Co-designing 7-day Community Services

Event Report

healthwatch
Camden Barnet Enfield Haringey Islington

Co designing 7-day community services

Purpose of the event

We need to have 7-day community services so that people can be helped to live well at home, to stay out of hospital and to get out of hospital faster – the event looked at:

- what we have and how well it works
- what we need to do better/what we need to add
- how we can work together to get there

The workshop brought together service users, carers, community and voluntary sector providers and organisations and health and social care staff.

Agenda:

- How it is now
- Our Ambition
- Mapping the journey
- Setting the vision for the future
- Mapping the gaps & blocks
- Agreeing the top actions
- Evaluation

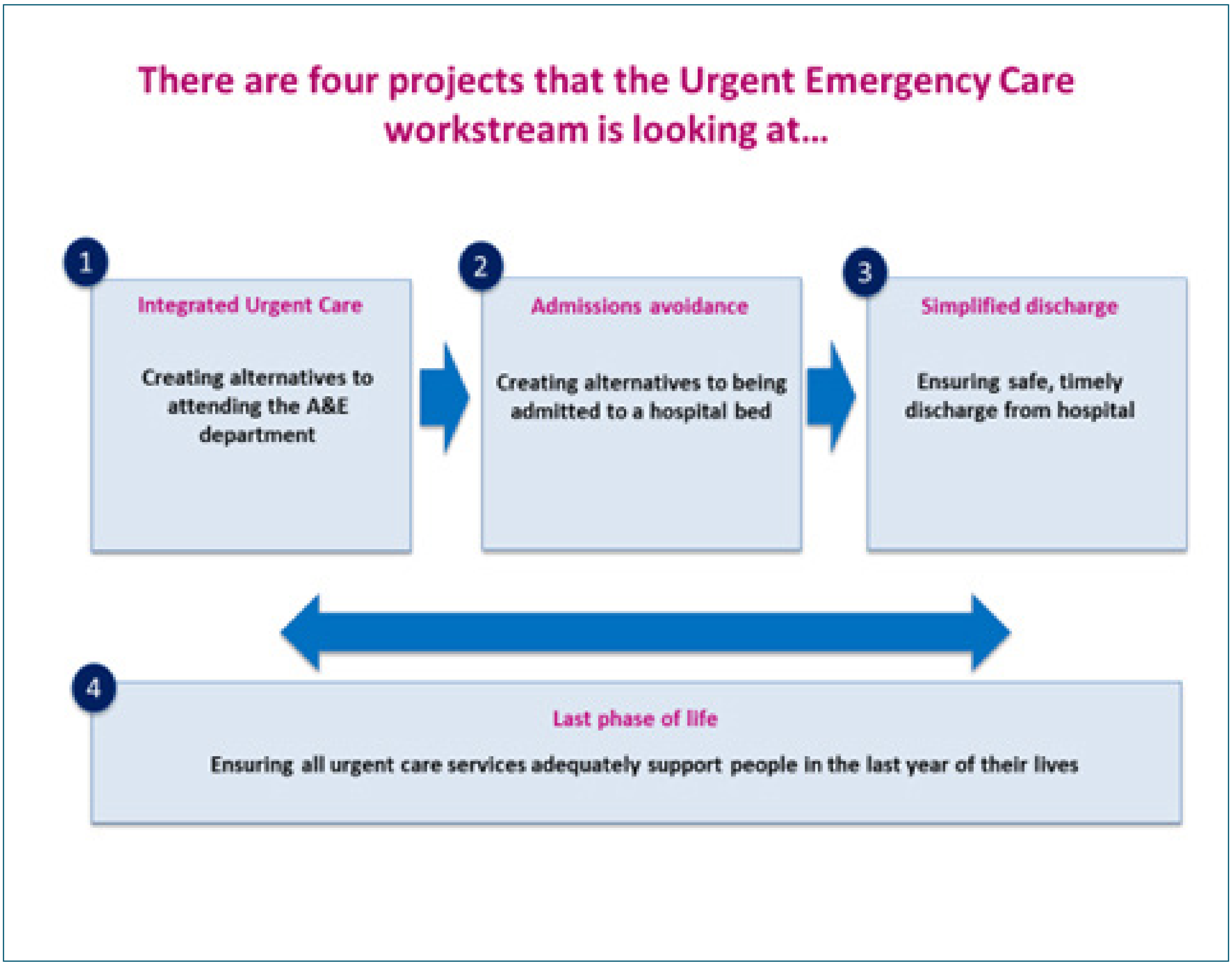
Introductions

Following brief introductions and warm up, the day started with 3 stories, based on case studies collected as part of the engagement.

How it is now / What's your story?

- Admissions avoidance
- Simplified Discharge
- End of Life

A Presentation from Jenni Frost, Programme Director – Urgent and Emergency Care, outlined the work underway currently with partners led by the North London Urgent Care Programme team.
This work is captured in the diagrams below.



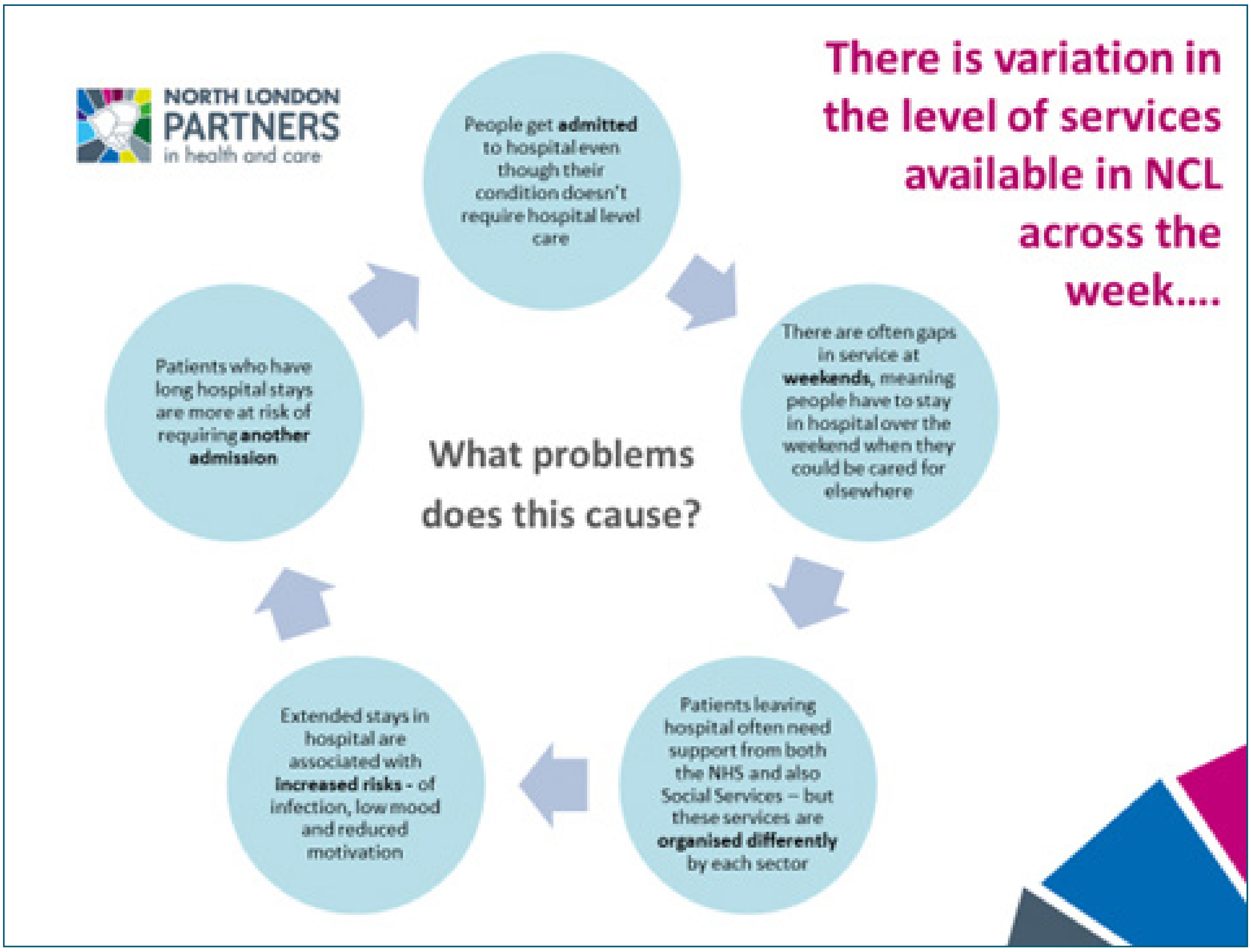
There are four projects that the Urgent Emergency Care workstream is looking at...

