‘Going Home’ Pilot
Project learning and next steps

Introduction

The Healthwatch Lambeth and Southwark Going Home pilot project aimed to test out an approach for building a picture of older people’s experiences of health and social care services following a stay in hospital. The project was devised in response to the need for a better understanding of current transfer of care experiences during and after hospital discharge – particularly the longer view of a patient’s recovery journey.

Healthwatch Lambeth and Healthwatch Southwark jointly ran the pilot to track people for up to 12 weeks once they were medically fit for discharge from hospital. The project aimed to explore:

- What the recovery journey was like
- How well the transfer of care from hospital to the community worked
- How the learning from these experiences could be used to help drive improvements.

This report presents the project’s key findings, maps how the insights have been used to date, and explores next steps.

‘Going Home’ methodology

Between autumn 2015 and spring 2017 we followed nine older patients as they left hospital and moved on with their lives over a three-month period. We aimed to meet each person once a week for up to an hour, from the moment they were ready for discharge from hospital, to talk with them and any family members providing support about their experiences.

Our participants

We tracked five people who were discharged from St Thomas’ Hospital and four people discharged from King’s College Hospital. Participants were drawn from a Healthwatch Enter and View visit to St Thomas’ Hospital older person’s unit[i] and two test projects initiated by Southwark and Lambeth Integrated Care programme (SLIC) offering short-term stays at local extra care schemes for either assessment away from hospital and/or step-down support.

One participant was discharged from hospital directly back home where she lived with her daughter; four participated in the 'discharge to assess' test project at Helmi House, and four took part in the step-down initiative at Lime Tree House.

SLIC Discharge to Assess and Step-down Extra Care Pilots

In January 2016 SLIC launched two pilot schemes to test the benefits of using extra care facilities (blocks of flats with 24/7 on-hand care teams) for older people medically fit for discharge from hospital but not ready to return home. Eight of the nine people we spoke to went through these pilot schemes.

The schemes operated differently in each borough as described below.

In Lambeth, the Discharge to Assess (D2A) scheme was hosted by Helmi House in Stockwell. It involved a stay of up to four weeks (later extended to six weeks) to enable people to be assessed away from hospital in a domestic setting, to see whether they would be able to return home or to plan their next move (e.g. a care home).

In Southwark, the step-down scheme was hosted by Lime Tree House in Nunhead, providing accommodation for up to six weeks for patients in need of a further short period of intensive support or assessment before they went back home or to an alternative setting.

Six of the nine interviewees had family members who we spoke to during the course of the project. The family carer of the person discharged straight home (recruited through the Enter and View visit) took part in all the interviews. We spoke to the family members of other participants between one and three times.

Interview scope

Interviews were semi-structured and followed a topic guide exploring:

- The hospital experience and information about discharge
- The transfer of care experience on discharge
- The range and quality of care after discharge, compared with any support received before the hospital admission
- Information, assessments, planning, and the experience of moving on
- Wellbeing and levels of independence (including social interactions and activities)
- Family views and, where relevant, family carer experiences.

The majority of interviews were conducted face-to-face, however some family feedback was gathered over the phone. Interviews lasted between 30 minutes and an hour.

Limitations

Cohort profile

We had initially planned to recruit up to six interviewees for the pilot through our Enter and View visit to St Thomas' Hospital older person's unit. However, sign-up opportunities were limited as only a few patients were well enough to speak to us on the day of the visit. We therefore recruited only one person and their carer via this route, resulting in the majority of the stories we collected reflecting D2A and step-down experiences.

We interviewed all but two D2A and step-down participants made known to us over the course of the feedback periods. However, one interviewee spoke to us only retrospectively after moving out of the assessment accommodation and another individual was admitted back into hospital soon after an initial interview and did not return, as the scheme was not suited to their needs.

Interview periods

For project participants discharged from King's Hospital, we conducted initial interviews before their discharge as planned, which helped build a picture of their expectations and concerns about leaving hospital. However, Guy's and St Thomas' Trust asked us not to visit participants in hospital for interviews, due to concerns about their frailty. Although we asked these participants later about their initial thoughts on the discharge process, some could not recall much detail.

We followed seven participants for the planned three-month period but only conducted a couple of interviews with two participants because of our concern about their mental capacity.

There were a few other variations to the interview time period:

- Due to the end of year festive break, we met one of the participants over a four-month period.
- Two interview schedules were interrupted temporarily by unplanned hospital admissions.
- One person moved away from the area six weeks after leaving hospital. However, an eighth final interview conducted by telephone captured their experience of the move and their new home life.

