



# Safely home:

What happens when people leave hospital and care settings?

**Healthwatch England**  
Special inquiry findings  
July 2015

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## Foreword

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### **I am pleased to be able to share the findings from this special inquiry.**

In our role as the champion for those using health and social care services, it is vital that people are always at the heart of our work. That is why this inquiry was not led by academics, practitioners or policy makers, but by the very people who have experienced the discharge process going wrong.

When we started this inquiry, we knew this issue affected thousands of people across the country. But it was still shocking to hear the sometimes tragic consequences of what people had been through. Even more so, when often just a simple thing could have made all the difference.

We are thankful to everyone who came forward to share their experience with us. From older people stranded in discharge lounges waiting to go home, those with mental health conditions left with nowhere to turn after leaving care, to homeless people made to feel unwelcome in hospital.

This evidence was all particularly hard to hear as nothing about this issue is new. The problems have been recognised for many years and although the consequences are particularly detrimental for the three groups we focused on, we know that the discharge experience is often also unsatisfactory for the wider public too.

When people fall through the gaps between different parts of the health service or between health and social care, it causes a huge amount of suffering, and comes at a cost of billions to the taxpayer too.

We know there is no simple fix, but nonetheless we saw and heard about lots of great efforts to make the discharge process work better for people. Unfortunately this good practice is simply not widespread enough to resolve the issues.

We know this is a big issue and there is no shortage of guidance and good practice identifying solutions, yet in practice too few hospitals make full use of the available knowledge and experience to ensure people have the basic support they need when they leave.

We have concluded that to truly change people's experiences, we need a system wide commitment to putting their needs at the heart of processes. That is why we are working with the Department of Health who are taking a leading role in encouraging key organisations to tackle this issue.

I hope that the power of people's stories will bring a new imperative for change and drive health and social care agencies nationally and locally to ensure they get discharge right. For our part, we look forward to working with local Healthwatch to ensure that people's voices are heard up and down the country, calling for a new approach to discharge.

**Anna Bradley**  
**Chair, Healthwatch England**

## Thank you

**We could not have conducted this inquiry without the help of a huge number of people and organisations.**

**Thank  
you to:**

- + All of the people who contributed to the 3,000 pieces of evidence we gathered for sharing their experiences. By telling us your stories, you're helping us call for change so that this does not happen to anybody else.
- + The 101 local Healthwatch who helped run focus groups, spoke to local people affected by this issue and researched this problem in their local area.
- + Our inquiry panel and advisory board – for overseeing the special inquiry from start to finish, for leading our investigations, and making sure we always had the people we're representing at the heart of our work.
- + All of the Royal Colleges, charities, such as Mind and The Centre for Mental Health, frontline professionals, regulators and other health and social care organisations who contributed evidence and insight.
- + The Department of Health for its assistance with the inquiry and for its commitment to working with us in using the findings to galvanise change.



## About us

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**To help realise the ambition of putting people at the centre of health and social care, the 2012 reforms created Healthwatch England, the national consumer champion in health and care, and a Healthwatch in every local authority area across England.**

We have statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.

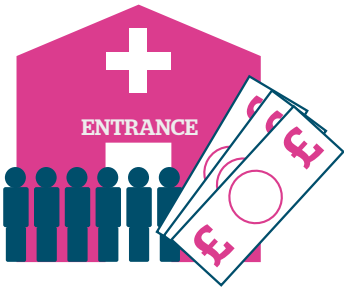
Healthwatch is unique in that its sole purpose is to understand the needs, experiences and concerns of people who use services and to speak out on their behalf.



## What we found

When discharge goes wrong, it comes at significant cost, both to individuals and to the health and social care system.

### The cost of readmission



In **2012 - 13** there were more than **one million** emergency readmissions within **30 days** of discharge, costing an estimated **£2.4 billion**.<sup>1</sup>

Whilst the financial cost of this problem is recognised, not enough is known about the human cost. We undertook this inquiry to bring the true emotional and physical impact of this persisting problem to light.

With the help of 101 local Healthwatch, we heard from over 3,000 people who shared their stories with us about their experiences of the discharge process. People told us that they were either discharged before they were ready, or that they were kept in care for too long, which had a significant and detrimental effect on their lives.

Many people said that, although they may have been deemed medically safe to leave hospital, they did not feel safe or adequately supported to do so. Others told us about experiences of delays to their discharge and the significant consequences of being kept in care too long.

Throughout this inquiry, we focused on the experiences of older people, homeless people, and people with mental health conditions - three groups for whom the consequences of a failed discharge process were particularly detrimental.

These three groups are not mutually exclusive. In many cases, homeless people experience mental health as well as physical health problems, as do older people, thus contributing to the complexity of their needs and the particular importance of ensuring that they receive all the support they need after discharge.

### The public's experience of the discharge process

In a YouGov survey of 3,495 people across England:

- + 18% of people who have been discharged from hospital in the last three years did not feel they received all the social care support they required after leaving hospital.
- + 1 in 4 (26%) people felt their friend/relative who had been discharged from hospital in the last three years did not receive the social care support they needed.
- + 1 in 5 (21%) did not feel they were fully involved in decisions concerning hospital treatment and planning discharge, and the same proportion (22%) felt their friend/relative was not fully involved as an equal partner.
- + 1 in 8 (12%) did not feel they were able to cope in their own home after being discharged from hospital. 1 in 4 (24%) did not feel their friend/relative were able to cope.
- + 14% did not know who to contact for further help following treatment, 18% of people felt their friend/relative did not know who to contact.<sup>2</sup>

<sup>1</sup> Emergency admissions cost NHS £12.5 billion in 2012/13. 19% were readmissions. <http://www.nao.org.uk>

<sup>2</sup> Online poll carried out June, 2015 by YouGov

## Five reasons things go wrong

**We found that there are five core reasons people feel their departure was not handled properly:**

1. People are experiencing delays and a lack of co-ordination between different services;
2. People are feeling left without the services and support they need after discharge;
3. People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances;
4. People feel they are not involved in decisions about their care or given the information they need; and
5. People feel that their full range of needs is not considered.

The purpose of this report is to bring to light the human consequences of getting discharge wrong and to outline some of the key reasons this is happening.

We cannot claim that what we heard is representative of all people's experience. However, we heard from more than 3,000 people and the volume, nature and geographical spread of stories shows that this is a significant issue.

What we heard was also reinforced by what we found during our thorough review of existing evidence.

We also heard about numerous examples of good practice which are making a real, if small-scale, difference to people. However, in spite of these efforts, this problem still persists.

We were struck by how stark some people's stories were, especially as it has been widely recognised that discharge processes need to be improved.

This is reflected by the more than 20 pieces of guidance produced over the last decade in an attempt to address the issue.

We are using this inquiry and the stories of the human and financial cost of discharge going wrong to call for national change to the discharge process.

It is vital that we take concerted action now to ensure that it meets all people's needs, however complex they may be.

## Use of discharge checklists

**Responses received from 120 trusts indicate that:**

- + Almost all had a discharge checklist but less than half check whether people have a safe home/place to go when discharged, or whether there is basic food, water, heating etc.
- + 1 in 3 do not ensure notes about new medication are properly recorded and passed on to GPs or carers.
- + 1 in 10 trusts do not routinely notify relatives and carers that someone has been discharged.
- + We established that trusts used a variety of guidance from 57 different documents - creating huge variation.<sup>3</sup>

<sup>3</sup> Healthwatch England Freedom of Information Act request results, May 2015



## About the inquiry

When we heard from local Healthwatch around the country that people were leaving hospitals and mental health settings feeling badly prepared for their departure, and with medical or social needs that had not been addressed, we decided to investigate further.

We wanted to enable people to share their experiences of the issues surrounding discharge and the impact it has on them when it goes wrong.

Our inquiry advisory group and panel included older people, homeless people, and people with mental health conditions. These individuals set the terms of reference for our investigation, worked with us to investigate how the discharge process could be improved and ensured that their experiences and those of their peers were represented throughout.

### Sources of evidence

The Healthwatch network was free to investigate the issue through the most relevant means locally - which meant we heard people's views on discharge through focus groups, surveys, visits to services and received evidence submitted from a range of organizations. This evidence incorporated local people's experiences from a range of different hospital and other service settings from across England.

We reviewed people's stories and drew out the key themes relating to their concerns and structured our findings around what people, rather than existing system-focused research told us. We have used pseudonyms throughout this report to protect people's identities.

Having built up a picture of the hospital discharge process through the eyes of people, we compared this existing policy documentation and research to build our understanding of the discharge process.

In addition to the three groups we focused on, the discharge experience is often also unsatisfactory for the wider public. We conducted a YouGov poll of 3,495 people across England to find out about their experiences. We also sent a Freedom of Information

(FOI) request to 164 trusts (to which 120 responded) to ask about their use of discharge checklists.

With the support of the Royal Colleges, we also undertook a survey of frontline staff about their perception of the impact of the discharge process on people.

### Seeking solutions

Healthwatch England also brought together over 30 health and social care sector leaders, as well as those with a negative experience of leaving care. Whilst this discussion brought to light some useful examples of good practice which are helping to improve the discharge process, many professionals struggled to think beyond current practice, as well as existing funding and organisational arrangements - demonstrating the complexity of the issue, and the current perceived limitations in resolving it.

We have come across evidence during this inquiry which suggests that some groups have particular experiences of discharge from hospital, for example Black Minority Ethnic experiences of mental health services.

However, we did not receive enough evidence to be able to explore these experiences as fully as they deserve and believe that they need further investigation.

### The inquiry in numbers

**3,230**   
people shared their experiences

**101**   
local Healthwatch contributed.

## What were people's experiences?

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### 1. People are experiencing delays and a lack of effective coordination between different services

Homeless people, older people and people with mental health conditions told us about problems they experienced as a result of poor coordination between different parts of the health system, and between health services and community support. The impact, however, was often experienced quite differently by different groups of people.

Older people and their organisations told us about delays with assessments for ongoing care needs.

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**“It took another four weeks before I could negotiate a safe level of care so discharge could take place. My wife had to endure an unnecessarily prolonged stay in the care home because of the administrative failure of all concerned.”<sup>4</sup>**

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We also heard about disputes between local authorities about who would pay, resulting in assessments not taking place.

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**“I was told I could go home without the assessment, [but] when I got home I couldn't get up the stairs. [I] had to sleep downstairs for nearly six weeks.”<sup>5</sup>**

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We also heard from patients who had been detained unnecessarily in mental health settings when they posed no risk to others. We also heard about delays while care co-ordinators and social workers tried to get funding for ongoing support in the community.

**An estimated one in 20 bed days<sup>6</sup> are used by people experiencing a delayed discharge in a mental health setting.**

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<sup>4</sup> John, online submission, local Healthwatch, Midlands

<sup>5</sup> Elsie, local Healthwatch focus group, Midlands

<sup>6</sup> Healthwatch England analysis of My NHS Mental Health Hospitals in England data at October 2014 <http://www.nhs.uk/Service-Search/performance/Results?ResultsViewId=1014>

## Jess's experience:

**Detained under the Mental Health Act in a low secure unit, Jess had been assessed as fit for discharge. However, an agreement could not be reached about the funding of her care and accommodation in the community.**

The delay in her discharge was causing significant distress as she was away from her young daughter.

Jess went through a multitude of routes to try to resolve these funding issues. She contacted her 'home team' (from whom she had not received any correspondence for over a year) and instructed a solicitor who applied to the Mental Health Tribunal. She remained in hospital throughout this time.

The authorities finally reached an agreement and Jess has moved into her new home. She now has contact visits with her daughter, who lives with a family member. She is still waiting for discharge from her residency order as she cannot access legal aid and cannot afford to fund court costs herself.<sup>7</sup>

People also told us that information is not always being passed on to their GPs as quickly as it should be, leading to delays in receiving aftercare treatment, or medication once they return back to the community.

The Care Quality Commission echoed this finding in a 2009 report: **"Information shared between GPs and hospitals when a patient moves between services is often patchy, incomplete and not shared quickly enough."**<sup>8</sup>

**"I received an out-patient appointment six weeks after discharge. It then took 20 months to obtain records. [Once they were received] the GP referred me [for physical tests] and immediately commenced B12 injections and iron tablets when the notes revealed I had a deficiency. None of these issues were mentioned [to the GP after discharge]."**<sup>9</sup>

<sup>7</sup> Jess, online submission

<sup>8</sup> Care Quality Commission (2009) 'National report: Managing patients' medicines after discharge from hospital'

<sup>9</sup> Bill, online submission to Healthwatch England

## 2. People feel left without the services and support they needed after discharge

We heard from hundreds of people verging on crisis as a result of not being able to access community support and services after being discharged. In many cases, the consequence was often another admission to hospital or mental health service.