1 **Integrated Urgent Care**
Creating alternatives to attending the A&E department

2 **Admissions avoidance**
Creating alternatives to being admitted to a hospital bed

3 **Simplified discharge**
Ensuring safe, timely discharge from hospital

4 **Last phase of life**
Ensuring all urgent care services adequately support people in the last year of their lives



NORTH LONDON PARTNERS in health and care

There is variation in the level of services available in NCL across the week….

What problems does this cause?

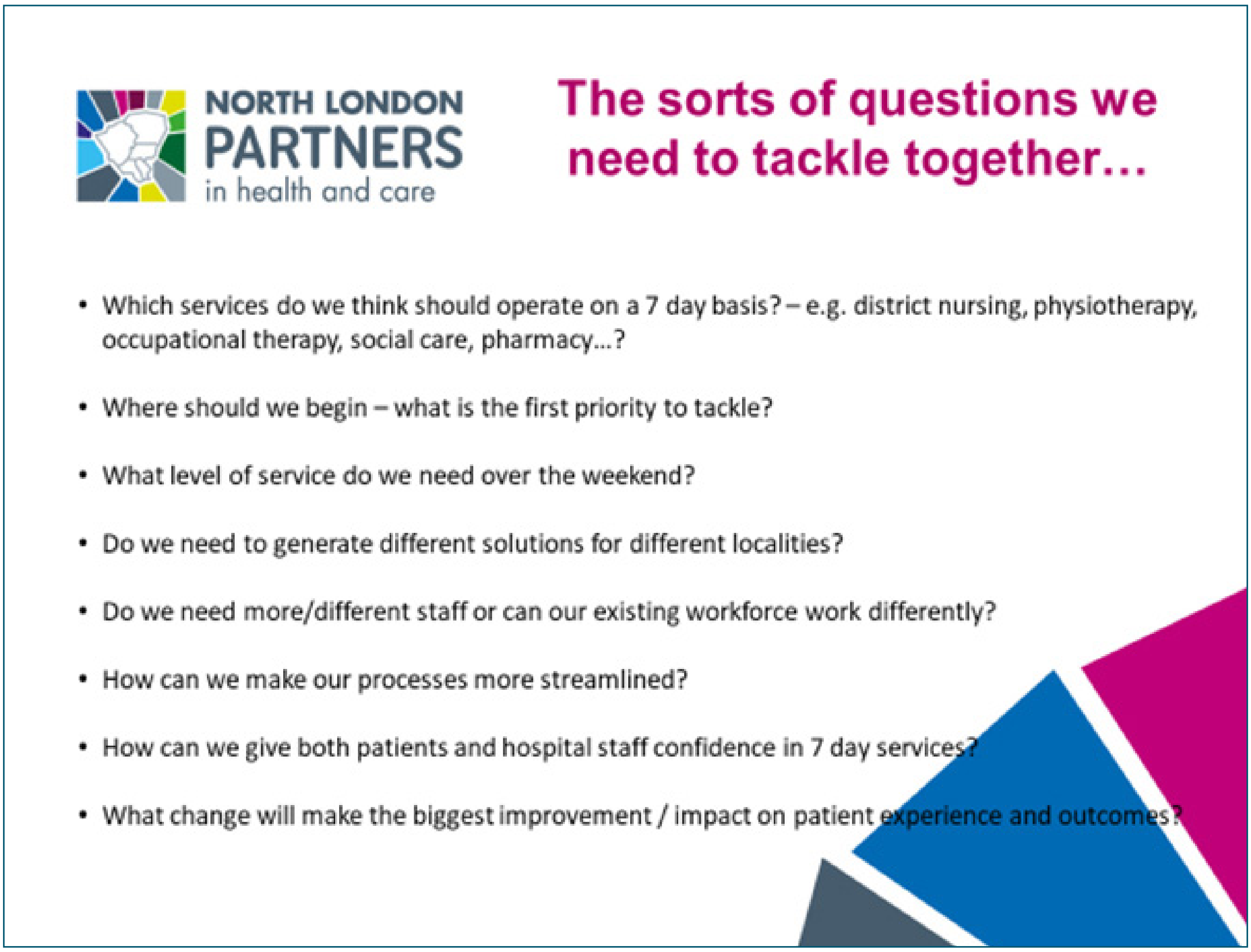
People get **admitted** to hospital even though their condition doesn't require hospital level care

There are often gaps in service at **weekends**, meaning people have to stay in hospital over the weekend when they could be cared for elsewhere

Patients leaving hospital often need support from both the NHS and also Social Services – but these services are **organised differently** by each sector

Extended stays in hospital are associated with **increased risks** - of infection, low mood and reduced motivation

Patients who have long hospital stays are more at risk of requiring **another admission**



NORTH LONDON PARTNERS in health and care

The sorts of questions we need to tackle together…

- Which services do we think should operate on a 7 day basis? – e.g. district nursing, physiotherapy, occupational therapy, social care, pharmacy…?
- Where should we begin – what is the first priority to tackle?
- What level of service do we need over the weekend?
- Do we need to generate different solutions for different localities?
- Do we need more/different staff or can our existing workforce work differently?
- How can we make our processes more streamlined?
- How can we give both patients and hospital staff confidence in 7 day services?
- What change will make the biggest improvement / impact on patient experience and outcomes?