Key findings

Here, we summarise our key insights across all the 'Going Home' stories we collected, in relation to the project aims of recording recovery journeys and assessing the effectiveness of transfer of care processes.

Recovery journeys

- In following our participants over several months, we captured the ups and downs of recovery experiences including hospital readmissions, problems with medications and the frustrations of changing mobility.
- In addition to health fluctuations, most of our interviewees described feeling out of control, isolated and unhappy about their situations, which undermined their psychological wellbeing and affected their sense of recovery; notably, these feelings were experienced by family carers as well as those recovering from their hospital stay.
- In a number of cases, individuals were not supported to take control of their own health and wellbeing, to the extent of feeling institutionalised rather than regaining independence.
- Half of the stories we gathered can be summarised as having positive outcomes for the individuals involved: the person discharged home felt she could enjoy her life again, another was happy to move in with family, others were content to move into extra care flats permanently.
- Other less positive experiences included: two D2A and step-down participants who returned to their original home but experienced ongoing problems with building repairs, domiciliary care, limited mobility and hospital readmission; a move to a nursing home which failed to support the person's main wish for increased social contact.

Transfer of care processes

At hospital

- Participants reported generally good care during their stay in hospital; however, all were keen to leave.
- For those signed up to the D2A and step-down pilots, participants reported a lack of information and understanding about the scheme, its purpose, expected timeframes and the facilities; the feedback indicated that participants and their families were unable to make an informed choice about taking part in the pilots.
- Family feedback and our own observations suggest the schemes were unsuitable for some of the participants due to physical frailty and limited mental capacity.
- The participant discharged home and her family felt equally unprepared for leaving hospital particularly in terms of the intensity of care required from the family carer, sourcing specialist equipment and supplies, and coordinating tasks.

At the extra care facilities hosting the pilot schemes

- The flats used for the pilots were spacious and in good repair; however, as furnished accommodation, there were some key items missing such as spare pillows, bedside lamps, cleaning equipment and a landline phone facility.

- Some participants didn't access the onsite activities and visiting services due to mobility problems, lack of information about what was available, ineffective referrals and lacking a sense of belonging as a temporary resident.
- Feedback about the onsite carer support was generally positive, although staff were described as very busy and occasionally off-hand; care from the onsite teams did not seem to support the reablement process, for example participants were reliant on carers to take new medication.
- Participants and their family felt in the dark about plans for moving out of their temporary accommodation; however, several participants told us they were happy for family to handle the arrangements.

Other agencies

- Care from different agencies often appeared slow or disjointed, such as a two-week wait for a district nurse visit to replace dressings, lack of awareness about someone's preferred name and prescription delays.
- The number of different agencies visiting and needing follow up often felt overwhelming and exhausting to coordinate.
- Participants wanted more information about specific support they were receiving for example medication side-effects and planned outcomes for physiotherapy.
- Participants expected their GP to be more aware of their circumstances and offering proactive support.
- Social workers played the biggest role in coordinating support but this was limited and participants reported difficulties in making contact at times.

Using project insights

Informal real-time feedback

The project provided live feedback to services as stories were collected, both to address and resolve problems faced by individual interviewees and to help support service-wide improvements. Issues identified included:

- Chasing a foot clinic appointment and providing phone numbers for alternative services.
- Asking the extra care managers to provide details and reminders of in-house activities and services such as the home library service.
- Reporting the need for a bedside lamp in one of the scheme flats, to mitigate a fall risk.
- Referring a participant to a befriending service.
- Feeding back to a participant's social worker his wish to build his walking stamina.

- Informing scheme staff that a participant had received a letter from GSTT about urine measurement and needed assistance.

Informal feedback from the step-down scheme participants was also presented by a Healthwatch representative at monthly multi-disciplinary team meetings at Lime Tree over the course of the project.

Project reports

A report[ii] on the Southwark step-down pilot was published in February 2017, which included over 30 recommendations. In its response, Southwark CCG, Southwark Council and Lime Tree House confirmed that many of the recommendations had been actioned, such as use of the welcome pack (see below) and better ward-based communication, especially around medication. An extension to the scheme has been proposed, to include dedicated staff to support participants during their stay at Lime Tree House.

An internal report on the D2A scheme was produced and presented to Lambeth Adult Social Care senior managers and the commissioner for extra care. A learning seminar for the agencies involved in the pilot has been proposed for autumn 2017.

