiving inadequate support post-discharge and feeling like they were left to &quot;just get on with it&quot;. Lack of support post-discharge, including the loss of patient-to-patient support experienced on the ward, can have a detrimental impact on a patient’s experience of recovery and adjustment to life post-injury. Support is crucial, including psychological support.</td>
</tr>
<tr>
<td>Doos et al., 2014</td>
<td>Heart failure and COPD</td>
<td>England</td>
<td>To explore the experiences of heart failure and chronic obstructive pulmonary disease multimorbidity patients and their carers on hospital discharge.</td>
<td>Communication between staff and patient/carers is important to ensure an understanding of the condition and a supported recovery post-discharge. Patients and carers want more information and support post-discharge.</td>
</tr>
<tr>
<td>Fitzgerald et al., 2011</td>
<td>Family carers of people with dementia</td>
<td>Australia</td>
<td>To explore whether metropolitan and rural hospital discharge practices meet the needs of the family carer of a person with dementia.</td>
<td>Although this and other research indicates that a continuum of care model is beneficial to family caregivers, no evidence has been identified that family carers currently experience this type of quality planning. Family carers were often unaware of the existence of a hospital discharge plan and were rarely engaged in communication about the care of their family member with a dementia or prepared for discharge.</td>
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<tr>
<td>Hesselink et al. 2013</td>
<td>Patients, relatives and care providers</td>
<td>Netherlands</td>
<td>To identify barriers experienced and perceived at discharge by physicians, nurses, patients and relatives.</td>
<td>Information going from the hospital to community care is often incomplete, unclear and delayed. Especially hospital physicians (52%) and general practitioners (GPs, 63%) experience the quality of information exchanged from the hospital to the GP as poor. Coordination of care is often frustrated by a lack of care provider knowledge and collaboration. Hospital physicians (47%) and GPs (71%) felt that hospital physicians were often not sufficiently aware of the patient’s home situation. Respectively, 59% and 81% experienced that the GP was often not clearly informed about expected tasks and responsibilities at discharge.</td>
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<tr>
<td>Hanratty et al., 2012</td>
<td>Older people (69+)</td>
<td>England</td>
<td>To explore older adults’ experiences as they move between places of care at the end of life.</td>
<td>Staff prioritised process over patient needs and wishes. Patients and carers needed support across the setting and to be heard by services providers.</td>
</tr>
<tr>
<td>Fuji et al. 2013</td>
<td>Patient, caregiver, health-care providers</td>
<td>USA</td>
<td>To describe the experience of care transitions from patient, caregiver, and health-care provider perspectives in a single metropolitan Midwest city.</td>
<td>Five themes emerged: pre-planned admissions were ideal; there was a lack of needed patient information upon admission; multiple services were needed in preparing patients for discharge; rushed or delayed discharges led to patient misunderstanding; and there were difficulties in following aftercare instructions.</td>
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<tr>
<td>Foust et al. 2012</td>
<td>Patient, caregiver, clinicians</td>
<td>USA</td>
<td>To describe the experiences of patients, informal caregivers, and home health clinicians during the post-hospital transition.</td>
<td>Patients recalled receiving discharge instructions but with few details and limited information about follow-up actions if they had problems. Discharge instructions were a versatile means of communication. Home health clinicians used these instructions to guide discussions with patients and their caregivers. Both informal caregivers and home health care clinicians emphasized the inadequate preparation of caregivers during the discharge process.</td>
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<tr>
<td>Huby et al., 2007</td>
<td>Older people (60+)</td>
<td>Scotland</td>
<td>To understand how older patients and health professionals perceived, experienced and enacted &quot;participation&quot; in discharge planning, shaped by discharge planning structures.</td>
<td>What at first appeared as a lack of engagement by patients in discharge decision-making, turned out to mask a rich language and action about ways in which older people accepted, managed and made decisions about their declining physical and mental powers, through increased dependence on others, particularly family. However, to a large extent this was made &quot;invisible&quot; and &quot;screened out&quot; of the view of staff by the complexity of the care and daily practice of assessment, which also excluded staff from active decision-making.</td>
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<tr>
<td>McMurray et al. 2007</td>
<td>Surgical patients</td>
<td>Australia</td>
<td>To investigate general surgical patients’ perspectives of the adequacy and appropriateness of their discharge planning.</td>
<td>Themes included a ‘one-size-fits-all’ approach to providing discharge information; inconsistent or variable advice from different health professionals; a lack of pre-discharge assessment of their home and/or work conditions and the need for follow-up assessment of patient and carer needs.</td>
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<tr>
<td>Knight et al., 2013</td>
<td>Older people (75+) on 4 or more medications</td>
<td>England</td>
<td>To explore older people and their carers’ experience of discharge regarding organization and management of medicines.</td>
<td>Very little information was given to patients and carers about medication upon discharge, despite medication often being changed during the hospital stay. Lack of knowledge and understanding around medication caused anxiety. Patients and carers felt staff were too busy to discuss medication and explain it effectively.</td>
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<tr>
<td>Pompeo et al. 2007</td>
<td>Patients in medical-surgical wards</td>
<td>Brazil</td>
<td>To know the hospital discharge process in place and the nurse’s performance in preparing patients for discharge.</td>
<td>The majority of patients (83.72%) received tailored discharge instructions. However, a great number of patients (72.08%) reported discharge instructions were not given by nurses. Almost a half of patients (48.84%) reported that discharge instructions were given by their physicians.</td>
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<tr>
<td>Williams et al. 2009</td>
<td>Older people, family carers and ward-based staff</td>
<td>England</td>
<td>To explore the experiences of discharge from three different units: an acute surgical ward, an acute medical ward and a specialist ward for older people.</td>
<td>The quality of discharge hinges largely on whether the focus of efforts is on ‘pace’ (the desire to discharge older people as rapidly as possible) or ‘complexity’ (where due account is taken of the complex interaction of medical and wider social issues). When pace is the focus, ‘pushing’ and ‘fixing’ are the main processes driving discharge. However, when attention is given to complexity, far more subtle processes of ‘informing’ and ‘brokering’ are in evidence. These latter processes are conceived of as forms of ‘relational practice’ and it is argued that such practices lie at the heart of high quality care for older people.</td>
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<td>Care Quality Commission, 2009</td>
<td>UK</td>
<td>To determine what organisations were doing to ensure the safety of patients who had been discharged from hospital with a change of medication.</td>
<td>It is important that patients are given clear information about their medicine and possible side effects, and then have an opportunity to discuss how the regimen is working out.</td>
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<tr>
<td>Commission for Social Care Inspection, 2005</td>
<td>UK</td>
<td>Follow-up study, reports on the progress made by older people who had been in hospital some time during March 2004, and who, when discharged, needed the support of social services.</td>
<td>Continuity of care is a top priority for patients and their carers. Better contingency planning is needed in response to the assessed risks that people face. A focus on rehabilitation, as opposed to simply administering care, results in sustained improvement and the maintenance of independence. A move to residential care is likely to be permanent.</td>
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<tr>
<td>Ellins et al., 2012</td>
<td>England</td>
<td>To understand older people’s experiences of care transitions, and to conduct the research in a way that would help to embed the findings in health and social care policy and practice.</td>
<td>Poorly planned and coordinated transitions can be detrimental to older people’s health and well-being and are a source of major disagreement between service commissioners and providers. Experiences of transition were frequently accompanied by a sense of disorientation and feelings of fear, worry and uncertainty. Good communication by service providers assisted sense-making activities and helped people to feel safe and connected.</td>
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<tr>
<td>Healthwatch England, 2015</td>
<td>England</td>
<td>To bring to light the human consequences of getting discharge wrong and to outline some of the key reasons this is happening.</td>
<td>Homeless people, the elderly and people with mental health conditions experience delays due to lack of cooperation between services. People feel left without the services and support they needed after discharge. People feel stigmatised and discriminated against, and that they are not treated with appropriate respect because of their conditions and circumstances. Patients’ full range of needs were not being met.</td>
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<tr>
<td>Healthwatch Gloucestershire, 2015</td>
<td>Gloucestershire</td>
<td>To understand patient experience of discharge.</td>
<td>Many patients had positive experiences, however some reported not feeling ready for discharge, lack of support and resources, poor communication, and a lack of information provided to carers.</td>
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<td>Healthwatch Suffolk, 2014</td>
<td>Suffolk</td>
<td>To understand patient experience of discharge.</td>
<td>A clear majority of respondents felt they were not ready to leave the care of the hospital (respondents were not representative of all hospital users). Patients had a mixed experience of the quality of information and support received.</td>
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<td>Healthwatch Sutton, 2014</td>
<td>Sutton</td>
<td>To provide an updated national picture of hospital admission and discharge practice for people who are homeless.</td>
<td>A number of patients felt that they were not provided with enough information about discharge. Following discharge, patients and their families reported not having enough information about follow-up care.</td>
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<tr>
<td>Healthwatch Dudley</td>
<td>Dudley</td>
<td>To understand patient experience of discharge.</td>
<td>Many patients had positive experience. However, some reported that they lacked information and understanding about care, discharge planning and follow-up support.</td>
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<td>Homeless Link, St. Mungo's and Department of Health, 2012</td>
<td>England</td>
<td>To provide an updated national picture of hospital admission and discharge practice for people who are homeless.</td>
<td>Only a third of homeless people had received any support around their homelessness. Many homeless patients were discharged straight back to the streets. Where effective processes were reported, housing was viewed by local partners as a key part of a 'safe discharge' from hospital. However there is a lack of accountability in ensuring this happens. Homeless patients repeatedly flagged up the prejudice of staff and this was seen as contributing to the poor level of care and support being offered both on admission and in relation to early discharge.</td>
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**References**


Commission for Social Care Inspection (2005) Leaving Hospital – revisited, available on request to the CQC.


To best understand the complex factors involved in participant experiences of discharge, we adopted a mixed-methods approach (Creswell, 2003; Morgan, 2007). While largely qualitatively driven, we drew on both qualitative and quantitative research methods. This approach was designed to produce: in-depth accounts of patients’ and carers’ lived experiences; a rich description of both cultural practices and processes surrounding discharge; and an analysis based on statistical survey methods to suggest causal factors or correlations in patient and carer experiences of discharge.

Our design was premised on our initial understanding that hospital discharge is a fluid process that begins once a patient is admitted, and carries on throughout their stay in hospital and beyond. It is a dynamic negotiated process involving a number of key people - patients, doctors, other members of the clinical and social care teams and patients’ family members and/or carers (formal and informal). We applied academic rigour with a degree of pragmatism (what is achievable, practical and ethical), thinking carefully about how best to capture the dynamic discharge process (movement over time) from the perspective of the patients, their family members (carers) and key staff involved in the process.

To this end we designed a three lens framework (see Figure 2 overleaf) to capture experiences of hospital discharge from different perspectives in anticipation that these perspectives, when analysed, would help present an overall picture, capturing the dynamic nature of hospital discharge, to inform a broad understanding of the issues.

For Lens 1 we developed a survey to capture patient experiences on the day of discharge, administered in the hospital’s discharge lounge by a team of three trained HWE volunteers who collected answers to pre-set questions, including...
some free-text questions. The survey consisted of 32 questions and provided a snapshot of what the participants thought of their experience of hospital discharge while waiting in the discharge lounge. At the heart of the survey were five evaluative questions which covered: how well participants felt their discharge was going; how they rated the discharge lounge; how they rated the arrangements for leaving hospital; how well staff listened to them; and how happy they were with arrangements for their health and social care after leaving hospital. In addition, the research volunteers were asked to complete diaries on their observations while in the discharge lounge. Quantitative survey data was analysed by a member of the research team with expertise in statistical methods, who had also designed the survey. Answers on survey forms were copied into a spreadsheet using numerical coding. This data was then analysed using the open source statistical software, R, to produce tables and graphs showing summary information about the people who took part (e.g. age, gender, whether they had a disability) and about their experiences and opinions of hospital discharge. The free text questions served to elucidate the issues participants faced during hospital discharge. The open ended qualitative survey data and contextual notes made by the researchers who carried out the survey interviews were also transcribed and subjected to thematic analysis. The qualitative and quantitative data set was subsequently triangulated (Patton 1999) to elucidate complementary aspects of the same phenomenon. Twenty-seven people gave their consent to participate in the survey. Twenty-four were patients who answered the questions themselves, while a further three patients requested that a friend or family member do
so on their behalf. All but one of the survey participant’s left free text comments.

Lens 2 involved the recruitment of patients and carers from two wards who were invited to complete diaries (either using digital recorders or in written form) providing information about their experiences of hospital discharge as they occurred during their stay in hospital and following discharge, and to participate in interviews following their discharge from hospital. Six patients and two carers participated in this aspect of the study. See Table 1 (pg. 15) for a profile of participating patients. Our participant samples were purposive insofar as we set out to include a large proportion of elderly patients, as we know they often experience problems during and following discharge. In conducting ethical research, a balance has to be struck between ensuring no inadvertent harm is caused to participants, while recruiting a broad spectrum of experiences, especially capturing the experiences of the most vulnerable. Researchers worked closely with staff in both the wards and the discharge lounge to identify suitable patients to approach. While wishing to ensure we were able to interview as broad a sample of patients as possible we experienced ethical challenges in recruiting those who were particularly sick and vulnerable. We also experienced challenges in recruiting carers (family members/friends) of patients in cases where patients did not have sufficient mental capacity to consent. We found that family members were often in a hurry and too distressed or anxious about their relatives, so when we mentioned the study to them they were reluctant to participate. While our sample was not a representative one (indeed, this is not the aim for qualitative research), it provided a descriptive picture of the experiences of participants and we identified common themes across their narratives. The follow up interviews were designed to explore in more detail patient and carer experiences during the patient’s stay in hospital and post-discharge. They were conducted with participants in their place of residence to gather an in-depth account of their experiences related to their hospital discharge and transition from hospital care to care at home. Interviews and audio diaries were transcribed (verbatim) and the resulting data analysed. We applied thematic analysis, and searched for themes that emerged as important to the description of the phenomenon (Daly, Kellehear and Gliksman, 1997). This involved the identification of 12 themes through ‘careful reading and re-reading of the data’ (Rice and Ezzy, 1999). Our first level of analysis utilised a thematic approach (looking for broad/common themes and variations); with the second level of analysis using more detailed coding, demarcating segments within the themes so that the data ‘emerged’ from participant experiences. This is a form of pattern recognition within the data, where emerging themes become the categories for analysis. To ensure rigour in the analysis this process was carried out by the researchers involved in the data collection, and analysis checking and discussion meetings took place at HWE and the University of Essex with the entire research team. Any areas of contest concerning data findings and interpretation were resolved through discussion and re-analysis of the primary data.

In Lens 3 we present our analysis of our observational/ethnographic data, which includes observations of more complex discharge cases. We wanted to find out more about some of the challenges that staff face in preparing patients for discharge and, in particular, how they deal with planning for complex discharge cases. We
chose to use ethnographic methods (observation and interviews) to study the processes and challenges staff face, and their views of these. Ethnography is a qualitative approach that involves relative submersion in the studied setting, and is historically associated with observational work and interviews carried out in everyday settings. It has been used in healthcare research and medical settings (see Savage, 2000; Pope, 2005) and focuses on the meaning of an individual’s actions and explanations, rather than their quantification. Although time consuming, it is a particularly useful method in revealing complex or unfamiliar cultural practices. The ethnographic observation of the discharge team was carried out between June and September 2015. This involved shadowing the discharge team during week-days and weekends. As discharge planning occurred mainly during working hours (8.00–16.00), observation took place during these hours. Our researcher shadowed different members of the discharge team (both health and social care) during their day-to-day clinical work (i.e. board rounds, interactions with patients and ward staff, decision support tool [DST] meetings). The health and social care teams were located in different offices. The researcher spent 65 hours at each hospital under observation. The discharge teams welcomed the presence of the researcher and worked collaboratively to facilitate the research process. In cases where a member of the discharge team had to interact with a patient, verbal consent from the patient was obtained. If patients were not able to provide verbal consent (i.e. they lacked mental capacity) the researcher stayed in the nursing station until the discharge member of staff had finished talking with the patient.

When a member of the discharge team being shadowed interacted with other healthcare staff, the researcher’s role was described to the healthcare staff. The researcher also attended board rounds in a number of different wards at each hospital. The discharge member of staff introduced the researcher and explained the reasons for their presence in the board round. The researcher recorded field notes during fieldwork and at the end of the fieldwork day to capture the overall experience of spending the day with the discharge team. In addition, semi-structured interviews with members of the discharge team and interviews with senior staff involved in discharging patients were carried out. The interviews were primarily reflexive and focused on how the team experienced the overall discharge process and their collaboration with other colleagues and agencies based in or outside the acute care setting. The interviews lasted approximately 20–30 minutes and were carried out in private rooms. Each Lens data set was analysed separately before the entire data set was triangulated and overall findings produced. See bibliography to the main report (page 63) for the sources used in Appendix ii.
Patient narratives, and listening to the patient voice in particular, are important as they focus attention on the ‘lived experience’ and can provide a context that encompasses both the illness event and surrounding life events and recreates a state of interrelatedness (Hyden, 1997).

In this case summary we recount the stories of two of our study’s participants, Samantha and her daughter Fiona. Their particular narratives illustrate many of the themes and issues we identified in our study and are discussed within our report.

Ninety-one-year-old Samantha, who lived alone, was admitted as an emergency patient to hospital following advice from her GP when it was discovered that she had a cyst on her liver. Fiona coordinated her mother’s care and was present when Samantha was recruited, and she participated in her mother’s interview, and also conducted the diary describing her mother’s experience of care, both pre and post discharge. After Samantha’s local GP had seen her liver cyst, her family were instructed to take her to hospital. They left her there overnight and when Fiona came in to visit her the next day, she was told without warning she could go home. Fiona described the scene as she arrived to visit her mother, and her subsequent feelings of distress:

*When I turned up on the Wednesday mum was sitting there ready to come home, in her nightie. They hadn’t telephoned me like they said they would, so I wasn’t prepared... I had nothing in place... I had no food at home.*

When she questioned this decision, worried by the amount of pain the cyst was causing and the effect it had on her mother’s ability to eat, she was told the discharge was appropriate because Samantha’s condition was ‘not life-threatening’.
Our HWE researcher had just approached Samantha when Fiona arrived to visit her, and reported that she seemed surprised her mother was being discharged that day; she had received no prior warning. In this initial conversation, Fiona told our researcher that:

*Her mother had been very sick when she was brought in and she was under the understanding that her mother would not be going home until the doctors had worked out the medical problems her mother faces.* (Researcher field notes)

They were informed that Samantha was being sent home while the hospital waited for her test results. Fiona had not been aware that the test was happening, nor had she been asked about her worries regarding her mother’s ability to care for herself post-discharge. It was decided though that Samantha’s cyst needed to be drained, she should await the procedure at home, because there were no appointments for ‘six to eight weeks’. A doctor prescribed her paracetamol for the pain caused by the cyst, which was pressing on her stomach. This pressing made it additionally painful for Samantha to eat; Fiona tried to discuss this with staff, as she believed it increased her mother’s care needs while waiting for the procedure. However, she recalls staff telling her:

*“If you want to have mum checked over as regards carers and so on it will probably take a fortnight,” by which time, when mum heard this, she was crying... “I want to come home.” That puts big pressure on you.*

Samantha, like many other elderly patients, had problems with her memory, and staff seemed not to take this into account. As Fiona told us:

*Unfortunately, with Mum’s memory being bad, she was getting shooting pains, and then she could go a few minutes without, and if a nurse said, “are you in pain?” she would say, “no.” [But] on the way home in the taxi she was getting regular shooting pains.*

Furthermore, Fiona worked full time and not being told in advance that her mother was being discharged that day meant that Fiona was unable to be with her the following day, as she had no time to have arranged cover for her job the following day. Fiona rang the local GP again the next day, concerned that her mother’s discharge had not adequately assessed her care needs, nor had it taken into account the seriousness of her health problems. The GP described the discharge as ‘outrageous’, telling Fiona:

*That’s an inappropriate discharge from hospital. Get her back in. I will refer you.*

Samantha was helped by the fact that her daughter was present and able to advocate for her mother’s care needs, meaning she was able to question the doctor’s decision to discharge her; however, this is a not a position that many vulnerable and elderly patients are always in. When Fiona tried to readmit her mother she had to fight to get her a bed; telling staff, ‘Mum is not coming home. You will have to find a bed, because this needs doing’.

Once Samantha was readmitted, she was given a bed and the family were told she had to wait until it was possible to have the procedure. Fiona told us that ‘it was just day by day waiting’ for news, and she found it difficult to ascertain when the drain would take place, and if there was a schedule for her mother’s health needs. There seemed to her no forward-planning and/or no record of these plans.
I would have thought you got on the computer and the answer would be there, but nobody... they did their best. They chased around. They found a doctor... he did his best.

Once again, it was Fiona’s presence and ability to advocate for her mother that meant her problems were addressed within a reasonable amount of time (two weeks). However, this is not the case for all patients. Fiona managed to speak to an individual doctor who ‘pushed it and pushed it and got that in a couple of days.’ While praising the efforts of staff, Fiona criticised the system in general and the seeming lack of structure or organisation; it seemed that the procedure should have been scheduled within the next week or two regardless of speaking to a staff member about it. This was a criticism that came up continually in Samantha’s experience of discharge, and is reflected in the stories of many other participants in this study.

While being interviewed, Fiona was asked what she would alter about the experience, if she could choose only one thing. She answered:

The continuity... you ask a question... and they say “Yes,” and then they don’t... they must keep records, whether it’s writing it down, whether it’s on a computer.

Having experienced difficulty caring for their mother when she was discharged without warning on her first hospital visit, Fiona and her sister specifically asked several members of staff to telephone them before she was discharged the second time:

The one regular thing we were saying to all the different people was, “Phone us so that we can be prepared.”

However, although the staff did ring Fiona to inform her of her mother’s discharge, it was on the day of discharge, rather than a couple of days before, which is what Fiona had intended and expected. She felt disappointed at the hospital’s inability to assess and ‘anticipate’ in advance when considering her mother’s discharge.

Like the first time, Fiona also felt her mother was not totally fit and ready to leave. Though she had now had undergone the procedure, Samantha’s health was still poor and she was leaving hospital considerably weaker than before:

My impression was that once they took the tube out there would be a couple of days recuperation, just to make sure she was going along all right, but then when I got there that day she was ready to come home.

This contributed to Fiona’s reports of feeling distressed when she went to pick her mother up. She was told on the phone, on the same day, to ‘turn up with some clothes for Mum.’ When she arrived that evening she felt that she could not process all the information being given to her at once (where to go for a taxi, how to work the wheelchair and the various equipment given to her) telling our researcher:

I said, “Do you know what? I’m in such a state, with Mum being discharged in this way, I can’t even take on board what you’re saying.” One very kind nurse said “I will come with you.”

On leaving the hospital, Fiona reported her mum was in a wheelchair. She had also been given two walkers to take home, and Fiona was carrying several bags. This contributed to her feeling overwhelmed and unsupported once out of hospital, and in the actual transition from hospital to home. Fiona told us there was no possibility of hospital transport leaving hospital, and so she had to pay for a £40 taxi ride whenever she transported her mother to and from the hospital.
As a 91-year-old, living alone, it seemed fair to suggest that Samantha might need some assistance, but the hospital-based Occupational Therapist (OT) assessed this to be unnecessary, telling Fiona:

“Yes, she’s fine. She can make a cup of tea.” I said, “But you’ve not seen Mum in her house.”

The basis for this assessment was a conversation between the OT and Samantha (without Fiona present), regarding the layout of her house (they discussed the fact that she walks down a hallway and up only two steps), and the fact that he had seen her make a cup of tea at the hospital. This was especially problematic because, as Fiona pointed out earlier, and as several carers of the elderly have indicated in this study, elderly patients with memory problems or dementia have to be treated differently to young or middle-aged people. This means involving their carers in such decisions. Fiona additionally reported that her mother had not actually been using her walker, which was putting her at risk, and so Fiona, her sister, and the carer they had personally hired, still checked on her regularly. Her mother felt she did not need the walker but to Fiona it seemed evident that her mother was weaker and less well-balanced after she’d left hospital. Just because she had been given new equipment and was physically able to use it, she was not necessarily safely using it. It was a similar predicament with another piece of equipment, the alarm bell worn around Samantha’s neck, intended to be rung if the wearer had a fall. Fiona and her sister were not convinced that if their mother fell she would remember the bell or what its purpose was, rendering it useless. Fiona made the additional point that the OT seeing Samantha make a cup of tea in the hospital did not mean she would be able to do so at home. This supports the idea raised during interviews with staff, that care assessments would be more successful if conducted in the patient’s home.

Fiona told us that it seemed to her that:

If you take an elderly person away from their usual environment... it's like if I move this I notice mum moves it back... it has to be in exactly the same place... two and a half weeks in hospital has wiped out a lot of that familiarity. This is only my guess work, but that's how I see it. For mum to come back, I was asking her if she was going to do this, that, and the other, and she said, ‘Oh, is this what I usually do?’ She’d forgotten her routine.

At the point of the interview with the HWE researcher, Fiona said that they were ‘now waiting for a letter from them to go back for a check-up’ and had been told by staff: “if you don’t get a letter you ring us.” Prior to this, the hospital, upon discharge, had informed Fiona that:

I would need to organise a couple of blood tests, one a week after mum came out and then a week later. Even that was not straightforward... they said, “ring the district nurse.” When I rang she said... “You will have to get a referral from the GP”.

The district nurse came the following week, and they then got another referral for the next week (the week prior to the interview). Fiona and her sister had to arrange and pay for their mother to have food delivered and said that they were not given adequate information about food service options before their mother was discharged, although the OT did give them a leaflet for a service and provided them with a phone number that they were unable to get through to.

Fiona also took on increasing caring duties for her mother and while she and her sister were doing many of these tasks before their mother was admitted to hospital, she had much more to do following her mothers discharge.
What was in place before, which was I do mum’s shopping, I do mum’s gardening, and I help her with the housework. Well, it will have to be even more now.

Fiona and her sister organised the bulk of their mother’s post-discharge care and had to navigate around the system, being sign-posted along the way by various people they contacted. However, because some of the information they received was inaccurate, the organisation of their mother’s care was delayed and complicated unnecessarily. This story presents us with a prime example of a patient whose carer must be treated as a partner in care; someone who is informed equally and provided with adequate instructions for post-discharge care. Most of the patients we interviewed described their main carers as family/friends, and pointed to these people as their first point of contact if they were in trouble. However, several participants in this study lived alone and/or relied on friends or neighbours. Especially within the elderly population, but generally when one suffers with chronic or long-term health difficulties, the desire to not ‘burden’ oneself on non-professional carers became evident during the HWE investigation into hospital discharge. This makes it especially necessary for hospitals to arrange post-discharge care that carefully considers the needs of the patient, making sure they are medically and socially fit to leave and transition into an appropriate care environment.
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