Mapping the journey

The main tasks for the day were carried out on six tables addressing three service areas. There were dozens of ideas, experiences and challenges. Immeasurable passion. World Café rules of engagement i.e. go where the mood takes you.

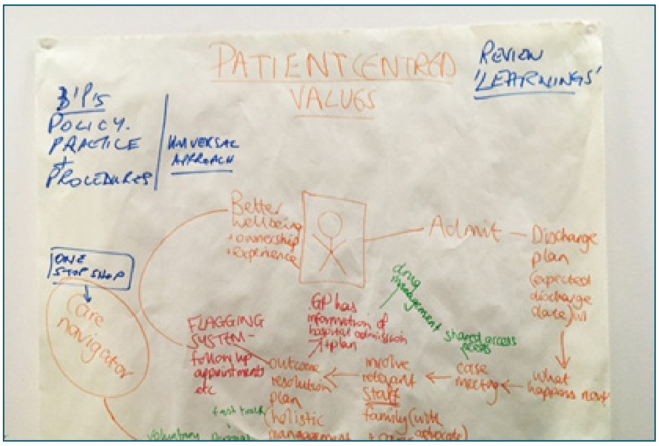
Over a period of the four hours each table mapped, recorded, discussed, had difference and consensus.

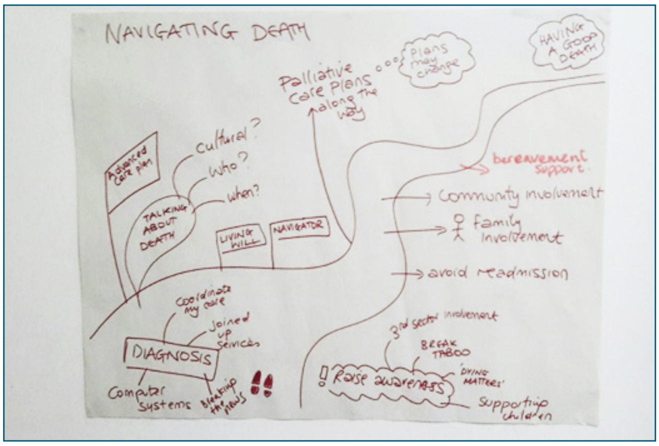
When plotting the map of the patient's journey, the groups discussed the various interventions and questions that they had experienced (or knew about) on similar 'patient' journeys.

- The experience – what is it like now?
- What do we need to know?
- Missed connections – what is not working?
  - As a patient/service user
  - As a service provider

The themes which become evident from this discussion were:

- 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.
- Levels, accessibility and accuracy of information.
- Treating the whole person.
- Differences in services across boroughs – which changed and influenced views of the map.

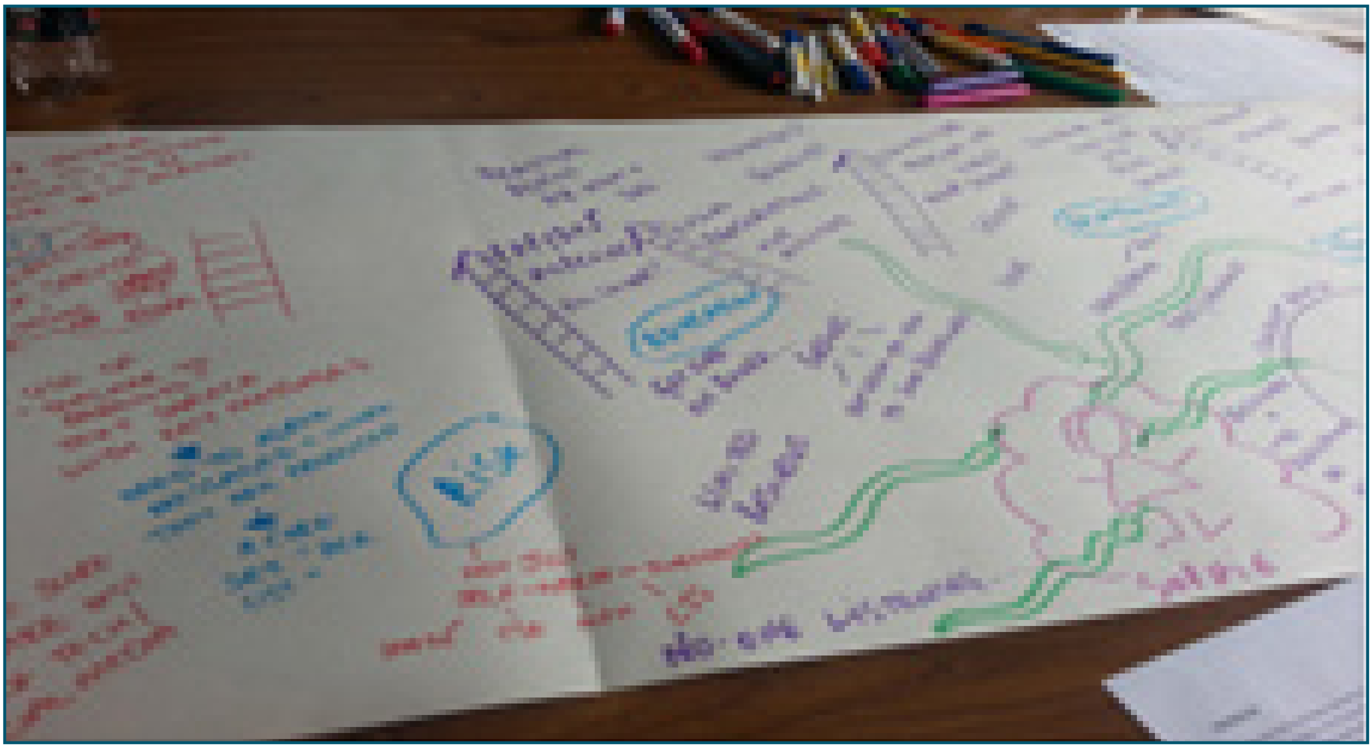




Exercise two

Setting the vison for the future - the journey as it should be

- Can you draw the ideal experience?
- How would it work?
- Who would be involved?
- If you could move resources around the system, what would you move where?



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The discussions over the day have been captured in the tables on the folloiwng pages. Each of the comments and all the input from the participants has been included. This information is based on the experience of both service users, carers, community and voluntary sector providers and organisations and health and social care staff. The tables build a picture of all the views expressed over the workshop.