We were told multiple stories of people contacting out-of-hours mental health crisis support services only to receive no response or to be told to call back later.

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**“I rang the out-of-hours number to be told: “I can’t access your notes, can’t you just read a book or do a crossword for the next 5 hours?”<sup>11</sup>**

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**The first **three months** after discharge are a time of particularly high suicide risk; this is especially true within the first **1-2 weeks**.<sup>12</sup>**

Between 2002-12 there were 3,225 suicides in the UK by mental health patients in the post-discharge period, 18% of all patient suicides.<sup>13</sup>

Our analysis of NHS data from mental health hospitals suggests that one in five patients is still not being followed up with within seven days of a hospital discharge.<sup>14</sup> It is vital that people are contacted after leaving services and that crisis support is available.

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<sup>11</sup> Jason, focus group, South of England.

<sup>12</sup> Appleby L, Kapur N, Shaw J, Hunt IM, While D, Flynn S, et al. (2013) The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness: <http://www.bbmh.manchester.ac.uk/cmhs/centreforsuicideprevention/nci/reports/Annualreport2014.pdf>

<sup>13</sup> The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (2014) Annual Report 2014: England, Northern Ireland, Scotland and Wales. July 2014.

<sup>14</sup> Healthwatch England analysis of My NHS Mental Health Hospitals in England data at October 2014: <http://www.nhs.uk/Service-Search/performance/Results?ResultsViewId=1014> - although the Monthly Mental Health Minimum Data Set (MHMDS) for July 2014 suggest nearer 1 in 4 (24%) did not receive a follow up within 7 days: <http://www.hscic.gov.uk/catalogue/PUB15733>

## Shaz's experience:

**With a known history of self-harm, Shaz was discharged from hospital, armed with only the phone number of the crisis mental health team.**

Following suicidal thoughts, she rang the crisis team that evening but they were not available. She also contacted her out-of-hours GP services, which were unable to see her that night.

Distraught, she walked to her local pharmacy to buy medication. The pharmacist recognised her and, worried about what she might use the medication for, refused to serve her.

Shaz told the pharmacist that she felt she was in crisis and concerned that she might harm herself. He gave her a phone to call NHS 111, who told her to go to the Accident and Emergency (A&E) department of the hospital she had been discharged from that day.

Following an assessment by an A&E nurse, Shaz was told it was fine for her to go home. The next day she visited a different pharmacist, took an overdose and was taken by ambulance to the A&E department she had been discharged from the night before.<sup>15</sup>

**“I used to be able to access a women’s crisis house but they won’t take me anymore. [In some places] there’s no such thing as voluntary admission to hospital now... to get a bed you have to be detained under the Mental Health Act”<sup>16</sup>**

We heard that people believe that it is very difficult to access support for mental health conditions without use of the Mental Health Act, under which people are compulsorily admitted to hospital if approved mental health professionals consider it necessary.

In 2013-14, the Mental Health Act was used 53,176 times to detain patients in hospital for longer than 72 hours, which is 5% (2,768) more than 2012/13 and 30% more than 2003/04.<sup>17</sup> This raises significant concerns about how access to support is secured and whether the Mental Health Act is used appropriately.



**A survey of 576 junior doctors working in psychiatry found that a quarter had been told their patient would not get a bed unless they had been sectioned.<sup>18</sup>**

<sup>15</sup> Healthwatch England focus group

<sup>16</sup> Case study - Voluntary sector submission, Mind

<sup>17</sup> Monitoring the Mental health Act 2013/14 <http://www.cqc.org.uk/content/mental-health-act-annual-report-201314>

<sup>18</sup> Royal College of Psychiatrists (2014) Psychiatric Trainees' Committee Survey: <http://www.rcpsych.ac.uk/>



Older people also told us that they struggle to access support after discharge. Many said that after returning home from hospital nobody had followed up with them, they did not know where to turn for support, and they had been left to arrange their own aftercare.

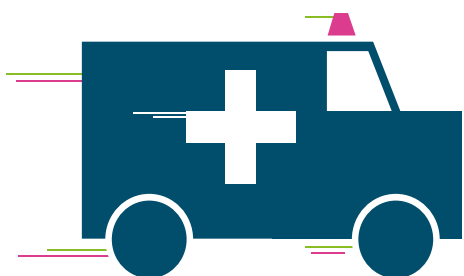
Older people explained the physical and emotional effects of this, ranging from additional falls in the home leading to readmission, to a feeling of being abandoned by the health system at their time of need.

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**“A patient can be confused [when discharged from hospital] and needs to be confident in the people around them.”<sup>19</sup>**

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**This lack of vital support is leading to significant levels of readmissions.**



**In 2010-11 201,000 older people over the age of 75 experienced an emergency readmission.<sup>20</sup>**

In the last decade, emergency readmission for those aged 75 and over increased by 88%.<sup>21</sup>

Some older people told us they were left confused about the new medicines they had been prescribed, and weren't told how it might fit with their existing medicine.

Our survey of healthcare professionals told us that breakdowns in communication can lead to older people taking multiple drugs simultaneously after discharge, which can result in adverse drug reactions, and readmission.

This lack of seemingly simple provision is putting people at significant risk.

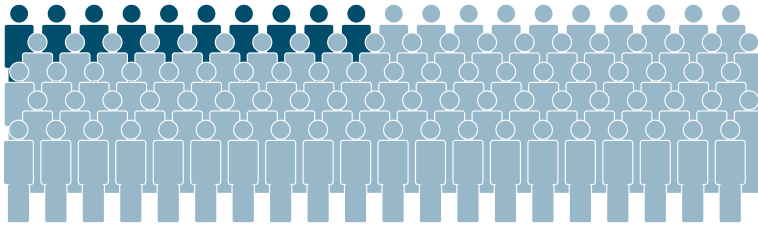
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<sup>19</sup> Jean, written submission, local Healthwatch, North of England

<sup>20</sup> Nursing Times 'Growing readmission rate sparks concern around early discharge' (2013) <http://www.nursingtimes.net/nursing-practice/specialisms/older-people/growing-readmission-rate-sparks-concern-around-early-discharge/5054823.article>

<sup>21</sup> Royal Voluntary Service Report 'Unhappy Returns' (2014) [http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Get%20involved/avoiding\\_unhappy\\_returns.pdf](http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Get%20involved/avoiding_unhappy_returns.pdf)

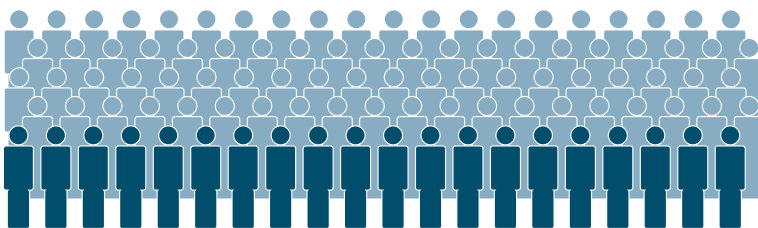
## Prescribing problems



The likelihood that an elderly medical patient will be discharged on the same medicines that they were admitted on is less than **10%**.<sup>22</sup>

**60%**

of older people have three or more medicines changed during their hospital stay.



Adverse drug events occur in up to **20%** of patients after discharge.<sup>23</sup>

Poorly managed discharge also affects people at the end of their lives. We heard stories of older people dying in hospital against their wishes because they could not be transferred to somewhere with suitable palliative care.

Families told us about loved ones being discharged from hospitals to care homes that are ill-equipped to deal with their palliative care needs. We also found out about others dying at home without adequate support, causing unnecessary pain and distress. These terrible consequences were often the result of basic communications failures.

**“The home didn’t know my mother was in need of palliative care (I didn’t know either), they didn’t have the equipment she needed (the hospital hadn’t sent a nebuliser over), the discharge plan was carried out over the phone to a nursing care member of staff who didn’t record anything. It was appalling. My mother could’ve had a much more peaceful and dignified death.”**<sup>24</sup>

<sup>22</sup> Royal Pharmaceutical Society report: ‘Keeping patients safe when they transfer between care providers - getting the medicines right’ June 2012 <http://www.rpharms.com/current-campaigns-pdfs/rps-transfer-of-care-final-report.pdf>

<sup>23</sup> Royal Pharmaceutical Society report: ‘Keeping patients safe when they transfer between care providers - getting the medicines right’ June 2012 <http://www.rpharms.com/current-campaigns-pdfs/rps-transfer-of-care-final-report.pdf>

<sup>24</sup> Marion, online submission, local Healthwatch, South of England

Homeless people told us about being discharged without support – often straight back to the street without accommodation in which to recover.

**“A heroin addict was seen six separate times at A & E about an abscess in his groin. He was ‘treated’ every time, not admitted and was discharged in a confused state. Paramedics were called out and said that if he had been left he would have died within a couple of hours.”<sup>25</sup>**

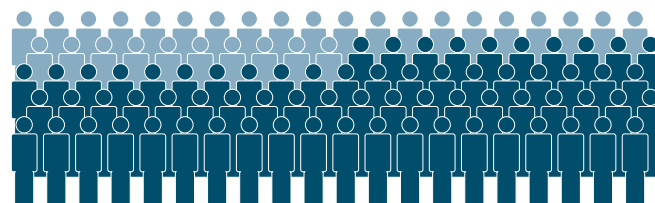
Homeless people use four times as many acute health services and eight times as many inpatient health services as the general population, but receive lower levels of follow-up care.<sup>26</sup>

Individuals can find themselves going in and out of hospital repeatedly because their housing, benefits and support structures are not in place to enable them to fully recover.

This can create a damaging cycle of poor health, admission, discharge and then readmission for those experiencing homelessness. Kings Health Partners estimate that some homeless people attend hospital as many as 30 times per year.<sup>27</sup>

Homeless Link and St Mungo’s Broadway found that more than

**70%**



**of homeless people** had been discharged from hospital back to the streets, without their housing or underlying health problems being addressed.

This leads to **‘revolving door’** admissions and poor health outcomes for homeless people.<sup>28</sup>



<sup>25</sup> Focus group Healthwatch North East Lincolnshire

<sup>26</sup> Healthcare for Single Homeless People’ Department of Health (2010)

<sup>27</sup> Nigel Hewett and Sam Dorney-Smith, Kings Health Partners and the Impact of Homelessness 2013,p 42

<sup>28</sup> Inclusion health, St Mungo’s and Homeless Link (2012) ‘Improving hospital admission and discharge for people who are homeless’ [http://www.homeless.org.uk/sites/default/files/site-attachments/HOSPITAL\\_ADMISSION\\_AND\\_DISCHARGE\\_REPORTdoc.pdf](http://www.homeless.org.uk/sites/default/files/site-attachments/HOSPITAL_ADMISSION_AND_DISCHARGE_REPORTdoc.pdf)

### **3. People feel stigmatised and discriminated against, and that they are not treated with appropriate respect because of their conditions and circumstances.**

Throughout this inquiry we heard examples of the ways in which all three groups felt that they experienced stigma and the impact that perceived staff attitudes had on their treatment and interactions. We found that people's basic expectations that they would be treated with respect and compassion were not being met.

Those with experience of being homeless told us they often felt discriminated against and judged by health workers and not treated with kindness or respect during their stay.

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**“I felt stigmatised during my stay, that I was a junkie. I feel I was treated differently to others and was always left until last for food, water, medication etc.”<sup>29</sup>**

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**“They are never nice to me. They are not gentle when they treat me and put the needle in my arm for the drip to help me get hydrated. I am not a drug addict. They should talk to me differently but instead they say things like ‘get out drug addict, go and get a job’.”<sup>30</sup>**

Others said that they felt unwanted in hospital and perceived that they were discharged too early as a result of this stigma.

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**“They cleaned me up overnight and discharged me the next day. I didn't feel ready to leave.**

**“They always get you out as fast as they can. I never get a treatment plan. I get treated as fast as possible and no follow-up.**

**“After being beaten up with a crow-bar I got x-ray and stayed overnight and had a headache when they discharged me but got no plan or support.”<sup>31</sup>**

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People with mental health conditions also shared this experience of stigmatising treatment and a lack of compassion. Those who had been hospitalised due to self-harming or suicidal behaviours reported hearing healthcare workers ‘tutting’ when they walked past their bed, or making unkind comments about being ‘a waste of hospital beds’ or ‘not worth spending NHS money on’.

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**“I felt I was in an emotional maze internally and externally... when I arrived to the hospital a nurse told me how much I was costing the NHS. I felt more guilty and suicidal.”<sup>32</sup>**

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<sup>29</sup> Focus group Healthwatch Rotherham

<sup>30</sup> Focus group, The Passage

<sup>31</sup> Focus group – The Passage

<sup>32</sup> Addison, third sector organisation focus group, South

We also heard about the indignity with which older people are treated when being discharged.

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**“When discharged, [Doris] was sent home with just an incontinence pad between her legs with no knickers or net to hold in place.”<sup>33</sup>**

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**“I rang shortly after lunch to be told [Mum] had been discharged. I was shocked. She lived alone and was still delusional.**

**“A neighbour rang to say mum had been brought home by ambulance in her nightgown and left at the cold house after the driver got a key from another neighbour.**

**“The elderly neighbour stayed with her all night. She was readmitted the next morning.”<sup>34</sup>**

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Poor treatment of older people is leaving patients in very vulnerable situations after discharge, and feeling uncared for by the health and social care system. In many cases it is also leading to readmissions which could have been avoided if suitable care had been taken to ensure they had the support they needed.

## **4. People feel they are not involved in decisions about their care or given the information they need**

Older people and those with mental health conditions told us about being sent home from hospital despite raising concerns about their ability to cope.

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**“I was deeply concerned whether I would be able to cope on my own in a first floor flat with no lift. When I challenged [the assessment that I did not need support] on the basis that they hadn’t even seen where I lived, I was told that they couldn’t spare the staff for a home visit.”<sup>35</sup>**

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Homeless people said they felt rushed through hospital and sent back to the streets without being advised where they might seek further support to recover or manage their condition.

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<sup>33</sup> Case study, voluntary / community sector organisation submission

<sup>34</sup> Julie, family member, online submission to Healthwatch England

<sup>35</sup> Alfred, online submission to local Healthwatch, North of England



**“I was admitted for alcohol withdrawal. I also have a permanent disability and I walk with a severe limp. I was rough sleeping at the time of being admitted.**

**“I was discharged at 3 a.m. on a very cold night, during heavy rain. I wasn’t offered any transport and not even a blanket. I don’t think staff listened to or cared for my needs on any of the occasions that I was admitted.**

**“I wasn’t asked how I felt, simply told my time as a patient on the ward was up. I did not feel involved in the decision making process to leave hospital. I was re-admitted within 2-3 months with the same problem.”<sup>36</sup>**

Families and carers reported not having been informed about changes in discharge planning, meaning that they did not have enough time to prepare for the return home, or understand the different support role they needed to play.

**“Staff on the ward are really supportive but the process of discharge is confusing at best and damaging to wellbeing at worst.**

**“It’s the communication and expectations that is very hard to keep track of: decisions reversed with no notice, no clear guidance to the family of who makes the decision.”<sup>37</sup>**

Many said they had not been properly informed about their relatives’ conditions or consulted about the level of support they could provide for them. People who were involved in discussions about their condition and care plans fed back that they found the conversations confusing.

We heard how this lack of involvement of people in decisions about their care, and a lack of understanding amongst patients and their families about their conditions and support requirements, can lead to terrible consequences.

## **John and Anne’s experience:**

**John suffered with severe episodes of depression and anxiety.**

While having some building work done at home, his condition intensified and his wife Anne discovered him engaging in suicidal behaviour. She took John to hospital where he was voluntarily admitted.

A few days later, Anne received a text telling her to collect John from the hospital. She was told John would be leaving with medication and she would need to provide him with additional support.

John was agitated and did not want to return home, but the hospital rejected his request to stay. He asked if he would be able to return if he felt unable to cope at home but the hospital said no and discharged him with an appointment for further assessment a week later.

One evening the following week John said he was going to visit a friend and did not return home. Anne contacted the police who told her that he had committed suicide.<sup>38</sup>

<sup>36</sup> Focus group, Healthwatch Luton

<sup>37</sup> Jackie, online submission, local Healthwatch, South West of England

<sup>38</sup> Citizen advice bureau - written submission

## 5. People feel that their full range of needs is not considered

People expressed their frustration that their full range of needs - including their physical and mental health, housing, care responsibilities and financial situation - were not all taken into consideration at point of discharge. Failure to do this can make recovery on departure from care more difficult and result in worsening symptoms.

We heard that organisations deal with either physical health or mental health, but rarely both. The result of this focus on the presented problem, rather than considering people's full range of needs, is a series of missed opportunities.

The three groups we focused on for this special inquiry are not mutually exclusive - in many cases, homeless people experience mental health as well as physical health problems, as do older people. By not identifying these issues early on, people are being discharged without sufficient treatment and support for their full range of needs, often resulting in conditions worsening and readmissions.

**“My depression was not recognised, my Asperger’s was not recognised, my pleas for support and help ignored.**

**“I was discharged against my will, left terrified and vulnerable on numerous occasions. Poor help and support led to more feelings of suicide not less.”<sup>39</sup>**

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This was a particular issue reported by those with experience of homelessness. Individuals said that often only the immediate physical problem they'd presented would be treated. Wider needs - especially mental health conditions - were often ignored. People felt their treatment was rushed rather than used as an opportunity to ensure that they had all of the support they needed.

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**“The stay is normally very short - they want to get rid of you ASAP. I think I had depression which I now get treated for from my GP, but nobody asked me about me, or helped my health needs.”<sup>40</sup>**

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<sup>39</sup> Paul, online submission

<sup>40</sup> Focus group - The Passage

**“My previous admissions and medical history were not discussed.**

**I would have liked more support, such as advice about support services within the community.**

**I would have liked a more joined up approach, not the feeling of being rushed so that I could be discharged as soon as possible without any serious consideration about my needs.”<sup>41</sup>**

We heard about people experiencing assessments as being too ‘rigid’, and not incorporating sufficient flexibility for changes to their support needs as a result of their condition worsening or changing.

Individuals also told us about caring responsibilities or family circumstances being overlooked when their support needs were being considered, hindering recovery and stability for many.

## **Evelyn’s story:**

**As a carer for her 85 year old husband who has dementia, Evelyn had to make plans for his care while she was in hospital. A few days after her operation a student social worker told her: “You can’t have a care plan. There aren’t any carers. I haven’t been able to fix anything, not even for you to pay for. I’ll keep trying.”**

Evelyn didn’t know how she would cope. Her husband also has Reynard’s disease which affects his hands and means he cannot grip and would be quite unable to help with Evelyn’s personal care, or with meals.

**Evelyn said: “[The ambulance drivers] left me standing in my kitchen supported by two crutches. I am no wimp but on that afternoon I was devastated. I had not felt so abandoned since my mother died when I was 25. I had not felt so abandoned since my mother died when I was 25. Bossy, organising me didn’t know how I was going to cope. Even now, several weeks on, I find it difficult to talk about, or even as I write, without crying.”<sup>42</sup>**

<sup>41</sup> Focus Group Healthwatch Luton

<sup>42</sup> Evelyn, Healthwatch Salford

## **In focus: Impact on older people**

### **Older People in the UK**

There are more than 10.3 million older people over the age of 65 in the UK. This represents an 80% increase since the 1950s.<sup>43</sup> The population will continue to grow older, with the 65+ population expected to reach 16.9 million by 2035.<sup>44</sup>

Over a third of the 15.5 million people admitted to hospital last year were over the age of 65. Many had existing and complex medical conditions that require particular consideration and care in planning discharge and aftercare at home or in the community.<sup>45</sup>

Today, family members provide the majority of informal care to older people at home or in the community. However, with people born since the mid-1950s showing different patterns of family formation and dissolution, the longer-term prospects for the familial support of older people are likely to be less favourable.<sup>46</sup>

### **How we gathered evidence regarding older people**

The experiences of over 1,000 older people, their families and carers helped inform this inquiry. We heard people's stories via focus groups, online submissions and by carrying out visits to services.

We worked with organisations including Age UK, Age Concern, Parkinson's UK and the Health Foundation, and heard about existing projects designed to support older people following a stay in hospital, such as projects being undertaken at The Royal Free and other local hospices.

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<sup>43</sup> House of Commons Briefing, Rutherford, T. (2012) 'Population ageing: Statistics' [www.parliament.uk/briefing-papers/sn03228.pdf](http://www.parliament.uk/briefing-papers/sn03228.pdf)

<sup>44</sup> Kings Fund 'Life expectancy' figures <http://www.kingsfund.org.uk/time-to-think-differently/trends/demography/life-expectancy>

<sup>45</sup> Hospital Episode Statistics, Admitted Patient Care, England (2012-13), Nov 2013

<sup>46</sup> Rutherford (2012)

## Overview of findings

### 1. People are experiencing delays and a lack of coordination between different services

**“The doctor came at 9.30 a.m. and said that I could go home but needed medication and would have to wait for that. At 12.45 I was still there waiting and apparently all I needed was some paracetamol.”<sup>47</sup>**

Hundreds of people told us about their experiences of delayed discharge, sometimes waiting all day for medication or transport. We heard that for older people with conditions such as dementia, hearing or sight loss, having to wait for hours in a discharge lounge, with little or no information, can be particularly distressing and disorientating.

**“Discharge depends on medication being sent to the ward from [the] dispensary and [a] nurse writing the discharge letter. This can take hours.”**

We also heard about significant delays older people experience awaiting transfer to a residential home, for grab rails or ramps to be fitted at home, or for social care packages to be put in place.<sup>48</sup>

According to Age UK, since June 2010 the NHS has lost almost two million bed days owing to patients waiting for social care assessments, a care home place, a care package or adaptations to be made to their own homes.<sup>49</sup>

The cost to the system is an estimated £526 million.<sup>50</sup> 80% of all delayed discharges or transfers of care are experienced by people over the age of 70 so this issue is affecting older people more than any other group.<sup>51</sup>

<sup>47</sup> Jim, local Healthwatch, East of England

<sup>48</sup> Age UK (2014)

<sup>49</sup> Age UK (2014) 'Nearly 2 million NHS days lost to delayed discharge' <http://www.ageuk.org.uk/latest-press/archive/nearly-2-million-nhs-days-lost-as-people-remain-in-hospital/>

<sup>50</sup> Age UK (2014)

<sup>51</sup> Royal Voluntary Service Report 'Unhappy Returns' (2014)



## Jackie told us about her father's experience:

**“They had suggested that they wanted to get my father into a community hospital. Staff talked to him about going, his expectations were raised and he wanted to go. The message came back that the community hospital wouldn't take him and he needed to stay at hospital to finish his IV antibiotics.**

**“My stepmother [is] distraught at another two weeks of driving in to see him; he's disheartened and I'm trying to manage the process from the family's point of view.**

**“As we thought he was going into a community hospital we were advised not to go looking at nursing homes again. Getting into the right one is really critical to his wellbeing so now we are ringing around (with the help of the onward care manager) trying to sort something out that might be suitable.**

**“We questioned whether he would get any rehab support and this has led the team to re-considering what [Dad] might be able to achieve. We are now back into the possibility of him being sent to a community hospital but we don't know until they've done more baseline assessments and in order to know what's happening I need to give up work a couple of afternoons a week to go in and talk to staff.**

**“I'm self-employed so I'm fortunate in having the ability to control my time however I would have really valued having access to a member of the medical team to be able to talk to / email with so not to be losing work as well.”<sup>52</sup>**

Long waits for assessments can have a significant impact on people's conditions, as Albert's daughter explained:

## Albert's story:

**Albert is a Parkinson's patient who didn't get the right support in hospital while waiting for assessment, and for intermediate care.**

His medication was not given on time and the limited physiotherapy he received while in hospital was inadequate. Health staff did not seem to realise the importance of administering Parkinson's medication at specified times and the direct impact this can have on mobility if medication times are not adhered to.<sup>53</sup>

Albert's daughter described a shocking lack of awareness by healthcare staff of the specialist care a Parkinson's patient needs. He was kept in hospital waiting for assessment and then for a place in a rehabilitation unit.

By the time the rehabilitation place became available his mobility had deteriorated so badly that they could no longer do anything for him. During the hospital stay his physical health had deteriorated to a point beyond repair.

Albert has now been moved into a care home, where his health has continued to go down-hill, to the extent he cannot walk at all now. Albert did not qualify for NHS continuing care and all of his savings have now been spent on care home costs.

<sup>52</sup> Jackie, online submission, local Healthwatch, South West of England

<sup>53</sup> Parkinson's 'Get it on time' campaign' For more information; <http://www.parkinsons.org.uk/content/get-it-time-campaign>

Individuals told us about difficulties people experience accessing NHS continuing care, which is arranged and funded by the NHS for adults with ongoing primary health care needs outside of hospital.

We heard that the system for accessing this type of care isn't working and is 'shrouded in mystery and disarray', leaving thousands of ill people with no choice but to pay for care.<sup>54</sup>

Department of Health and NHS guidance recognises that assessments for NHS Continuing Care and Community Care need to take place as soon as possible and well before a person is discharged but people have told us that often this is not happening.<sup>55</sup>

We also heard that there is huge variation in the way assessments are undertaken and decisions on eligibility for NHS Continuing Care are made, both in terms of process and criteria used, in different parts of the country.

## John told us about his wife's experience of applying for NHS continuing care

**"The [care] home manager claimed she did not know an assessment was required. After six weeks we were informed of the continuing healthcare outcome, given the poor standard of the assessment, unsurprisingly we failed to qualify.**

**"At this point the care home attempted to discharge Jane home, however the local authority took the decision to stop the two overnight 'sits' they had provided for several years as they reassessed this to be a primary health need and not personal care.**

**"It took another four weeks before I could negotiate a safe level of care so discharge could take place. My wife had to endure an unnecessarily prolonged stay in the care home because of the administrative failure of all concerned.**

**"I as the main carer could not manage [all] the 'night sits', having severe sleep apnoea I was already paying for a one night sit each week to cope.**

**"The guidance states when such an impasse occurs, a mechanism to resolve the issue should take place - this never happened. I had to involve my MP and negotiated evening sits to be [exchanged] for night sits.**

**"I am glad to say we were eventually awarded full Continuing Healthcare via the local Independent Review Panel taking 18 months and after much determination and effort."<sup>56</sup>**



<sup>54</sup> Voluntary / community sector organisation submission

<sup>55</sup> Department of Health (2010), 'Ready to Go? Planning the discharge and the transfer of patients from hospital and intermediate care.'

<sup>56</sup> John, online submission, local Healthwatch, Midlands



**2/3** of the UK's population want to die at home

**28%** would prefer to die in a hospice

**8%** want to die in a hospital or care home

However, only  
**21%**  
die at home



**4.5%** die in a hospice

**55%** die in hospital

**18%** die in care homes <sup>57</sup>

Data suggests that older people have the least choice over where they die and have the least access to specialist palliative care. Only 8% of those over the age of 85 dying of cancer, die in a hospice, compared to 20% of all cancer deaths and only 15% of over 85 year olds have access to palliative care when dying.<sup>58</sup>

These statistics were supported by what we heard about the difficulties people face at the end of their lives. Individuals reported problems with getting a social care package put in place quickly enough to enable their discharge from hospital in time, despite the 'fast track' system designed to escalate assessments for those nearing the end of life.

Findings by the National Audit Office suggest that 40% of end of life care patients have no medical need to be in hospital.<sup>59</sup> Family members said they felt health staff frequently focus on continued treatment of the condition rather than controlling symptoms or providing pain management.

<sup>57</sup> Marie Curie 'Patient choice versus cost graphic': <https://www.mariecurie.org.uk/>

<sup>58</sup> Centre for Policy on Ageing 'Ageism and age discrimination in secondary care in the UK' (2009) [http://www.cpa.org.uk/information/reviews/CPA-ageism\\_and\\_age\\_discrimination\\_in\\_secondary\\_health\\_care-report.pdf](http://www.cpa.org.uk/information/reviews/CPA-ageism_and_age_discrimination_in_secondary_health_care-report.pdf)

<sup>59</sup> National Council of Palliative Care 'Commissioning end of life care' (June 2011) <http://www.ncpc.org.uk/sites/default/files/AandE.pdf>

**“The treatment [during his hospital stay] has restored my father to a state of relative comfort. He is now anxious to come home, where he wishes to die.**

**“The hospital is just as keen to discharge him, in order to free up the bed. However, the discharge process has been a fiasco.”<sup>60</sup>**

At least a fifth of NHS costs are thought to be spent on end of life care<sup>61</sup>, highlighting that there is also a financial importance of properly assessing potential savings arising from earlier hospital discharge of terminally-ill patients.

The estimated cost of a day of community care at the end of life is £145 compared to the cost of £425 for a specialist palliative care bed day in hospital. This indicates that changing the setting of care of a patient at the end of life has the potential to reduce the daily cost by £280.<sup>62</sup>

We were told by professional organisations that end of life discharges normally require specialised equipment such as an air mattress, bed rails, safety bumpers and moving and handling equipment.

If the authorisation for this is queried by the local Clinical Commissioning Group or if there are hold ups in accessing medication, this causes delays to the person’s discharge.

We heard that some people are spending the last few weeks and days of their lives trying to get equipment like hoists, hospital beds, commodes and shower stools. Family members are often performing too much of a coordinating role, trying to get the right services and medication, or chasing people, services or equipment that has not arrived. This is all happening when they should be able to spend time with their loved one as they approach the end of their life. An estimated 92,000 people die every year without the support they need.<sup>63</sup>

When a person is discharged, a summary of their care and treatment should be sent to their GP so that prescriptions for new medication can be generated. In a 2009 report the CQC found that ‘Information shared between GPs and hospitals when a patient moves between services is often patchy, incomplete and not shared quickly enough.’<sup>64</sup>

Since April 2010 there has been a national standard to address this. Hospitals must send a discharge summary to the patient’s GP within 24 hours however, as we have heard, this does not always happen and we also could not find evidence showing compliance against this standard.<sup>65</sup> We also received anecdotal evidence to show that when summaries are received by the GP, the details within the summary are not always acted upon.

<sup>60</sup> Case study, voluntary sector organisation submission

<sup>61</sup> Demos ‘Dying for Change’ report (2010)

<sup>62</sup> Final Report, Palliative Care Funding Review (2011) <https://www.gov.uk/government/publications/independent-palliative-care-funding-review>

<sup>63</sup> National Council of Palliative Care (2014) ‘Mapping England’s Health and Wellbeing Boards’ vision for dying people’ [http://www.ncpc.org.uk/sites/default/files/HWBs\\_Report.pdf](http://www.ncpc.org.uk/sites/default/files/HWBs_Report.pdf)

<sup>64</sup> Care Quality Commission (2009) ‘National report: Managing patients’ medicines after discharge from hospital’

<sup>65</sup> British Medical Association (2014) ‘Hospital discharge, the patient, carer, doctor perspective’

## 2. People are feeling left without the services and support they need after discharge

**“I was told I could go home without the assessment, [but] when I got home I couldn’t get up the stairs. [I] had to sleep downstairs for nearly six weeks.”<sup>66</sup>**

We heard from hundreds of older people who left hospital without adequate assessments, care plans, or physical and emotional support in place. In 2013 Age UK reported an estimated 830,000 older people in need of care were not receiving any formal support, while local authorities cut back on the support provided to older people with ‘moderate’ needs.<sup>67</sup>

Many older people struggle to cope with everyday activities after being discharged, such as washing and cooking and are unable to leave the house to get to the shops.

We know that in many cases nobody had followed up with the people we spoke to and many did not know where to turn for support and had been left to arrange their own aftercare.

### Iris’ story:

**We heard about 82 year old Iris, who had fallen and injured her right knee. After a visit to A&E and an x-ray, Iris was told to go home and rest. No follow up was arranged.**

On arrival home, she was carried from the car to her bedroom by her friend’s husband. That night, despite borrowing a walking-aid, she fell twice while going to the toilet.

After two weeks Iris had a visit from her GP, who immediately made a correct diagnosis and referred Iris to an orthopedic surgeon where she had surgery.

Iris was in plaster for nine weeks and now walks with crutches and feels very angry about the delay in her treatment due the initial missed diagnosis.<sup>68</sup>

The 2012 Care and Support White Paper says reablement services - a short, intensive period of support (normally a maximum of six weeks) to enable people to regain skills and confidence to care for themselves after hospitalisation - are a priority for local authorities. Data suggests that the number of people offered reablement / rehabilitation is increasing in line with the rise in those accessing services.<sup>69</sup>

We heard that many people are still missing out.

<sup>66</sup> Elsie, local Healthwatch focus group, Midlands

<sup>67</sup> Age UK, Brookes, R ‘Two thirds feel badly treated by the government over care’ (2013) <http://www.ageuk.org.uk/latest-news/archive/two-thirds-of-poll-cite-poor-care-as-reason-why-they-feel-older-people-are-being-treated-badly-by-the-government/>

<sup>68</sup> Focus group, voluntary sector organisation, South of England

<sup>69</sup> QualityWatch ‘Supporting older people’s recovery after illness’ (2014) <http://googl/k3AYc7>



## Usman's story:

**Usman was a widower living on his own and was given a six week care package following his hospital discharge - to help with every-day care like cooking and cleaning.**

After the six weeks ended he soon became unwell again. He was unable to cope on his own and to take care of himself. A local community group tried to help Usman as they were concerned his living conditions had become unsanitary.

They reported the situation to the local authority, which later assessed his flat to be of an 'acceptable standard'. A few months later the community group requested a reassessment through Usman's GP.

Unfortunately before the assessment could take place Usman was hospitalised with a respiratory infection and compromised immunity and died soon after on his 88th birthday. The local authority was later found guilty of neglect.<sup>70</sup>

Those who did receive visits said this tended to be from many different carers and that they found having to explain their situation to each new person distressing. They said they would have liked more continuity in their care.

A Healthwatch England survey completed by over 100 pharmacists from around the country found that a breakdown in communication and confusion can lead to older people taking multiple drugs simultaneously after discharge, which can result in adverse drug reactions, medication errors and re-admission.

## 3. People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances

People's families and friends told us about the lack of dignity with which some older people are being treated during the discharge process, such as Doris who was sent home with just an incontinence pad between her legs, and Julie's mum who was brought home by ambulance in her nightgown and left at home.

Poor treatment is leaving older people feeling uncared for by the health and social care system and is also leading to readmissions. From what we heard, we understand there may be an undercurrent of ageism within some parts of the health and social care sector and, whilst other forms of discrimination are no longer deemed to be acceptable, this continues.

<sup>70</sup> Submission from local Healthwatch, South East

## **4. People feel they are not involved in decisions about their care or given the information they need**

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**“My father [was] discharged from hospital late 2013. At no time has he been assessed as to whether he can climb stairs, get into a shower or bath.**

**“My mother is of poor health herself and is struggling to cope. She has not been told of any services she may be eligible for, to help my father. She is relying on word of mouth from other people.”<sup>71</sup>**

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Hundreds of older people and their families told us how important it is to be involved in planning for discharge and informed about the on-going treatment and care they are entitled to and to know what will happen during and after discharge. However, this is not happening enough.

We heard that people often emerge from assessments ‘bewildered and disappointed’ and that they are not clear about what they are entitled to. We found that a lack of information causes people to feel that they were discharged too early because they do not have the basic knowledge they need about their condition, medication, after care and support available to them in the community.

**“When you are being discharged you should be given all the information you need about your condition and clarity about any preventative measures you need to take to ensure your health doesn’t worsen or deteriorate.”<sup>72</sup>**

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A lack of information and involvement in discharge planning can lead to uncertainty and to added stress for the older person being discharged from hospital and for their families.

We heard about Jack who read about his mother’s cancer diagnosis for the first time in a discharge letter once she had returned home. None of the family had been told about the diagnosis or the prognosis and Jack was left wondering how to tell the rest of the family.

The government is committed to bringing shared decision-making into every day practice in the NHS, but from what we have heard this is not happening consistently. This is corroborated by a recent national study of over 62,400 patients in England, which found that 46% of people did not think they were fully involved in decisions about their discharge from hospital.<sup>73</sup>

## **5. People feel their full range of needs is not considered**

**Throughout the inquiry we heard that assumptions are frequently made about people’s family support and home situations. Many family members and carers told us that they were not sufficiently involved in discharge planning or asked about the level of support they can provide.**

**Bob was being discharged back home where he lives alone. His daughter Pauline lives in a different part of the country but told us she had been reassured by the hospital that Bob would be looked after by visiting nurses for the next two weeks as he was frail and confused after his hospital stay.**

This did not happen – carers called Pauline’s sister in law, Margaret, to express their concern for Bob’s situation and that he was very frail and vulnerable.

Margaret is the closest relative living 50 miles away but also had a broken leg at the time so was restricted in how she could intervene. Occupational Health visited Bob and advised family on changes made at Bob’s home, but Pauline, Margaret and the rest of the family soon realised they needed to arrange carers to help with the routine every-day tasks.

**“There was a presumption that we were available to care for Dad and that we knew the system and what to do. None of this was true.”<sup>74</sup>**

We heard from a number of family members, living far away from their parent or older relative, feeling uninformed and helpless about how to help.<sup>75</sup>

We also heard about older people who are also full time carers for their partners with disabilities, degenerative diseases and /or chronic conditions. They spoke of concerns about the need to return home with adequate support so that they can recover as quickly as possible and return to their caring responsibilities.

However people told us their assessment process did not take into account their partners’ condition and needs and was therefore inadequate. Dennis shared the distress he felt when being discharged from hospital.

**“Will someone please accept that a permanent carer and cared-for relationship is a combined unit where this individualising policy causes more problems than it cures?”**

**“I understand this is a difficult process, but like many others this is when you just give up, because you simply can’t get past the wall!”**

**“The anxiety with the overall situation has intensified, am I going to be OK, how do I re-plan our increasing care needs, is it decision-time for the dreaded care-home and its financial implications?”<sup>76</sup>**

The Care Act gives carers parity of esteem with the person they are caring for, which should mean the needs of carers and cared-for people should be better taken into account.

Where possible a joint assessment should take place covering the person needing care, their main carer and any other relevant family members, ensuring services take a holistic view of the situation.

<sup>71</sup> James, written submission, local Healthwatch, South of England

<sup>72</sup> Local Healthwatch focus group, South of England

<sup>73</sup> Care Quality Commission ‘Encouraging improvements in people’s hospital experiences’ (2014) <http://www.cqc.org.uk/content/national-survey-shows-encouraging-improvements-people’s-hospital-experiences>

<sup>74</sup> Pauline, written submission, local healthwatch, North of England

<sup>75</sup> Carers Trust (2013) A Road Less Rocky supporting carers of people with dementia

<sup>76</sup> Online submission to Healthwatch England, North of England

## **In focus: Impact on people with mental health conditions**

### **Mental health in the UK**



**adults experience at least one  
diagnosable mental health problem  
every year<sup>77</sup> - that's over**

**13 million  
people** across  
England.<sup>78</sup>

People with mental health problems have a vast range of symptoms and conditions, including depression, anxiety disorder, schizophrenia, psychosis, and bi-polar. Just like physical conditions, some are temporary and triggered by a life event, others fluctuate, and some are life-long and require constant management and adaptation.

The Mental Health Act 1983 sets out a legal framework for treating people with mental health problems. When people object to treatment and are believed to be at risk of harming themselves or others, the Act allows (if certain conditions are met) for them to be detained and receive treatment.

### **How we gathered evidence regarding people with mental health conditions**

This inquiry has been informed by the experiences of more than 300 people with a range of mental health conditions around the country. We heard from John, detained in secure services for more than 30 years; Lisa, with experiences of discharge from both child adolescent and adult mental health services; Helen, who had suffered postpartum psychosis; Gary, discharged from acute services following a suicide attempt; Claire, sharing the experience of her daughter who had died and many more people.

We carried out site visits at various settings including a low secure mother and baby unit, an acute hospital ward, 'step down' supported housing, medium and low secure forensic hospitals and community groups for those with complex needs and for those who had been discharged from acute settings. We worked alongside specialist mental health organisations, such as National Survivor User Network and Together for Mental Wellbeing, to access places many statutory inquiries cannot.

<sup>77</sup> Office for National Statistics (2001) Psychiatric Morbidity report: [www.ons.gov.uk](http://www.ons.gov.uk)

<sup>78</sup> Based on the 2011 Census estimate of the population of England: <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Population>

## Overview of findings

### 1. People are experiencing delays and a lack of coordination between different services

**“I was ready to move on, to start rebuilding my life, but I was kept in hospital for months longer, costing hundreds of pounds per day because the authorities couldn’t agree how much they were willing to pay to support me after discharge”<sup>79</sup>**

We heard from a significant number of people who had been kept in a mental health setting longer than necessary due to delays arranging their aftercare, housing and support. **An estimated one in 20 bed days are used by people experiencing a delayed discharge in a mental health setting.**<sup>80</sup>

In some cases people were involuntarily detained under the Mental Health Act. Aisha’s psychiatrist and wider clinical team had assessed her as being ready to return to the community, however, she told us that the local authority would not fund her accommodation and the final community care package could not be agreed.

Aisha told us the delays were having a big impact on her psychological wellbeing. She was living in a facility a long distance from her son who was living with another family member. Aisha had not yet had the opportunity to start rebuilding their relationship and explain the mental health crisis she had experienced.

Raj said that he was still waiting for a response about attending a family funeral and that it had taken months to arrange permission for him to walk up and down the road outside the secure unit.

**“Step down to what? No-one actually tells us what this step down and discharge journey is. [A starting point would be] to know - even if it’s years or decades away.”<sup>81</sup>**

We also heard from people who felt that they were held back from ‘stepping down’. This term describes the move from a medium to a low secure unit, to community support, or being discharged. Individuals believed this was because professionals were unwilling to take responsibility for the risk involved.

Patients cited comments that suggested staff could be concerned about being blamed if an individual, upon discharge, ended up posing a risk to others. Both the staff and patients in our focus group said discharge centred on attempting to find an ‘unattainable assurance’ that the person would not be a risk to others in the community.

**“The threshold is uncertainty and you pay for that with years of your life.”<sup>82</sup>**

People told us that they felt intensified feelings of isolation and that delaying their discharge had increased the risk of further institutionalisation. We were told how an unexpected delay could knock already fragile confidence and build unnecessary dependency on routines and practices used within the setting, like medication or restricted use of space.

<sup>79</sup> Online submission

<sup>80</sup> Healthwatch England analysis of My NHS Mental Health Hospitals in England data at October 2014: <http://www.nhs.uk/Service-Search/performance/Results?ResultsViewId=1014>

<sup>81</sup> Ben, focus group, medium secure mental health hospital

<sup>82</sup> William, focus group supported housing, South of England

Some patients require the permission of the Secretary of State for Justice in order to be discharged from a secure unit, transfer to another hospital or undertake leave of visits to the community. We were told that permission could be hard to attain and many had to wait long periods of time before knowing whether they would be able to go on a community visit – a prerequisite to starting the journey towards discharge.

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**“I had to wait over six months for a response [from the Ministry of Justice], well after the event I requested leave for had taken place.”<sup>83</sup>**

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Individuals also told us about delays caused by the inability of care coordinators or social workers to secure funding and commitment for ongoing support in the community. This was most acute in situations where a patient would be returning to community-based mental health or social care provision.

Under Section 117 of the Mental Health Act, NHS and local authority social services have a joint responsibility for arranging aftercare services for people who are being discharged from hospital or secure settings. This is supported by duties set out in the Care Act 2014 to strengthen cooperation between the NHS and local authorities.

## **2. People are feeling left without the services and support they need after discharge**

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**“The pressure to discharge people without the necessary planning is only getting worse...some people are just left to exist rather than getting support to pick up the reins of their lives”<sup>84</sup>**

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**There were 121,499 admissions to mental health hospitals in 2013-14.** We estimate that almost 16,000 of these people were readmitted shortly after discharge, giving a strong indication that many are being discharged too soon or without the right support in the community.<sup>85</sup>

People told us that the first couple of days after discharge were the most important for building the confidence, routine and networks necessary for everyday life. However, many people described their return to the community as ‘isolating’, ‘distressing’ and ‘disorientating’; lacking the continuity of care that would enable them to manage their condition. Some had been told by their doctor, nurse or social worker to expect a call or visit within the first week whilst others were left wondering when they might next hear from someone.

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<sup>83</sup> Scott, focus group, medium secure mental health hospital

<sup>84</sup> Anne Beales, Special Inquiry Advisory Group

<sup>85</sup> Mental Health Bulletin: Annual Report from MHMDS Returns 2013-14  
<http://www.hscic.gov.uk/catalogue/PUB15990/mhb-1314-ann-rep.pdf>



Research by the Care Quality Commission<sup>86</sup> found that one in three mental health patients do not know who to contact when they need out-of-hours crisis support. The CQC also found that people using community mental health services do not feel that their care plan adequately covers what they should do if they are approaching or are in crisis. People in medium and low security mental health settings told us that failures in their community crisis team led to an escalation of a serious mental health problem that they felt resulted in them offending and/or ending up in a secure hospital.

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**“The treatment is not there, the support non-existent, the framework is dangerous, vulnerability is not recognised, if one complains through correct channels, in my opinion - one is punished”<sup>87</sup>**

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The stories we have heard indicate that the National Institute for Health and Care Excellence (NICE) guidelines<sup>88</sup> are not being put into practice - In particular guidelines that state that ‘changes, especially discharge, are discussed and planned carefully beforehand with the service user and are structured and phased,’ (noting that) ‘transition from one service to another may evoke strong emotions and reactions in people using mental health services’. NICE provides evidence-based guidance and quality standards and whilst not mandatory, provides important practical support to improve quality of health and social care.

Even when people did know who to turn to, they found the quality of these interactions varied greatly. We spoke to people who valued their crisis team, citing individuals who had gone above and beyond to ensure they were supported through their crisis and in other cases we heard about professionals seeming to downplay the significance of how people were feeling.

People who had more challenging experiences said that they would only contact the crisis team ‘as a last resort’. They would avoid at all costs speaking to ‘uncompassionate’ and ‘aggressive’ members of staff, with a number giving examples of putting down the phone if a particular staff member answered.

Jason shared his experience about when he was told to ‘call back later’ despite having told the crisis team he was having suicidal thoughts and it being known that he had a long standing and complex mental health problem. Similarly, Nathan was told by his crisis team to ‘stop looking at the internet’ and was asked to get back in touch if ‘things took a turn for the worse’, which he found distressing.

People are at the highest risk of suicide and self-harm in the three months after they are discharged from hospital, and this is most acute in the first one to two weeks.<sup>89</sup> **One in five patient suicides between 2002 and 2012 happened during the post discharge period. The University of Manchester’s National Confidential Inquiry into Suicide and Homicide by People with Mental Illness found that about 3,225 patients died by suicide in the UK within the first three months of their discharge from hospital - 18% of all patient suicides - between 2002 and 2012.**

The peak time of risk was found to be the first week after discharge. Data shows the first three months after discharge remain the time of highest risk but especially in the first one to two weeks. This emphasises the need for careful and effective care planning before patients are discharged from mental health settings.

However, many people we spoke to felt they were put at unnecessary risk of further self-harm and suicide because no one contacted them after discharge.

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<sup>86</sup> Care Quality Commission Bulletin (2014) Community Mental Health Must Improve <http://www.cqc.org.uk/content/community-mental-health-care-must-improve-warns-regulator>

<sup>87</sup> Mark, local Healthwatch questionnaire, South West England, July 2014

<sup>88</sup> NICE (2011) Service user experience in adult mental health: improving the experience of care for people using adult mental health services

<sup>89</sup> Appleby L, Kapur N, Shaw J, Hunt IM, While D, Flynn S, et al. (2013) The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness: <http://www.bbmh.manchester.ac.uk/cmhr/centreforsuicideprevention/>

## Jean's experience:

**Jean was discharged from hospital after a suicide attempt. She told her local Healthwatch that she felt she wasn't taken seriously by doctors when she had turned up to hospital and was quickly discharged.**

**'Living alone means I have to cope alone, like shop for food, cook, take all meds properly as prescribed'.**

Being discharged without any support meant that she had to "travel home alone on buses whilst still under influence of tablets taken to 'end my life' in a state of 'shock at what I had done... and how I had been treated'.

Reflecting on the isolation and distress she experienced in the first week back at home she said that 'having somebody visit on those two days afterwards or at the very least a phone call... would have made all the difference!' <sup>90</sup>

Our analysis of NHS data from mental health hospitals suggests that one in five patients is still not being followed up with within seven days of a hospital discharge.<sup>91</sup> This is despite the financial incentive for NHS providers, who are not reimbursed for the proportion of avoidable readmissions to hospital within 30 days of discharge. Channel 4's Dispatches investigation of these financial penalties found that over £390 million had been withheld across the NHS as a result of avoidable hospital readmission within the after discharge period between 2011 and 2014.<sup>92</sup>

<sup>90</sup> Jean, Healthwatch Cornwall

<sup>91</sup> Healthwatch England analysis of My NHS Mental Health Hospitals in England data at October 2014: <http://www.nhs.uk/Service-Search/performance/Results?ResultsViewId=1014> - although the Monthly Mental Health Minimum Data Set (MHMDS) for July 2014 suggest nearer 1 in 4 (24%) did not receive a follow up within 7 days: <http://www.hscic.gov.uk/catalogue/PUB15733>

<sup>92</sup> For information see Channel 4 (2014) A&E's Missing Millions - Channel 4 Dispatches: <http://www.channel4.com/info/press/news/1-billion-nhs-funds-withheld-dispatches>

<sup>93</sup> Sam, online submission, Healthwatch Camden

People told us that the inadequacy of mental health crisis teams often left the police as the frontline of crisis intervention. Under the Mental Health Act, the police have the power to remove someone from a public place if they believe the person poses a threat to themselves or others because of a mental illness. This person should be taken to a designated 'place of safety' where they can be detained for up to 72 hours and can have a proper assessment of their needs by a qualified mental health professional.

## Sam's experience:

**Sam was sectioned for a third time under the Mental Health Act by the police and detained in a psychiatric hospital.**

Four weeks later he was discharged back to the community without an assigned GP - having deregistered during a psychotic episode - and did not receive care planning meetings or a follow-up meeting with his psychiatrist.

Without access to crisis mental health support, he was unable to alert services when he felt he was approaching crisis again, which resulted in a further detention in police custody.

During these experiences Sam was left for long periods of time in police cells without an assessment by the community mental health or crisis team.

**"I was severely manic, paranoid, psychotic and barricading myself in my home. [There were] multiple police interventions. As [I had] no community team at all, the mental health trust did not respond.**

**"Crisis Services refused [to attend] when police requested assessment under the Mental Health Act at home and in cells. This is now under investigation and the mental health trust refuses to offer me crisis support of any kind."** <sup>93</sup>

The Mental Health Act: Code of Practice, revised in 2015, states that a police station should 'not be used as a place of safety except in certain circumstances'.<sup>94</sup>

The code also states that 'proper planning should ensure that it is not necessary to use' one as a place of safety. The revised Code of Practice dispels the assumption that a police station should be an 'automatic second choice' if a health-based place of safety is unavailable.

Instead it suggests alternatives including a care home, home of friends or a family member or a psychiatric ward should be considered as temporary options. This is reiterated in the Mental Health Crisis Care Concordat<sup>95</sup>, which makes a commitment to reducing the number of times a use of police cell is used as a place of safety for people in mental health crisis.

Despite this, evidence suggests that in practice police stations are still being used as a default when people were involuntarily detained because of a mental health crisis occurring in a public place.

We also heard from carers who told us they were not given enough time to prepare for the support role they needed to play for people after discharge, affecting both the person's recovery and the carer's wellbeing.

## Rachel and Sabina's experience:

### Following her mother Sabina's stay in a mental health service, Rachel attended her mother's discharge and care plan review at the hospital.

During the meeting, Rachel explained her concerns that she would not be able to support her mother's needs whilst caring at the same time for her young family.

Sabina's psychiatrist said she would be discharged and whilst he understood the predicament 'perfectly', he offered an ultimatum: 'well it's that or a homeless shelter'.

As a result, Rachel felt unduly pressured into moving her mother into her own home. Following discharge Sabina's mental health deteriorated further, meaning she required more complex care.

Rachel was forced to ask the community mental health team to help support her mother but it came too late and Sabina was readmitted to the hospital with a higher level of need.<sup>96</sup>

Recent monitoring of the Mental Health Act, undertaken by the Care Quality Commission, found that over a quarter of care plans reviewed showed no evidence of people or carers being meaningfully involved in their creation: an issue reflected in what people told us.

<sup>94</sup> Code of practice: Mental Health Act 1983 <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

<sup>95</sup> Mental Health Crisis Care Concordat <http://www.crisiscareconcordat.org.uk/>

<sup>96</sup> Carer's Trust submission

### **3. People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances**

**“I feel defined and confined by my illness, it’s difficult to break free of that.”<sup>97</sup>**

Many of the people we spoke to expressed concern about the assumptions, stigma and myths they encountered in trying to access treatment or care. Individuals told us that once they were assigned a clinical or descriptive label (i.e. bi-polar or a self-harmer) professionals - particularly those with less understanding of mental health - would shape their behaviours and interactions around responding to the cultural myths and knowledge they had about the label.

**“I felt I should have stayed in longer, but it was made clear “ill-er” people needed the bed.”<sup>98</sup>**

<sup>97</sup> Lucy, Voluntary sector focus group, South East of England

<sup>98</sup> Alex, third sector organisation focus group, South of England

<sup>99</sup> Carer’s Trust submission

### **4. People feel they are not involved in decisions about their care or given the information they need**

Another important factor we heard about was the lack of involvement of people and their families in discharge planning and in the decision-making process.

People repeatedly told us they didn’t feel their concerns were listened to and that they wanted to be involved in the decisions that affect their lives.

#### **Laura and Isaac’s story:**

##### **Isaac had been admitted to hospital following an episode of psychosis.**

His mother, Laura, had been told that he would gradually leave the hospital, and once well enough he would be able to return home.

One afternoon Laura went to visit Isaac, but when she arrived she was told that his bags were packed and that he would be discharged that day. Laura was concerned that she had not been able to make any preparations.

Unfortunately, when he returned home he became increasingly anxious and was readmitted.

Laura felt that if she had had sufficient notice of Isaac’s discharge, time to prepare and space to raise her concerns and anxieties with staff prior to discharge, the situation may not have escalated so quickly.

Similarly if she had been briefed by staff on Isaac’s medication and care plan, she would have felt ‘less overwhelmed’ and ‘abandoned’ as she would have known who to contact if she had concerns about his behaviour.<sup>99</sup>

## 5. People feel their full range of needs is not considered

Throughout this inquiry we met people who had multiple interactions with hospitals and other health or care settings, however, their full range of needs were not addressed or recognised early enough, resulting in escalation and readmission to services that could have been avoided.

Anne's depression was not diagnosed because her mental health condition was overshadowed by the fact that she had a stroke. The clinical focus of the rehabilitation was on her physical health, meaning that her depression - which worsened now that she was less mobile - was neglected.

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**“I would have liked the psychologist to get to the bottom of it, find out why this [is] happening.”<sup>100</sup>**

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Anne's experience is not uncommon. A quarter of all patients with a physical illness also have a mental health condition. The mental health needs of patients in physical healthcare settings often remain undiagnosed, which can lead to longer stays, readmissions, discharge to services and poorer health outcomes including increased mortality and morbidity.

This issue - known as diagnostic overshadowing - can cause someone's mental health condition to get worse, even if their physical health is improving.

The opposite can also happen. A number of people we spoke to felt their physical health needs were neglected and that health professionals would work on the basis that any symptoms related to their mental health condition without taking proper efforts to rule out physical health issues.

This experience is documented in the 2013 report 'Lethal Discrimination' by Rethink Mental Illness.<sup>101</sup> The research found that many health professionals fail to take people with mental health conditions seriously when they raise concerns about their physical health.

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<sup>100</sup> Anne, South East England, Local Healthwatch focus group

<sup>101</sup> Rethink Mental Illness report 'Lethal Discrimination' (2013)  
<http://www.rethink.org/>

## **In focus: Impact on homeless people**

### **Homelessness in the UK**

Homelessness remains a persistent and complex social problem in England. People experience homelessness in different ways – some may be rough sleeping, whilst others may be living in temporary accommodation such as hostels or staying with friends or relatives.

**The Department for Communities and Local Government estimates 2744 individuals sleep rough on any one night in England.<sup>102</sup> In 2014, over 110,000 households in England applied to local authorities for help with homelessness.<sup>103</sup>**

### **How we gathered evidence regarding homelessness**

More than 200 people with experience of homelessness contributed to our inquiry. We also worked with homelessness charities, Homeless Link and St Mungo's Broadway, taking into account their research into homelessness and hospital discharge.

We heard from organisations such as Stonewall Housing, The Passage and The Queen's Nursing Institute. We also learnt about existing projects which aim to improve the health of homeless people, such as the Pathway project at University College Hospital and the Kings Health Partners (KHP) Pathway project at Guy's and St Thomas' Hospital.

<sup>102</sup> Department for Communities and Local Government: Rough Sleeping Statistics England - Autumn 2014 Official Statistics

<sup>103</sup> Department for Communities and Local Government 'Live tables on homelessness' (November 2012 - June 2015) <https://www.gov.uk/government/statistical-data-sets/live-tables-on-homelessness#live-tables>



## Overview of findings

### 1. People are experiencing delays and a lack of coordination between different services

**“I was admitted because I was suffering from a fit. I stayed in hospital for 10 hours. I was living on the streets at the time, rough sleeping.**

**“The staff at the hospital were nice to me and explained everything clearly, but when I told them I was homeless I wasn’t given any information or support about housing. The only thing they told me about was Alcoholics Anonymous (AA) and eventually I was discharged back onto the streets. I was re-admitted after two months for the same problem. I would have liked more joined up care and help with housing.”<sup>104</sup>**

Co-ordination between hospitals and housing services was identified as a significant issue affecting homeless people’s recovery after discharge. We learnt that local authorities can be slow or unwilling to respond to hospital requests for assistance with people who are homeless, and when they do respond, individuals can find that they do not meet the criteria for housing.

Even when it is agreed that someone should be provided with accommodation, it may only be temporary, such as a bed and breakfast or a hostel, which may not be appropriate for somebody who has just been discharged from hospital. We also heard how a lack of co-ordination can leave people in potentially dangerous situations.

#### Tom’s story:

**Tom is a young man with severe mental health conditions. Over a period of time he became very distressed, having been mentally and physically abused by other people in his shared accommodation.**

He was treated in A&E following one assault but not admitted. A crisis team nurse visited him and said that he was paranoid and would visit again. Tom then threatened suicide and the police and ambulance were called and took him to A&E.

Tom was discharged without a coat, in very cold weather and without money, food or warm clothing. The crisis team were shocked at his discharge.

His mother felt it was unsafe for him to be left at his flat, so it was arranged for him to stay at the MIND crisis house for two weeks. His mother then arranged for him to be moved to a different flat but he was asked if he would stay in hospital and he agreed.

He was seen by his psychiatrist who said that because of his situation, living accommodation and vulnerability he should not return to the shared flat.

A case meeting was arranged with the doctor, crisis team and family. However, before it took place, Tom was discharged, with no consultation, and without a treatment plan or medication.<sup>105</sup>

<sup>104</sup> Focus group Healthwatch Luton

<sup>105</sup> Focus group Healthwatch Stockport

The Department of Health guidelines on hospital discharge clearly state that hospitals must have guidance for staff on dealing with people who are homeless, and that local authorities and hospitals should have agreements on how to refer patients who are being discharged.<sup>106</sup>

However, we heard that, at present, the guidelines represent a set of suggestions, which staff and hospitals are advised to follow, rather than a set of actual statutory obligations, as people told us that they found staff to be ill-equipped to support and advise them regarding their options as homeless people.

## 2. People are feeling left without the services and support they need after discharge

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**“They discharged me and I was back on the streets. They could have kept me in there longer and made sure I was full recovered before being discharged. They don’t care; I don’t have anywhere to stay to fully recover.”<sup>107</sup>**

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Individuals told us that they had been discharged from hospital before they were ready and without the right support in place. People told us about finding themselves in a vicious cycle, repeatedly going in and out of hospital because they were continually not being given the care and support they needed to recover in the long term.

We heard about a lack of follow-up care, with individuals not being given enough information about their medication when discharged, and not being told where to go in the community for help when they need it.

Those who have been homeless told us that accessing community support - such as rehabilitation to regain strength, movement and stability following injury or illness could be extremely difficult.

This was particularly the case if someone was rough sleeping or in a low support hostel. This problem is particularly acute for homeless people as they are less likely to be registered with a GP than those who are not homeless.