Welcome pack

In agreement with Southwark Council and Lime Tree House, Healthwatch Southwark created a welcome pack for step-down scheme participants (see appendix in the report cited above).

Quality Summit

In July 2016, Lambeth and Southwark Clinical Commissioning Groups (CCGs) hosted with their Healthwatch a joint Quality Summit around the 'Going Home' theme. This event was attended by over 150 health and social care professionals, voluntary and community organisations, and patient and carer representatives across both boroughs. Service provider commitments from the summit were collated and until summer 2017 were monitored by the Transfer of Care Action Group on behalf of the Southwark and Lambeth Strategic Partnership.

Film

The experiences of our project participant discharged straight home was developed into a short film[iii] commissioned by both CCGs for the Quality Summit. It has since been used more broadly as a practitioner training resource to show the range of factors affecting the transfer of care and recovery journey. The film has been shown to various audiences to date:

- Local Care Networks (LCNs) across both boroughs
- GSTT Governors' Patient Experience Working Group in December 2016

- A Department of Health annual 'policy school' event hosted by Guys and St Thomas' NHS Foundation Trust (GSTT) in March 2017
- King's College Hospital consultant leading the development of the Trust's older people's pathway
- 14 CQC inspection teams in preparation for conducting new integrated care reviews across the country in autumn 2017.

Carers course input

The experiences of one of the family carers we spoke to helped to inform the development of a new course for unpaid carers delivered by GSTT to help them better support their loved ones, maintain their own wellbeing and ultimately help to avoid unplanned hospital admissions. The course was piloted in spring 2017 and participant experiences and outcomes were collected by Healthwatch and reported[iv] to the South East Lambeth LCN to inform its thinking on support for carers.

NHS quick guide

In summer 2016, the 'Going Home' pilot methodology was featured in an NHS quick guide on Discharge to Assess[v] as an example of patient engagement and feedback.

Reflections and next steps

Project value

The 'Going Home' pilot has been particularly effective in helping to deepen understanding about the complexities of care that many older patients and their families face when leaving hospital and the anxiety this can cause. Our project demonstrates that these feelings often last over a significant period, as people recuperate and adapt to different situations and changed levels of independence.

We noted that individuals with families seemed to fare better than those without this support. However, the stories we gathered also served to highlight the strains families also experience in caring for loved ones after a hospital stay.

Finding ways to better inform, support and empower people as they navigate transfer of care processes will be crucial, to offer the best chance of recovery and the regaining of independence.

Next steps

Using an adaptation of the 'Going Home' methodology, both Healthwatch are collaborating with King's Hospital Trust's Engagement Team over summer and autumn 2017 to collect patient stories from older people admitted to the Denmark Hill emergency department. In a lighter touch approach to the methodology, we are

interviewing people within days of their A&E visit and then again four weeks later to track their experience of A&E and subsequent transfer of care. We will look for additional opportunities to apply this approach to capture other transfer of care experiences where it can help inform service transformation.

We are also currently exploring how this methodology can support Southwark and Lambeth's Local Care Networks (LCNs) to collect care coordination stories from people with three or more long-term conditions. Work to gather feedback from those involved in the Lambeth pilot is already in train.

Healthwatch Southwark are contributing to discussions between Southwark Council and NHS Southwark CCG on the expansion of step-down in the borough. The team has also been commissioned by Southwark Council and Guys and St Thomas' NHS Foundation Trust to collect patient stories from people using their urgent response, short-term reablement and rehabilitation service beginning in November 2017.

The pending D2A workshop will inform further potential work on the scheme in Lambeth.

December 2017

References

[i] Healthwatch Lambeth Enter and View : St Thomas' Hospital Anne and Henry Wards Visit Report http://www.healthwatchlambeth.org.uk/newsite/wp-content/uploads/2016/07/hwl_enter_and_view_st_thomas_hospital_older_persons_unit_visit_report_0.pdf

[ii] Step-down scheme at Lime Tree House: the patients' perspective http://healthwatchsouthwark.co.uk/sites/default/files/stepdown-at-lime-tree-the-patients-perspective-feb-20171.pdf

[iii] View the 'Going Home' film at www.healthwatchlambeth.org.uk/goinghome

[iv] GSTT Caring with Carers Course: adapted for a community setting project evaluation: http://www.healthwatchlambeth.org.uk/wp-content/uploads/2017/10/Caring-with-Carers-course-LCCG-innovation-fund-report-FINAL.pdf

[v] NHS Discharge to Assess quick guide: http://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf