Engagement Summary

North London Partners
Urgent and Emergency Care Programme

healthwatch
Camden Barnet Enfield Haringey Islington

Introduction

This report summarises a year-long programme of engagement undertaken in 2017/18 by the five local Healthwatch in the North London Partners area. It is in three sections, summarising the local engagement on different topics, a co-design event on 7 day services and the input of a reference group of local citizens.

The North London Partners Urgent and Emergency Care Programme is focused around four broad work-streams:

- Integrated Urgent Care
- Admissions Avoidance
- Simplified Discharge
- Last Phase of Life

The first of these, integrated urgent care, was the subject of a major programme of engagement in previous years, so was not included as a specific topic in the work for 2017/18.

1. Engagement to date

1.1 Our work has focused on three topics: Admissions Avoidance, Simplified Discharge and Last Phase of Life. Specific reports have been published on each topic.

Simplified discharge

1.2 We spoke to 109 people, 38 via telephone surveys and 71 via face-to-face surveys. Participants were mainly Islington, Haringey and Enfield residents using North Middlesex Hospital, Royal Free London, Whittington Health and UCLH.

1.3 Headlines

- About two thirds of those we spoke to felt they had been given enough information before leaving hospital – the rest thought that they left hospital with unanswered questions about their treatment.
- In general, respondents' satisfaction with the information linked to them having been given follow up appointments, but in some cases linked to follow on care or what to do if the patient's condition deteriorated.
- About two thirds reported having a care plan when they were discharged and of these about half felt their views had been taken in to account in the planning process. Those who felt their views were taken into account said they had a chance to talk about treatment options, including access to specialist treatment.
- For those who felt that their views were not taken in to account, issues included unmet housing needs, being discharged while still in pain, and feeling that their well-being was not considered - only their practical, physical health needs.
- About two thirds felt that their discharge had gone as planned (though in one case a respondent who said it had gone to plan had to be re-admitted the following week).
- Some expressed concern and felt they were discharged too early whilst others were made to stay for longer than expected which resulted in them benefitting from care at the hospital.
- Only half of the people we spoke to felt well supported by health and social care services now that they were back at home. Where people did not feel supported, things they would like to see included better co-ordination between the hospital and the person's GP, with the GP calling to check up on the person a few days after discharge.
- Some people were expecting visits (e.g. from community nurses, physio etc.) that failed to materialise.

Admissions avoidance

1.4 Healthwatch Islington spoke to 39 residents across the four boroughs of Islington, Camden, Haringey and Enfield. 23 were face-to-face in a one-to-one, six took part in telephone interviews, and ten took part in a focus group. Age range varied, and 30 had a disability or long term condition. Healthwatch Haringey spoke to a group of older people in Tottenham.

1.5 Headlines

- 30 of the 39 Islington respondents felt they had no option about whether they attended hospital. All but three (i.e. 36) respondents were treated in the Emergency (or Urgent Care) Department and 26 had to be admitted to a ward (for between one night and two months).
- Most felt strongly that the best place for their treatment was in the Emergency Department at a hospital. Some were alarmed at the suggestion of some treatment being administered at home. All respondents felt that the visits they had described had been essential.
- The general consensus was that respondents would not have been able to manage their conditions at home. In one group, language was raised as an issue and the need for interpreting to be available for home treatment was raised.
- We asked about attitudes to who sees them. For many they felt that a quicker decision could be made by a doctor (because of their training and skill set). Though others simply wanted to be seen by whoever could see them quickest.
- We asked those with a long-term condition whether they felt they got the information they needed to manage their condition. Most did, but the need for more help with care once back home was highlighted several times in two groups.

Last phase of life

1.6 We spoke to 46 people about their experiences of last phase of life care, via in-depth interviews. We held one-to-one interviews with eight people from Barnet and nine people from Camden. We did group interviews in Camden, one with five older African people, one with 10 Somali women, and we spoke to 14 carers at a Barnet support group. The interviews took place between September and December 2017.

1.7 Headlines

- Once there is recognition that the last phase of life has been reached, support is generally good, and hospital staff at both Barnet General and UCLH were praised for their skill, care and compassion.
- Too often the recognition comes very late.
- For respondents from BME communities, late diagnosis was often cited as a problem, several felt that their loved ones had been fobbed off by GPs, so that cancers were advanced before a referral to secondary care was made.
- For some, getting the right community services to help someone die at home or in a homely setting was problematic. In one case the CCG officer with authority to approve a fast track CHC payment was on holiday so the person was stuck in hospital longer than necessary. In other cases, the lack of care workers who spoke the same language as the dying person was a barrier.

- Having staff understand specific cultural issues around death was important. Good experiences included the hospital removing foreign objects such as cannulas and catheters and giving the family time and privacy to clean the body, or the staff at Jewish Care reassuring the family about the timetable for burial. Bad experiences included a family being left at home with no support and the detritus of death around them, or a staff member of the opposite gender being assigned to clean the body. These things caused intense upset.
- Among the African people we spoke to, the role of hospices was not well understood, and some reported having no information about the palliative care available.
- In almost all cases, the biggest issue was staff awareness and attitude, not the actual nature of the service on offer.

2. Co-design event on seven day community services

2.1 This event was attended by 57 people, a mix of residents, patient representatives, voluntary sector, providers, commissioners and Healthwatch. The day began with some scene setting, hearing stories collected during our engagement, and a presentation from the Programme Director on the aims of the UEC programme. The main output of the day was mapping current experience and developing the ideas and actions we need for the future.

2.2 The report of the day contains a record of the ideas that were produced.

2.3 Some themes recurred in all discussion groups:

- Access to information for everybody, the patient, carer, family, staff, between professionals and between medical staff and patients.
- Education about use and navigation around services.
- Treating the whole person, using empathy and respect – various training needs were identified relating to this.
- Clarifying accountability – and individuals taking responsibility within the system, not passing the buck.
- Differences in services across boroughs – which changed and influenced views of the map.
- Shifting resources from acute to community and primary care – and developing a workforce that can move between them.
- Changing protocols so that people can work with the system not despite the system.
- IT that works, and supports people to do the job.

Simplified discharge

2.4 For simplified discharge the conversation centred around the 'map' of the journey through the services highlighted:

- Clear flows or journeys of the patient within the system.
- Discussion around the accountability of all involved, the staff and the patient.
- The ideal of treating the whole person rather than the immediate single conditions.
- Lots of conversation about work 'between services' and involvement and co-ordination by the GP.

2.5 **The solutions required involve:**

- Mapping a clear path to shifting resources into primary and community care (changing the pattern of spending).
- Multi professional learning, changing attitudes and increasing understanding of different roles.
- Incentivising responsible, responsive, problem solving behaviour.
- Delivering IT that works.

Admissions avoidance

2.6 **Discussions highlighted:**

- Lack of clear accountability.
- GP not proactive.
- Need for better care navigation.
- Fear that the best treatment is in hospital (admissions) and not in the community (culture change).
- Lack of clear information for patients.
- Lack of knowledge about community options among hospital staff in A&E.

2.7 **Solutions required include:**

- Joint roles between acute and community care.
- Work as one team from patient perspective.
- Care navigation available seven days per week.
- Mutual education – clinical / community / primary care/ patients.
- Integrate accountability, responsibility and authority with funding.
- Really understanding processes – who does what.

Last phase of life

2.8 Conversations on last phase of life focused on the Navigating Death journey and plotted and discussed a road map towards death for both the patient and the carer/ family.

2.9 **Themes from this discussion included:**

- Normalising death.
- The journey for all involved.
- Voluntary and Community sector providers and organisations involvement.
- Access to early information on both care and practical issues.

2.10 **Solutions required include:**

- Embedding the ‘6 ambitions’ into the approach in all areas.
- Advanced care planning so patient’s wishes are respected by family members and healthcare professionals.
- Training on conversations about dying.

3. Citizens' Reference Group

3.1 To support the engagement programme and to ensure that it has impact, a Citizen's Reference Group was set up. It is chaired by Helena Kania, an experienced patient representative, who also chairs a pan-London group on urgent and emergency care.

3.2 The Reference Group brings together representatives from across Barnet, Camden, Enfield, Haringey and Islington, who have experience of using local urgent or emergency are services, including service users and carers, to offer feedback and input into the development of the North Central London (NCL) Urgent and Emergency Care programme, including having a representative sitting on the programme board.

The reference group act both as advisors, commenting on plans, and as checkers, making sure that the programme is taking full account of feedback.

3.3 The group, who meet regularly, have commented in detail on project plans, and sought clarity on programme funding. They have raised concerns that the links between NHS and local authority partners need to be stronger. They have challenged the lack of progress in some areas. This includes challenging on the drawn out process for agreeing funding for some areas of work. They have advised on improving communication with local residents. They have sought assurance on improvements in mental health support, particularly in A&E. (Mental health is covered by a different programme with the North London Partnership.)

Next steps

3.4 The group will continue over 2018. They will be monitoring the implementation of the co-designed project action plans, and helping to design further engagement on implementation of the programme.

About this report and the work involved

This work was done as part of a programme of engagement on the North London Partners Urgent and Emergency Care programme.

North London Partners is the sustainability and transformation partnership for North London, formed of health and care organisations from the five London boroughs of Barnet, Camden, Enfield, Haringey and Islington. The five local Healthwatch in the North London area are collaborating to promote citizen engagement in the work of the partnership. This includes an extensive programme of engagement on urgent and emergency care, led by Healthwatch Camden.

The work was funded by the Healthy London Partnership which brings together the NHS in London (Clinical Commissioning Groups and NHS England) and other partners to deliver better health and care for all Londoners. Partners include the Mayor of London, Greater London Authority, Public Health England, London Councils and Health Education England. Their ambition is collectively to make London the healthiest global city in the world by uniting all of London to deliver the ambitions set out in ‘Better Health for London: Next Steps and the national Five Year Forward View’.

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