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<sup>106</sup> Department of Health, Discharge from Hospital: Pathway, Process and Practice p74 -75 Jan 2003

<sup>107</sup> Focus group Healthwatch Tower Hamlets

The Department of Health's report 'Healthcare for Single Homeless People' (2010) estimated that No Fixed Abode (NFA) patients stay approximately 6.2 days in hospital, compared to the general population which averages 2.1 days.

The research identifies that homeless people use four times as many acute health services and eight times as many inpatient health services as the general population, but have lower levels of follow up care. The ratio of outpatient appointments to inpatient episodes for follow up care was roughly 1.4 compared to the estimate of six for the general population.<sup>108</sup> **Kings Health Partners estimates that some homeless people attend hospital as many as 30 times per year.**<sup>109</sup>

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**“There were some injections that I had to carry out myself and I needed to be shown how to do this but I wasn't shown. I ended up doing them on my own for three months and I ended up with bruises everywhere from doing it myself. I was later readmitted.”<sup>110</sup>**

### **3. People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances**

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**“They treated me nicely at first because they thought I was a tourist. I lived in the USA for many years and have an American accent. When they discovered I was homeless and Polish they totally changed and said I should see a doctor privately.”<sup>111</sup>**

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Homeless people told us they felt stigmatised and discriminated against because of their homelessness. They felt that this led to them being 'last in the line' for services at the point of admission, during treatment and when being discharged.

We heard that because of the stigma they experience, homeless people believe that they have received poor care, which is a major reason they discharge themselves from hospital before their treatment has been completed.

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**“I did not feel well enough at the time of discharge but I wanted to leave. My treatment plan was to return in six months. I was discharged to my friend's sofa. I was readmitted three months later for the same thing.”<sup>112</sup>**

<sup>108</sup> Nigel Hewett and Sam Dorney-Smith, Kings Health Partners and the Impact of Homelessness 2013,p 42

<sup>109</sup> The Queen's Nursing Institute: [www.qni.org.uk](http://www.qni.org.uk)

<sup>110</sup> Focus group Healthwatch Rotherham

<sup>111</sup> Focus group - The Passage

<sup>112</sup> Focus group- Healthwatch Rotherham

Healthwatch Norfolk carried out a user-led survey of 88 people into access to health and social care services for homeless people.<sup>113</sup> When the issue of stigma was discussed the participants said they felt labelled by their history and were sure this affected the quality of their treatment.

Participants felt that hospital staff were quick to make negative assumptions about them and spoke differently to them compared to other patients. Some of the participants said that they were not offered medicines and pain relief in the same way as other patients.<sup>114</sup>

We heard how crucial the way someone is treated whilst in hospital is to their long term recovery. A good treatment can encourage somebody to start to make positive changes in their lives, whereas stigma and discrimination can alienate a person and discourage them from engaging with health service providers.

This problem has been recognised within health and social care.

The Chief Nursing Officer has set out standards for compassionate care in the nursing profession. Compassion in Practice<sup>115</sup>, the national strategy for nurses, midwives and care staff, was launched in December 2012 and includes a programme of work to raise standards in the nursing profession. The King's Fund also conducted research into compassionate care and how this might be developed in health services.<sup>116</sup>

## 4. People feel they are not involved in decisions about their care or given the information they need

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**“I was treated awful by the healthcare staff. I believe the decision was made to discharge me without my involvement. I don’t believe that I was ready to be discharged because I didn’t feel well enough.**

**“I wasn’t given a treatment plan and my housing situation was not taken into account at all. I was discharged to temporary accommodation which I had to arrange myself. It was very hard to obtain my medication after discharge.”<sup>117</sup>**

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Not being involved in discharge planning can have significant impact on a patient’s health and wellbeing.<sup>118</sup> We heard from many homeless people that, when in hospital, were not involved in decisions about their treatment or discharge. Individuals we spoke to often believed this was due to stigma and discrimination.

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<sup>113</sup> Healthwatch Norfolk, Homeless People’s Access to Health and Social Care Services 2014

<sup>114</sup> Healthwatch Norfolk, Homeless People’s Access to Health and Social Care Services 2014 p31

<sup>115</sup> Compassion in Practice – Nursing, Midwifery and Care Staff (2012) <http://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf>

<sup>116</sup> Building a culture of compassionate care in the NHS <http://www.kingsfund.org.uk/blog/2013/02/building-culture-compassionate-care-nhs>

<sup>117</sup> Focus group – Healthwatch Rotherham

<sup>118</sup> Carers Trust – Written Submission

**“On the occasion that I was admitted to hospital a consultant advised that my detox was not complete and that I should remain in the detox unit but they did not listen and I was discharged that evening. I did not feel involved at all.”<sup>119</sup>”**

If people are treated with dignity and respect and involved in decisions regarding their care and discharge, they are more likely to have the confidence to express their needs and concerns.

However, we heard about a lack of involvement. This can result in many homeless people not getting the opportunity to discuss their concerns with health professionals or how best to care for themselves once discharged, This hampers their recovery and ability to access additional care and support.

### **Julie’s story:**

**“I stayed in hospital overnight. I was living in temporary accommodation at the time. I was treated fairly well but I was not asked about my housing situation so no support or advice was offered.**

**“I was not consulted during the decision to discharge me and I did not feel well enough at the time of discharge. I needed medication and physio but was not offered any and I wasn’t given a treatment plan, nor was any transport made available to me.**

**“I was discharged to my temporary accommodation. After being discharged I was still in pain so I self-medicated on painkillers from the chemist. I would have liked to have received an aftercare plan and to have been offered physio.”<sup>120</sup>**

<sup>119</sup> Healthwatch Rotherham - Homeless person

<sup>120</sup> Focus group Healthwatch Rotherham

## 5. People feel their full range of needs is not considered

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**Amazed he had been discharged, the nurse had to wait three hours in the housing department to find his location.**

**The man's flat had no heating and it was mid-winter. The nurse had to break in to the man's flat to find him shivering in just a thin fleece.**

**He was struggling to breathe and had massive mucus discharge from his tongue tumour. She said that she suspects he would have died had she not intervened at this point.**

**He lived a further nine months.<sup>121</sup>**

We heard about the crucial opportunity hospital admission provides to establish homeless people's circumstances and find out the full breadth of their needs. However, we learnt that this is not happening enough and that, in some cases, the results can be life threatening for the patients involved.

It is not uncommon for individuals with a history of long-term homelessness to also face problems with a combination of mental ill health, physical ill health and drug/alcohol misuse. However, we heard that the support that people need to address this range of concerns is not always given when they are discharged.

Some people told us that they left hospital of their own accord before being formally discharged because their other medical needs were ignored. Many people require advocacy to enable them to access health services, which the voluntary sector plays a vital role in, however, we heard that a lack of co-ordination can limit the level to which this occurs.

We heard that the full extent of people's housing situation is not being understood, and that patients are simply being deemed of 'no fixed abode' which is not specific enough to identify their precise situation or needs upon discharge.

Research shows that improving health for homeless people who are in hospital starts by correctly identifying their health, social care and housing needs at the point of admission, and then engaging them in their care as individuals.<sup>122</sup>

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<sup>121</sup> Case study from Queens Nursing Institute Survey

<sup>122</sup> Homeless Link and St Mungo's Improving Admission and Hospital Discharge for people who are Homeless 2012 p6



**Matthew told us that he was admitted for an alcohol overdose. He is a long-term methadone and alcohol user but when he asked for methadone on the ward he was told that he had to wait until he visited his local pharmacy where he normally receives this.<sup>123</sup>**

This basic lack of understanding about the extent of a person's needs means that they will not receive the level of care they require to meet their needs. In some cases, this can lead to a person discharging themselves from hospital so that they can try to seek out what they need for themselves.

Failure to establish a clear understanding of a person's circumstances meant that some homeless people were discharged without basic things such as transport - in some cases being told that they would have to walk - as well as clothing and food. Research shows that because of the lack of transport, people have to rely on the kindness of strangers, such as security guards paying cab fares, or friends coming to collect them.<sup>124</sup>

<sup>123</sup> Focus Group - Healthwatch Luton

<sup>124</sup> Homeless Link and St Mungo's Improving Admission and Hospital Discharge for people who are Homeless 2012  
[http://www.homeless.org.uk/sites/default/files/site-attachments/HOSPITAL\\_ADMISSION\\_AND\\_DISCHARGE\\_REPORTdoc.pdf](http://www.homeless.org.uk/sites/default/files/site-attachments/HOSPITAL_ADMISSION_AND_DISCHARGE_REPORTdoc.pdf) p21

## Getting discharge right

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### Across all groups, we found that people expected some simple things from the discharge process.

They expected:

- + To be treated with dignity, compassion and respect;
- + Their needs and circumstances to be considered as a whole - not just their presenting symptoms;
- + To be involved in decisions about their treatment and discharge;
- + To move smoothly from hospital to onward support available in the community; and
- + To know where they could go for help once discharged.

The stories people shared with us show that people across the country are experiencing poorly managed discharge and are being left frustrated and bewildered when what appear to be simple requests cannot be met. When discharge goes wrong it has a significant physical and emotional impact on individuals, as well as on their family and friends.

This inquiry set out to make clear the human cost of poor discharge. The moving and troubling experiences we uncovered point to problems in the health and care system that have been known for some time and illustrated just how high the human cost of poor discharge can be.

Despite numerous pieces of guidance being issued over many years, these problems persist. We know that a significant new effort is being made at a national level to tackle these issues, such as NHS England's patient safety alert on risks arising from breakdowns in communication during discharge and specific provisions introduced in the Care Act.

There is also NICE's forthcoming guidelines on transitions between hospitals and inpatient mental health settings and community and care home settings<sup>125</sup> and The Royal Pharmaceutical Society's support for professionals to standardise and take responsibility for the transfer of information about medicines.

However, with all the guidance that is already available, it is not clear why further individual initiatives will make the difference without something more fundamental changing in the system


Many local initiatives do provide a better discharge experience for patients in specific areas. There also exist many local initiatives that do provide a better discharge experience for patients. We have included a number of the examples we came across during the course of the inquiry over the next few pages.

However, without good practice being adopted more widely, the problems and the costs to both individuals, their friends, families and the system will continue.

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<sup>125</sup> NICE guidance: 'Transition between inpatient mental health settings and community and care home settings' - anticipated publication date: August 2016

## Failings in discharge processes also have a high financial cost.

  
**£2 billion**

Emergency readmissions are thought to cost the NHS more than £2 billion every year.<sup>126</sup>

Our financial analysis endorsed by the Centre for Mental Health, estimates that over



**6,000**

patients remain in hospital longer than clinically necessary.<sup>127</sup>

We estimate that every additional day that these patients spend in hospital costs the NHS in excess of

**£2m**  a year.

During the course of the inquiry people suggested to us that funding cuts to mental health, social care and other services were partly to blame for the problems they experienced with the discharge process. We have not explored levels of funding but it is clear from our evidence that these problems have existed for a long time.

We hope that these stories of the human consequences of discharge going wrong, as well as the significant financial costs to the system that we have uncovered, will give a new imperative for change. The time has come for concerted action and coordinated national leadership to ensure the discharge process meets people's needs.



<sup>126</sup> Ibid

<sup>127</sup> Based on 1 in 20 discharges being delayed. My NHS data <http://www.nhs.uk/Service-Search/performance/search>

## Good practice in action: working with older people

During our research we came across a number of examples of initiatives and projects designed to help resolve the difficulties people experience during the discharge process. A number of these are showcased below.

### Royal Pharmaceutical Society (RPS)

The RPS has developed core principles to underpin the safe transfer of information about medicines whenever a patient transfers care providers, at any point in the care pathway. A patient fact sheet has been developed for patients, patient groups and the public to help raise awareness and actively involve patients in managing their medicines when they move care settings. This was supported by a video for patients to improve their understanding of issues around transfer of care. The guidance and supporting implementation resources were published on the RPS website and disseminated via other the key stakeholders.<sup>128</sup>

### Isle Of Wight Reablement Project

For this project, hospital pharmacists helped patients to understand their medicines while they were in hospital, addressing concerns and supporting them to take their medicines both in the hospital and when they left. Following patients' discharge, community pharmacists were given the results of the patients' hospital assessments then visited their homes to offer them further support, reinforce previous advice and assess how they were doing.

### My Medication Passport

Designed by patients for patients, the passport enables the user to record medications and other key medical information in a pocket size booklet easy to carry across care settings to ensure accurate transfer of information.<sup>129</sup>

<sup>128</sup> Royal Pharmaceutical Society, 'Keeping patients safe when they transfer between care providers - getting the medicines right' (3: 2012)

<sup>129</sup> NHS Networks 'My Medication Passport' For more information: <http://www.networks.nhs.uk/nhs-networks/my-medication-passport>

## My Discharge Project - Royal Free

Dementia patients are assessed for discharge within 24 hours of referral to build understanding of their needs and ensure that their departure from hospital will be safe. Patients are also provided with intense therapy and a single point of contact is available to people and their carers. They can also help family members prepare for coping with a dementia patient once they return home. When patients are discharged, they leave with a discharge letter and emergency phone numbers and are accompanied home with food and clothes if needed. The team will also liaise with social care colleagues and voluntary sector organisations to get care visits set up and equipment in place. This service helps people with dementia to stay in their homes after discharge, reduces readmission and discharge to nursing homes and supports family members to care for their partners in their own home.<sup>130</sup>

## St Christopher's Hospice - South London

This hospice has set up a service to enable local residents thought to be in their last six months of life to receive personal care in their own homes following discharge from hospital or hospice.<sup>131</sup>

## St Catherine's Hospice - Scarborough

This hospice is piloting four nurse-led end of life care beds to help facilitate rapid discharge from Scarborough hospital for patients in their last days of life. This has helped increase patient choice, enabling patients to receive high quality end of life care in a hospice setting and has helped reduce unnecessary deaths in hospital. With advice and support and expert co-ordination around the clock, the services have enabled more discharges from hospital into the community, and for support to be more easily and readily available and accessed once people are discharged.<sup>132</sup>

<sup>130</sup>The Health Foundation, 'Improving hospital discharge for dementia patients' (2013) <http://www.health.org.uk/news-and-events/newsletter/improving-hospital-discharge-for-dementia-patients/>

<sup>131</sup> St Christophers Hospice, for more information: <http://www.stchristophers.org.uk/>

<sup>132</sup> St Catherines Hospice, for more information: <http://www.stcatherineshospice-nyorks.org/>

## Good practice in action: working with people with mental health conditions

### SMHCAB

The Sheffield Mental Health Citizens Advice Bureau helps around 600 people with severe mental illness, including in-patients. It supports people to make sure they get the benefits and services they are entitled to and helps them speak up for themselves.

When Jane was referred to the bureau she had accrued significant debts which had contributed to an attempt to take her own life. During her three months on the ward, advisers worked with Jane to restructure her debts, stabilise her housing and resolve employment issues. With support, new accommodation was found and Jane was able to return to a new home with her children.<sup>133</sup>

### RAID

Based at Birmingham City Hospital, This initiative the patient's journey through rapid assessment, interface and discharge (RAID), 24 hours a day, seven days a week.

The team sees any hospital patients who might be suffering from mental health problems, and provides assessment, support and advice and, if appropriate, will arrange support in the community after discharge, communicating with GPs.

The RAID team of specialist psychiatrists, social workers and mental health nurses has expertise in old age, working age and postnatal mental health and substance misuse. They provide regular training for acute hospital staff in the diagnosis of delirium, depression and dementia.

**“It wasn’t rushed. It felt as if they were making the time to speak to you. They listened to me and ultimately they understood I didn’t want to be living the life I am at the moment. They had a very good appreciation of the difficulties it’s created for me within my life and how it’s affected the lives of those close to me”**

The RAID service has seen a dramatic reduction in admission leading to a decrease in daily bed use of 44 beds per day, and has reduced discharge of older people to institutional care by 50%, saving local authorities an estimated £3 million per year.<sup>134</sup>

<sup>133</sup> Mental Health Unit and Advocacy Service <http://www.smhcab.org.uk/>

<sup>134</sup> Birmingham and Solihull Mental Health NHS Foundation Trust <http://www.bsmhft.nhs.uk/our-services/rapid-assessment-interface-and-discharge-raid/>



## Bethlem Royal Hospital

This mother and baby unit is one of only 17 units in the country. Mothers with complex mental health conditions work with staff to establish a relationship with their child and enable them to have a graduated discharge, ensuring they are prepared for a lasting return to the community.

Gerry had been admitted to the mother and baby unit having experienced postpartum psychosis after the birth of her first son, Adam.

She told us that the turning point in her recovery had been 'in the middle of a session with the unit's child psychologist, [who had a] gentle, calming air and she encouraged me to actually look into my son's eyes and smile and laugh with him'. After many more weeks of confidence-building and continued treatment and support, Gerry felt well enough to be discharged.

**"[They gave me] the time and support to mother and love my son and he has become the centre and light of my life."** <sup>135</sup>

## Care Navigators

People in Waltham Forest are supported when discharged from specialist mental health services by a designated navigator for 12-18 months. They ensure that they have and attend appointments with GPs and practice nurses to monitor their mental and physical health and discuss the impact of their treatment.

Navigators support people to reduce their dependency on services and address any social isolation they may be experiencing. By building relationships, they are able to identify early signs of mental health crisis and help prevent relapse.

If someone does enter a period of crisis they receive increased contact with their navigator who can arrange re-referral, urgent out-patient appointments and development of a recovery plan.

Outcomes of the pilot showed an overall reduction in crises where regular contact with the navigator is maintained. There have also been reductions in the duration of crisis episodes and the time spent by individuals in secondary care.<sup>136</sup>

<sup>135</sup> For more information see: <http://www.app-network.org/what-is-pp/personal-experiences/story-kathryn/>

<sup>136</sup> For more information see <http://www.slcsn.nhs.uk/scn/mental-health/mh-urgent-commiss-cs-102014.pdf>

## Good practice in action: working with homeless people

### Healthcare Outreach: StreetMed

StreetMed is a nurse led project that combines the skills of nursing and homeless outreach to help clients overcome barriers to healthcare.<sup>137</sup>

Nurses work within homelessness outreach teams to provide advice and support to clients who are not currently engaging with primary health care.

After a full assessment, StreetMed support clients, addressing a range of interconnected needs including those relating to their health, housing and benefits.

Using a case management approach, the project aims to tackle the long term causes of homelessness rather than just treating an individual's symptoms.

StreetMed takes referrals from a range of agencies, including outreach teams and hospital staff, to identify people in need of support with accessing healthcare combined with other needs.

StreetMed nurses can facilitate access to substance misuse, alcohol, mental health and social services. In addition, the initiative helps people with housing, employment, training and benefits, as well as individuals in secondary care.<sup>138</sup>

### Kings Health Partners Pathway Project

The Kings Health Partners Pathway has been operating across Guy's and St Thomas' and Kings Hospitals since January 2014. The team aims to improve the quality of care for homeless patients, reduce delayed or premature discharges, as well as future unscheduled admissions and A&E attendance.

The team provides advice about homelessness, health, and housing law and supports people by providing a wide range of practical support and assistance including TV cards, clothing and canteen tokens.

The team works with a patient to conduct detailed diagnoses of all medical problems and address their homelessness by liaising with local authorities and other agencies and acting as advocates for the patient at Homeless Persons Units.

The team works to ensure health and social care needs are met in the community and safely reconnects people to their area of origin when appropriate.

The Pathway project started with one team in University College Hospital London and the approach has now spread with teams of different varieties now working in 11 acute trusts across the country. The Pathway Approach has shown a 30% reduction in annual bed days for homeless patient admissions.<sup>139</sup>

<sup>137</sup> St Mungo's Broadway StreetMed <http://www.mungosbroadway.org.uk/documents/6308/6308.pdf>

<sup>138</sup> For more information see: <http://www.app-network.org/what-is-pp/personal-experiences/story-kathryn/>

<sup>139</sup> For more information see: <http://www.pathway.org.uk/>

## Hospital Discharge Pilot Fund

In May 2013 the Government set up a £10 million hospital discharge pilot fund for voluntary sector organisations working in partnership with the NHS and local government, to improve the hospital discharge process for people who were homeless.

Fifty-two projects were funded and delivered between 2013 and 2014.<sup>140</sup> The findings from the evaluation show:

- + 69% of homeless people had suitable accommodation to go to when they were discharged.
- + This rose to 93% of homeless people in projects which combined NHS and housing staff.
- + 72% of discharged homeless people were not readmitted within 28 days of discharge.
- + 71% of agencies reported improved data sharing across housing, the NHS, and voluntary sector.
- + 84% of voluntary sector agencies reported good working relationships with the NHS.

Homeless people who received help from the pilots reported higher standards of care, with non-judgmental treatment and they experienced improved support throughout and after their time in hospital.

The discharge pilots also enabled improved working links across housing and the NHS, and

enabled access into accommodation and to ongoing medical care for homeless people.

Some of the projects managed to show cost savings by reducing the use of A&E by homeless people. The most successful projects were those which combined health and housing professionals in the homeless person's package of care, during and after the stay in hospital.<sup>141</sup>



<sup>140</sup> Homeless Link 'Why invest in improved hospital discharge process?' <http://www.homeless.org.uk/connect/news/2015/feb/09/investment-needed-to-continue-homeless-hospital-discharge-improvement>

<sup>141</sup> Homeless Link Evaluation of the Homeless Discharge Fund <http://www.homeless.org.uk/connect/news/2015/feb/09/investment-needed-to-continue-homeless-hospital-discharge-improvement#sthash.PycFdv7dpuf>

## Time for change

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**This report does not include recommendations; instead it poses a challenge to the health and social care sector to take action now to improve people's experience of leaving services.**

Why has this not happened to date? We believe that because there has been no single body responsible for this issue, there has not been the leadership to tackle poor discharge from health and social care services.

This is why we welcome the leadership shown by the Department of Health in working with us to bring together key health and social care bodies to devise a collective plan to tackle this issue and track progress.

We will continue to engage with the voluntary sector and other organisations to ensure that this issue remains a national priority.

We will also support local Healthwatch to ask providers, Clinical Commissioning Groups and Health and Wellbeing Boards to focus on the issues highlighted by this report.

As well as promoting services that are getting discharge right, local Healthwatch have shown that, in partnership with the voluntary sector, they can make a significant difference by highlighting poor practice and championing the need for change.

We believe that joint action now can deliver the step change needed to make significant improvements to the experiences of people leaving hospital and care settings.

# Appendix

## Existing and forthcoming guidance and research

- + Department of Health (2003) Discharge from Hospital: pathway, process and practice
- + Department of Health (2004) Achieving timely 'simple' Discharge from Hospital
- + Care Quality Commission (2009) National report: Managing patients' medicines after discharge from hospital
- + Department of Health (2010) Ready to go: Planning the discharge and transfer of patients from hospital and intermediate care
- + Mind (2010) We need to talk: Getting the right therapy at the right time. We need to talk coalition
- + NICE (2011) Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services
- + Coulter, A and Collins, A. (2011) Making shared decision-making a reality, no decision about me without me. The King's Fund
- + National Council of Palliative Care (2011) Commissioning end of life care: Initial actions for new commissioners
- + Royal Pharmaceutical Society (2012) Keeping patients safe when they transfer between care providers - getting the medicines right
- + Parsonage, M.; Fossey, M. and Tutty, C. (2012) Liaison psychiatry in the modern NHS. Centre for Mental Health
- + Mental Health Care (2012) Why people with mental health conditions might not get the treatment they need in A&E
- + Joint Commissioning Panel for Mental Health (2012) Liaison Mental Health Services to Acute Hospitals
- + Homeless Link (2012) Improving Admission and Hospital Discharge for people who are Homeless
- + National Audit Office (2013) Emergency admissions to hospital: managing the demand
- + Royal Voluntary Service (2013) Avoiding Unhappy Returns
- + NHS Networks (2013) My Medication Passport
- + Department of Health (2013) NHS Continuing Healthcare and NHS Funded Nursing Care' Public Information Leaflet
- + Rethink Mental Illness (2013) Lethal Discrimination: Why people are dying needlessly and what needs to change
- + Fernandez, J; Snell, T. and Wistow, G. (2013) Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. PSSRU
- + Centre for Mental Health (2013) Welfare advice for people who use mental health services
- + British Medical Association (2014) Hospital discharge: the patient, carer, doctor perspective
- + Department of Health (2014) Closing the Gap: Priorities for essential change in mental health
- + HM Government (2014) Mental Health Crisis Care Concordat: Improving outcomes for people experiencing mental health crisis
- + NICE (Forthcoming, 2015) Transition between inpatient hospital settings and community or care home settings
- + NICE (Forthcoming, 2016) Transition between inpatient mental health settings and community and care home settings









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