Task: Avoidable Admissions	**What do we think we know about what happens now?**	**What we think is possible to do in the future**	**What is stopping us? What / who can remove the block?**	**Actions: Who? When?**
The Service User Experience	GO didn't action letter from hospital which said 'your patient has been diagnosed with X' – GP should have made more contact with patient and checked in on him and developed a plan Salim – not taken seriously? Lots of waiting Lack of record sharing between GP & hospital medical notes means Patient not give consistent service Salim slipped through gaps between A&E and GP	Public education on which services to use e.g. 111; 999; GP; Walk-in; When & how accessible they are		Better Communications Joint roles between acute and community care Health Volunteers Health & Social Care barriers to be removed Work as one team from patient perspective Care navigation available 7 days per week
Question: What does the service user need to know?	Lots of points about understanding the pathway proposed – the word 'referral' may not mean anything to the patient Need better information given to patients if they are sent home from A&E e.g. if symptom X occurs, go to Y service. If you need to speak to someone call this number. Check patient understands this Information – empowering patients by providing contact numbers for who to contact and when Need to know what services there are in the sector (so many changes e.g. A&E don't know who to refer to / GP know who to refer to) Need to educate people about alternatives to A&E and when to attend Was Salim supported enough prior to collapsing? Did he have enough information to manage his own health? It is a culture change that's needed? Have enough knowledge to manage their own long-term condition?			Simplify the route to people's case record information Develop NHS online as a repository of information (NHS first / 111)
Touchpoints: what are the interactions with the service user?	GP 111 Pharmacy Walk in Clinical nurse Specialist Community team	Better discharge summaries and distribution list e.g. GP; Community Team; Social Care Admission avoidance teams to prevent unnecessary admissions (e.g. go and see person at home and treat them there)	Discharge letters / information & communication from A&E onwards. Give patient the letter. Issues – will GP have time to follow up actions / community to GP to Patient Admissions avoidance local team – lack of resources?	Integrate accountability, responsibility and authority with funding; Review monitoring procedures Mutual education – clinical / community / primary care/ patients

Task: Avoidable Admissions	**What do we think we know about what happens now?**	**What we think is possible to do in the future**	**What is stopping us? What / who can remove the block?**	**Actions: Who? When?**
	A&E Failings: A&E staff didn't treat Salim as a whole person; The GP has let Salim down – didn't support him Salim diagnosed with COPD but now given a treatment plan Staff feel overwhelmed by patient numbers, complexity and lack of resource Staff need access to shared information for services in order to keep people out of hospital (e.g. access to discharge letters/ clinic letters/ care plans)	Care package on discharge (shared approach across all 5 boroughs) Data sharing for all services (e.g. A&E can see GP notes; GP can see walk-in notes; social services can see community team notes) etc 111 or 999	Public education campaign on national services e.g. 999 & 111 Not having right care in right place (e.g. 999 calls for a fall – therapist or paramedic goes out?) Routing access to online records for the patient	Ensure capacity is available in community to deliver AA – this may mean shifting acute resources Describe/ map the size of problem re: community equipment – it will save money if it's in place so move the money. Thinking about this as soon as someone goes into hospital = free
Emotions: How is the service user feeling?	Effect on patient's relatives is an impact on the patient No diagnosis given @ 1st A&E attendance – just 'don't worry' – feels dismissive of Salim's fears and condition Patient feels scared, not happy to be told 'go away' Frustration as home oxygen service was solution all along and all of the anxiety could have been avoided Salim wasn't given information on his condition – patronising Anxiety about where to go and when: A&E, Walk in, GP? Unempowered; uninformed; not engaged; being 'done to'		Fear that the best treatment is in hospital (admissions) and not in the community (culture change)	

Task: Avoidable Admissions	What do we think we know about what happens now?	What we think is possible to do in the future	What is stopping us? What / who can remove the block?	Actions: Who? When?
Weaknesses: How are we failing the service user?	'Information giving' – have a 'booth' / 'health champion' or 'navigator' to help via video (for a condition) or have a 'blog' or You Tube to inform patients Funding system changes often confuses staff and patients Funding rules change and it affects patients – this is not considered Pathways: Pathways say 'every contact counts' but only talks about smoking – how about exercise / healthy eating (taking religion and culture views in consideration)? Preventative: Can we look at the different cultural practices – 'trans cultural medication' Lack of health promotion – not just in public health but in schools Overmedication is the problem. Should the focus on peer support; resilience; other support Need a clear pathway and care plan. Can feel guilty to return to services Need statistics on who presents with what and when? Have we defined what problem we are trying to solve? Patients info is poor, often don't get a copy of letters	Need similar services in each borough	Not all GPs are on the same IT system Lack of authority Lack of accountability Who is responsible for what? NHS managed vertically Patients move more disjointedly Is finance an issue? IT not joining up – but should not be an excuse for not communicating with each other Capacity at GPs Lines of responsibility are not clear Barrier: if the right assessment was done the, right decision and intervention would be in place. Targets inhibit e.g. 4 hour wait targets. So manage another target / contractual arrangement between primary and secondary care Lack of shared information (e.g. access to medical notes/social services) Method of information sharing (e.g. how does paramedic know prior information / management) Need equipment & resources to keep unwell people at home	A process map of what happened to referrals / letters to GPs / discharge summaries etc. who reads them? The GP or admin? What to they do with info? Do they action it? Clear lines of responsibility from CCGs/ Commissioners (re: GPs and rest of system) Relax our targets so A&E can complete tasks required (e.g. discharge letters, referral on – deliver quality care in reasonable time) Remove selective A&E targets to prevent inappropriate admissions and more time for investigation of diagnosis

Simplified Discharge

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

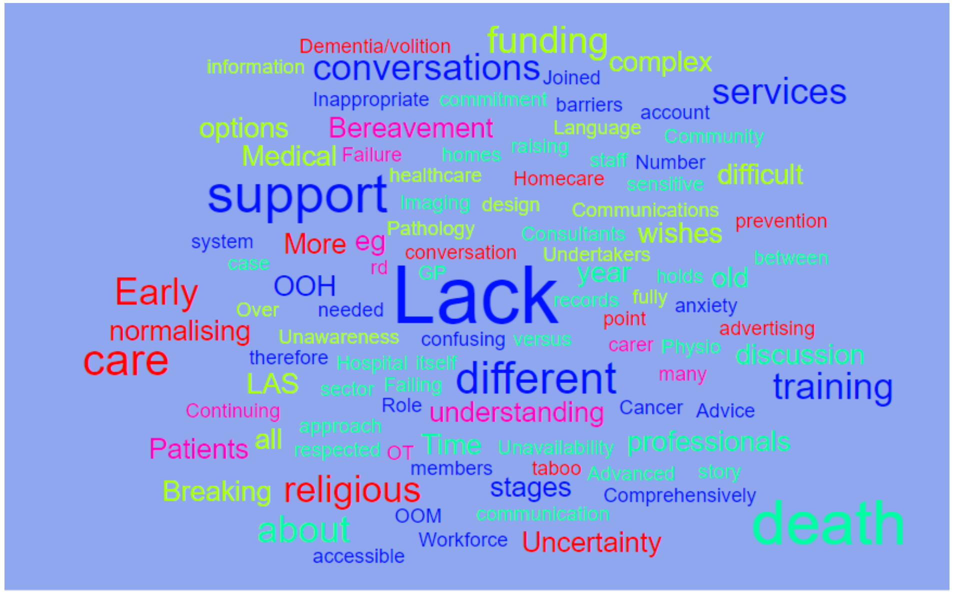
Task: Simplified Discharge	What do we think we know about what happens now?	What we think is possible to do in the future	What is stopping us? What / who can remove the block?	Actions: Who? When?
The Service User Experience	Patients having to contact numerous departments is not efficient for the NHS Mismatch between what is needed and offered Different parts of patient's body looked after by different departments – not patient centred, not joined up! Self-funding cuts service user off from service entitlements, despite helping the system to save Fragmentation – the NHS Is not one organisation it is many teams with different regulatory priorities	Local services should be based in local demographics and needs NCL wide – remove inconsistencies across areas Information & Responsibility Moving resources around the system; removing the red tape so less time is spent record keeping and more time is spent on patient care Accountability at each stage (individual and structural accountability) We want professionals to 'own' what happens How do we incentivise this?	If your GP is not in the same borough as you live Leadership, culture and behaviour – flexible and more patient focussed Friday 5pm – everybody goes home Joint funding Joint IT Funding/ capacity / resources Relationship building Boundary issues – different GP / CCG to Local Authority	Multi professional learning with patient input (co-production) open and transparent Set up innovation groups with staff and patients Nationalised centralised IT system (like Canada) Bring different roles together at every opportunity e. g. training, team meetings, case meetings Avoid duplication – e.g. history taking; basic common skills set Managers with good management skills Leading the team to have can do approach and be accountable to find solutions
Question: What does the service user need to know?	Patient / Service user needs information about who to call Patient needs to know: What should happen next? Who is responsible? What are the timescales? What to do if things aren't working? Single point of contact Who decides what the service user needs to know? Why just the service user? Hello! The carer; family; friend - what I call the user nucleus Service user needs information on how the system works (provider needs it to!) Need to know what can I do to help myself	Help to navigate the system Boot TV with information = access needs for conditions Patient and GP at centre of the process, each with their own accountability Working to one system Accountability – each service identified individual needs to take accountability of how to assist / change practices Information otherwise a foie	Information – access, quality, sharing, inter-operability Access issues – how do we all access these services	A phone number to navigate system – better use of 111 Patient leaflet with contact information and numbers Text to confirm appointments – all opt in Quicker appointments – to provide better access Left hospital - make own referral for future access – (admitted to A&E & told to go to GP for referral)
Touchpoints: what	2 x hospitals; 2 x community nursing teams; GP; Social	Moving local authorities	Target – quantity over quality	Shift resources from acute to primary care

Task: Simplified Discharge	What do we think we know about what happens now?	What we think is possible to do in the future	What is stopping us? What / who can remove the block?	Actions: Who? When?
are the interactions with the service user?	Services; Physio; OT; Nursing for dressings Patients need one point of contact to chase everything up Move adult social care resources and social work to GP practices	social care to GPs GP has the access to all information from a range of services i.e. social services; hospital discharge and needs to co-ordinate further as centre of patient care The accountability of each service also would rely on the different services working together constructively	Weakness in GP practice – shift resources to support co-ordination better A ‘them’ and ‘us’ mentality – acute versus community Lack of knowledge – e.g. consultants telling patients they need residential care then the patient doesn’t want it! Variations in service availability, procedures and practice across NCL Fragmentation – hospital – GP – breakdown Cumbersome processes IT systems – they don’t talk to each other Duplication and replication of recording Poor IT integration Lack of personal accountability change large numbers of staff Risk aversion and blame culture Separation of budgets between health and social care Bureaucracy – the tail is wagging the dog: we’re driven by the measurements not the other way around Time – when everything is urgent nothing is done properly Continuous cycles of change – nothing gets to ‘bed in’ properly Hostility – from regulators and politicians – totally unconstructive Constraints – teams not knowing what others can and cannot do! Vacancies – can’t fill posts	to strengthen / support co-ordination role that can be played out of GP practice Proper staff development and performance management Accountability, structure and taking criticisms constructively London wide housing scheme for key staff to help retain workforce. Staff incentives e.g. gym membership; theatre tickets; exhibitions Change focus from target – time, pressure and complexity Managing complaints positively and learn. Working in a co-productive manner Understanding power; oppression; discrimination; training acceptance of responsibility Pragmatic approaches Attitude and behaviour training

Task: Simplified Discharge	What do we think we know about what happens now?	What we think is possible to do in the future	What is stopping us? What / who can remove the block?	Actions: Who? When?
Emotions: How is the service user feeling?	Disempowered Loss of confidence & mobility Feeling Neglected Feeling Frustrated Patronised Neglected Rage Frustration Fear Helplessness Disempowerment Exhaustion / stress My time is valuable too! Experience feeling ‘lost’ and insecure. Cut loose between services			
Weaknesses: How are we failing the service user?	Falling between the cracks in services when specialisms are split Too much bureaucracy Sort out the difference in funding between the inner and outer London Boroughs Parts of the system undermine other parts of the system Passing responsibility for chasing back to patients (and doing this can lead to patients not getting necessary treatment and worsening conditions) Insufficient night care Community between hospital and community services are not good Failing – repeat a cancellation Failing to track experience – leaving it all up to the family		Lack of relations between different types of staff Lack of staff numbers Using skills appropriately Using volunteers appropriately Lack of shared IT systems Staff not understanding other staff roles Staff not empowered to use ‘common sense’ Staff not been able to treat patients ‘holistically’ Staff turnover doesn’t help to build contacts & relationships Upskilling required Lots of education and training Time to think Time to sit with colleagues and reflect and then innovate and change Think creatively Act proactively Do holistic care Work & life balance Good management Good professional mentors	

Task: Simplified Discharge	What do we think we know about what happens now?	What we think is possible to do in the future	What is stopping us? What / who can remove the block?	Actions: Who? When?
	Record sharing – a barrier Not working in partnership with the family / carer Communication between services as well as between service users and services Information provision Responsiveness Groups between plans and reality – implementation of the vision Can't copy with service users going outside prescribed processes When you're discharged from hospital you are no-one's responsibility Success often depends on individual accountability of individual clinicians bucking the system BUURTZORG! Purchaser / provider split – commissioning problems: 'we're not paid to do that' or 'it's not my job' Health/Social care divide Not listening to wishes of patients System forces patients to me assertive Problems with record sharing (poor IT is a massive problem) Hospitals don't have access to the X-rays!		Systems not fluid Funding arrangements fund staff using initiative IT systems don't join up Leadership cultures and behaviours Time on innovation taken away from day jobs Management is top heavy	

Last Phase of Life



The Navigating Death journey plotted and discussed a road map towards death for both the patient and the carer/ family.

Themes from this discussion included:

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

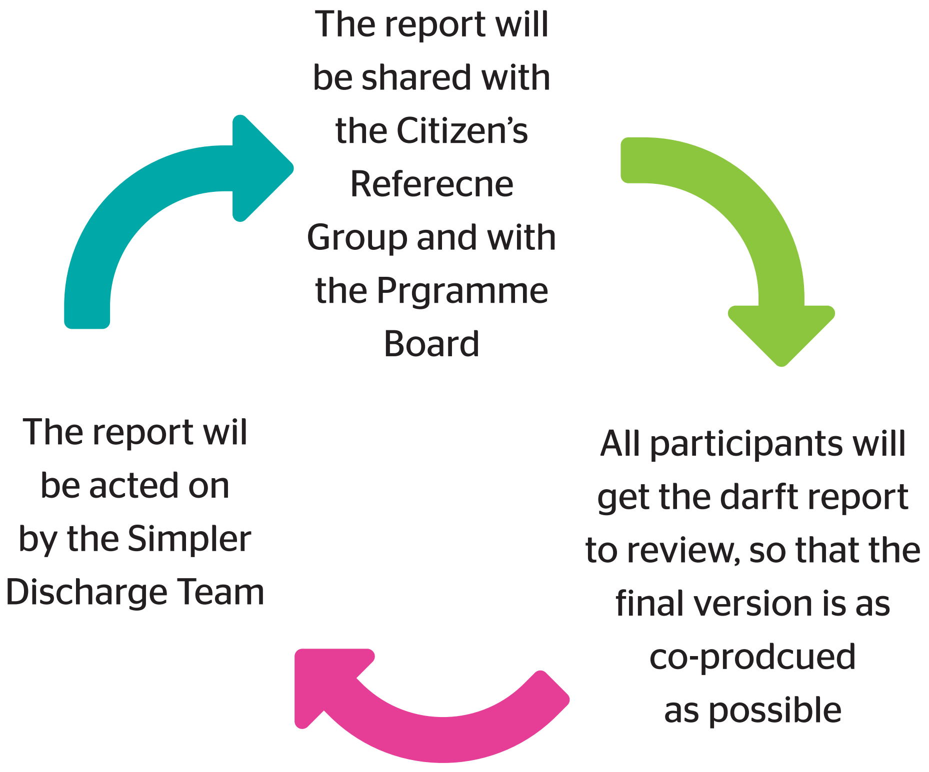
Task: **Last Phase of Life**	**What do we think we know about what happens now?**	**What we think is possible to do in the future**	**What is stopping us?** **What / who can remove the block?**	**Actions:** **Who?** **When?**
The Service User Experience	Bureaucracy Uncertainty Unawareness of options Telling story once Lack of consistency	More conversations about death Normalising it Recording it Sharing it Cultural and religious sensitivities – taken into account Early conversations about death. We are all going to die at some point.	Working across complex areas / conditions Technology issues e.g. EMIS system connected to LA's / OOH 24/7 case look at design to address this	Building communities to build resilient communities Shine the light on good examples Prevention strategies Share examples of how to advance care planning worked and the difference it made Got one provider to accept another's DNAR form

Task: **Last Phase of Life**	**What do we think we know about what happens now?**	**What we think is possible to do in the future**	**What is stopping us?** **What / who can remove the block?**	**Actions:** **Who?** **When?**
		Advanced care planning so patient's wishes are respected by family members and healthcare professionals Joined up care records between GPs, LA's, OOH, Hospital More advertising and raising awareness		Have bereavement services alongside End of Life Better community involvement
Question: What does the service user need to know?	Dementia/volition Breaking the taboo Role of the 3rd sector Navigator / advocate Living will Who does what Medical diagnosis / prognosis £ support Advice for carers Who to contact £ liability Transparency / understanding Options Who holds the information Early discussion of the patient's wishes of their death and documents and all in an accessible way.	In the future the 6 ambitions need to be fully embedded in End of Life care throughout the CCGs and therefore implemented in the process itself. This is bereavement support.	Bereavement support – available when needed Communications skills (sensitive area) Training (receptionists!)	Patient education & empowerment. Ensuring patients take responsibility for own care and well being Knowing what is available locally – signposting – pool resources Tapping into volunteers. Patient Reps to promote awareness of EOLC Voluntary sector organisations teaching wider organisations Training – carers / GPs having conversations about dying
Touchpoints: what are the Interactions with the service user?	Breaking the news Having a good death Culture/ religious considerations Adaptations Consultants Imaging Pathology Undertakers Care homes OT Physio Homecare Religious	Inform GP / documented Continuing the discussion about death normalising death		Improve joined up care between consultant and hospice or end of life team

What next?

1. A report of the event to be produced by the facilitators
2. The PowerPoint slides and attendance list to be circulated to all participants
3. Overarching report to be prepared by Healthwatch Camden in response to the engagement work undertaken and to consolidate main findings
4. The Patient Reference Group to review the report
5. The Report to be presented to the NL Urgent and Emergency Care programme Board

Report and follow up



The report will be shared with the Citizen’s Referecne Group and with the Prgramme Board

All participants will get the darft report to review, so that the final version is as co-prodcued as possible

The report wil be acted on by the Simpler Discharge Team

Evaluation


On a post-it, please
Venue
Organisation
Overall content
Specifics
Opportunity to network
Stories
Mapping the journey
Setting the vision
Agreeing actions
Outcomes
Very
A bit
Not at all
Usefulness to me
Usefulness to organisation/ my community

Salim and Aliya's story*

How it starts

Salim is in his 60s, widowed, he lives with his daughter and son in law. He had been getting lots of coughs and been advised to stop smoking. He collapsed suddenly at home and seemed to stop breathing for a short time. His daughter, Aliya, called an ambulance. Paramedics did checks then took him to A&E. After a long wait, the doctor in A&E said they would ask Salim's GP to make a referral to the chest clinic. She told Salim not to worry but to see his GP if he felt ill again.

What happened

Salim continued to feel unwell and breathless. He and his family were anxious. Before the appointment for the chest clinic arrived, he woke up in the night struggling for breath. His daughter called another ambulance and he was taken back to A&E. He was admitted to a ward, given a lot more tests, diagnosed with COPD and started on treatment.

Salim continued to be unwell. His daughter was finding it hard to care for him, and worried about leaving him alone. She gave up her job.

Salim again had severe trouble breathing at night. Aliya was frightened and called an ambulance. Again, the paramedics did some checks but decided to take him to A&E. This time, instead of being admitted he was sent home with a referral to a specialist nurse. She visited, gave the family information on managing Salim's condition, arranged for him to start on home oxygen and gave him IV antibiotics.

The family say that the nurse and the home oxygen service is what they needed all along. They are sad that Salim suffered so much discomfort and anxiety before he got this help.

*Salim and Aliya are fictional. Their story is based on a number of different experiences we have been told about.

Sue's story

How it starts

Sue lives alone. She is 83. She fell down some steps at a railway station.
She injured her spine and broke her wrist.
She was taken to hospital.
She stayed there for seven days.
She was told she was ready for discharge.
She was in a body brace, and unable to get up and go to bed or get bathed unaided. She was told she might have to wear the body brace for six months but this would depend on what the specialists told her at her follow up appointment. She was told it would damage her spine not to wear it. She would need physio, too.
She was told she would get a follow up appointment with a spinal specialist at a different hospital within five weeks.
Sue and her daughter asked lots of questions about what would happen.
She was offered two 'pop-in' visits a day. She was told this was all that was available to people in her situation.

What happened

Sue and her daughter did not know how Sue could cope on her own with just two quick visits a day. So her daughter stayed for the first couple of nights. Her daughter has a job and young children. She could not care for her mother all the time.
Then they found a paid carer to sleep in, and help Sue at night. Sue paid for this from her savings.

They waited for the follow up appointment.
Nothing happened.
Sue went to her GP to ask about follow up. The GP said to call the hospital. Sue called the hospital. Nothing happened.
Sue went back to the hospital to have her wrist plaster removed. She asked about the follow up for her spinal injury. Nothing happened.
Sue was fed up with wearing the body brace. After nearly 6 months she decided to stop wearing it.
Several months after discharge she got an appointment to see the spinal specialist. It was then cancelled. The next one was cancelled, too.
Six months after she left the hospital she had her appointment to see the spinal specialist.

Miriam and Len's story*

How it starts

Miriam had dementia, towards the end-stage of a terminal illness. She became acutely ill. Admitted to Whittington Hospital. Hospital social care worker arranged an enablement care plan, with care staff visiting three times a day.

Not what Len, her partner and long term carer, wanted. He preferred what he had before, one day's weekly respite, where the same person came each week and built a good rapport with Miriam.

The social worker said there had to be a trial of the enablement plan for one month. The reasons were not clear to Len but he felt obliged to accept. Assured that afterwards the old arrangement could be considered.

What happened

The trial went badly as anticipated; Miriam was highly agitated by the new carers. Len had to leave the house when they came because he couldn't bear to hear how upset she was. The carers were short of time and didn't attempt to build a rapport with Miriam. They were also sometimes late or came the wrong times, which only added to the stress.

Before the trial had finished Miriam suffered a new health issue and was admitted to Barnet Hospital, Larch Ward. Staff recognized she was in the final weeks of life and were very supportive. They discussed her end of life preferences and fast-tracked a continuing care application so she could die in a care home rather than in hospital.

The application was delayed. Len spent valuable time chasing it. PALS said they couldn't get involved when he asked. The CCG worker with the power to approve the application was on leave.

Subsequently, finding a home proved problematic. Homes recommended by the CCG charged more than the maximum fees allowed. One nursing home asked if Len wanted to pay for any 'extras' to meet the shortfall. There was no way of knowing how much this would cost. Eventually a nursing home was able to take her and she was there for two weeks before she died.

* Not their real names. Story used with Len's permission.

Appendix B: Background information:

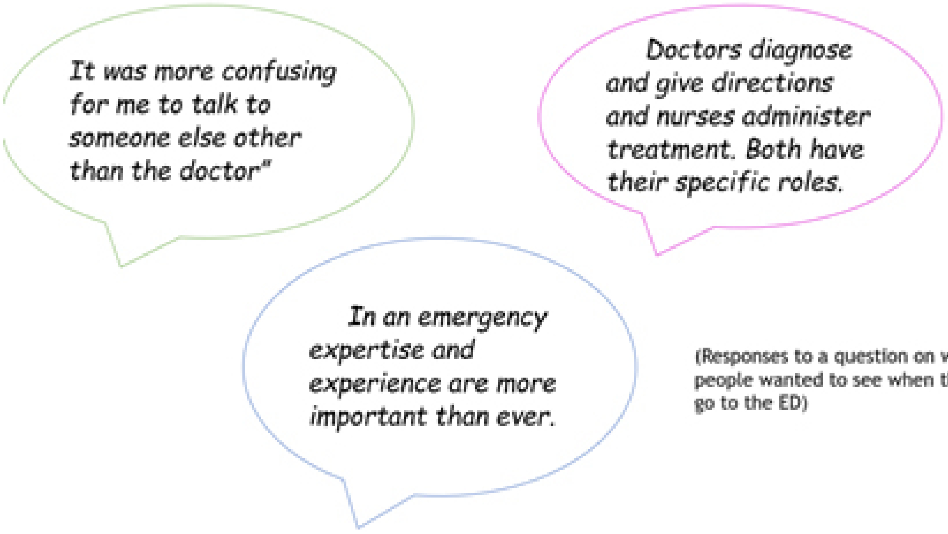
North London Partners Urgent and Emergency Care Programme

Emerging results from the engagement

Admissions avoidance

Healthwatch Islington has interviewed 39 people about admission to hospital. For 30 of the 39 respondents felt they had no option about whether they attended hospital. 36 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.



It was more confusing for me to talk to someone else other than the doctor"

Doctors diagnose and give directions and nurses administer treatment. Both have their specific roles.

In an emergency expertise and experience are more important than ever.

(Responses to a question on who people wanted to see when they go to the ED)

Accompanying patients home

32 of 39 respondents felt that it was a good idea for staff or volunteers to accompany patients home. Respondents emphasised that it was a good idea if the patient could choose it, rather than it being something obligatory.

Yes, it would be an excellent idea. When I was sent home from A&E the first time I was still ill and it caused my family and I a great deal of anxiety as we were none the wiser as to what was wrong with me or what to do. A follow up visit at home would have made all the difference.

It is definitely a good idea. Better to have paid staff as they are more likely to be trained and experienced. Could be risky with volunteers as they are not so well known.

Good idea, depending on what you want at the time. Sometimes having people at home is uncomfortable, but if it's to avoid going back to hospital then yes.

Seven respondents weren't sure whether this was a good idea or not, generally because they had not experienced this and so didn't feel they could comment. One respondent noted:

It would be better to concentrate efforts and get people allocated to wards or dealt with so they are well enough to go home before trying to spread resources to something else.
I don't think it is necessary. The patient should follow-up advice they have been given at the hospital. This is where the advice should be given properly.

Nine respondents would have been happy to be seen at home for some of their treatment (one stating 'if the correct equipment was there'), this included one person who had been conveyed to hospital in an ambulance. However, most felt that what they had needed was best delivered in a hospital:

I needed an x-ray and I was in excruciating pain. I was flat out on the floor when the ambulance arrived. My daughter was in when I fell but she was not able to move me as I could not move myself at all. I was bleeding from the head and was not able to stand up or even sit up.

My wife had to go to A&E as she had had a fall. She needed an x-ray, medication for pain and assessment by a doctor. She had broken a rib.

Who sees the patient

19 respondents expected to be seen by a doctor, several expected to be seen by a nurse, some had no expectation.

I prefer a doctor but whoever was there I would have made do as I was desperate.

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.

I suffer from a heart condition so a quick decision needs to be made.

So that a decision can be made instantly & I don't have to wait a long time.

For 23 of the 39 respondents it was important to them who they were seen by at the Emergency Department.

In an emergency expertise and experience are more important than ever.

Doctors diagnose and give directions and nurses administer treatment. Both have their specific roles.

We asked those with a long-term condition whether they felt they got the information they needed to manage their condition. 27 respondents stated that they did get enough support but their answers still highlighted poor communication within hospitals. The need for more help with care once back home was highlighted several times in two groups. For those managing their own condition they felt their test results were often enough to tell them what was needed.

In general I do get enough information to support myself but there have been may times when I have had to chase things up or there have been mix-ups between one hospital and another or within the same hospital. In general I have been well looked after by the actual doctors and nurses, but admin has been a problem.

Simplified discharge

To date, Healthwatch Enfield has surveyed a small number (36) of people. Almost half of the of the individuals they spoke to reported that they felt they did not get enough information about what was going to happen next when they/the person they care for was discharged from hospital (47%).

Individuals reported that the following information would have been useful when they/the person they care for were discharged from hospital:

- More information about discharge plans and follow up appointments
- A follow up telephone call following discharge
- Information in writing as well as verbally; particularly for those with memory problems
- An after-care plan
- Help organising transport for follow up appointments
- Help organising equipment, aids and adaptations
- Specific information relating to the individuals condition
- Contact information for a named person who can help post discharge.

Only 43% of people reported they had a care plan when they left hospital – although there was agreement that care plans are useful. There was limited support for having the care plan done once you have left hospital (‘discharge to assess) – only 35% said yes to this idea. Individuals commented on the following benefits of care planning post-discharge, at home:

- The ability for health staff to see and assess patients in their own environment
- Patients being able to listen and think more clearly in their own home
- The potential usefulness of re-assessment once at home
- The potential reduction of panic and anxiety related to going home

Individuals commented on the following concerns relating to care planning post-discharge, at home:

- The need to have an assessment before going home so support is already in place when an individual gets home
- The need to have an assessment before going home to ensure that the patient is safe at home

- The need for this assessment to be done on the day of discharge if it is conducted at home
- Invasion of privacy of having health care staff visiting one's home

Around two thirds of individuals felt that their views and wishes were taken into account during their hospital discharge (65%).

Individuals reported that their involvement could have been improved by:
- Listening to what the patient has to say
- Listening to and addressing patients concerns
- Talking to patients at a time where they are mentally able to converse
- Tell patients about results
- Ask patients outright what can be done to help
- Having continuity of care in the staff looking after patients

Although the majority (71%) of patients felt that their discharge had gone according to plan. When asked 'what could have made it better?' individuals commented that:
- Should have a doctor or nurse discuss discharge with the patient
- Need to fit timing of discharge in with what works for the patient
- More consultation with the patient about if they are ready for discharge

Similarly, most (70%) felt well supported post-discharge. Only a few (10%) did not feel at all supported. When asked 'what could they do better?' individuals commented that:
- They need to know exactly when they are going to be discharged and the specific support that they are going to get
- There should be more person-centred care
- Carers should come at regular times
- Help with bed sores should be given
- There should be better co-ordination and integration of services
- There should be help available for anxiety and not just physical needs

Around half the individuals felt confident that they know where to get further information if they need it. The overwhelming majority prefer face to face information. Leaflets were the next most popular choice. No one spoken to preferred an app.

Healthwatch Islington has also interviewed people about simpler discharge and we will be carrying out more surveys about it. While the overall picture may be slightly different, although we expect the key messages to be similar.

Last phase of life

Healthwatch Barnet and Healthwatch Camden have been interviewing people about the last phase of life.

The majority of people spoken to felt they had a largely positive experience of LPOL in Barnet, even if minor things had gone wrong occasionally.

Six out of eight interviewees had, or were currently using, North London Hospice or Jewish Care specialist End of Life services. Their experiences were very positive, whereas the two interviewees not using these services had experienced problems with Continuing Care Budgets and understanding LPOL pathways and had found the experience more difficult.

Some elements of LPOL that are working well and contributed to participants' having good experiences were:

- Having quick access to community health workers and responsive GPs at all times
- Being allocated a worker to act as navigator and co-ordinator
- Using the named nurse system (cancer and respiratory) at Barnet hospital
- Accessing a designated palliative care service
- Confidence in the knowledge and support offered by experienced specialised LPOL staff.

Other points that people felt were important:

- People value support in having difficult conversations about end of life.
- People want clinicians to be honest with them about end of life situations, and to ask about preferences.
- People need access to fast support about continuing care budgets and nursing home/ homecare provision.
- Where possible relative/carers views on care plans should be taken into consideration.
- Timely removal of equipment from the home after someone has died.

Being supported in the last phase of life

- Often there are several Last Phase of Life workers involved and people lose track of who belongs to what service, but this doesn't particularly concern them.
- People praised their GPs for being kind, compassionate and responsive on the whole, particularly during the final weeks e.g. making urgent referrals, fast-tracking prescriptions, doing home visits, returning calls, completing Attendance Allowance forms and death certificates quickly.
- Community health workers (district nurses, community physiotherapists and Occupational Therapists(OT)) were much appreciated for the tangible support they gave that enabled people to stay at home.

"The district nurse was very good. She kept an eye on things and spoke to the GP for us if needed."

"We had a wonderful OT who taught me some techniques so I could help my husband sometimes. It made us feel we could manage at home a bit better."

- Everyone spoke positively about having a good rapport with community health workers.
- People appreciated being able to draw upon community health workers' palliative care knowledge to know what to expect.

There was also praise for the services from North London Hospice and Jewish Care. However, it does not always go right – as this case study illustrates:
A woman with dementia was moving towards the end-stage of a terminal illness when she was admitted to Whittington Hospital following an episode of acute illness. On discharge, a hospital social care worker arranged an enablement care plan, with carers visiting 3 times a day even though this was not what the carer (her partner) wanted (the previous care arrangements had been working well). For reasons that aren't clear, the hospital worker said there had to be a trial of the enablement plan for one month and her partner felt obliged to accept this on the promise that afterwards the old arrangement could be considered.

The trial went badly as anticipated; the patient was highly agitated by the new carers, the carers were short of time and didn't attempt to build a rapport with her. They were also sometimes late or came at times that didn't match the couple's routine, which only added to the stress.

She became ill again and was admitted to Barnet Hospital. Staff recognized she was in the final weeks of life and were very supportive. They discussed her end of life preferences and fast-tracked a continuing care application so she could die in a care home rather than in hospital.

Unfortunately, the application was delayed and the partner spent valuable time chasing it without the assistance of PALS, who said they couldn't get involved when he asked. It transpired the CCG worker with the power to approve the application was on leave.

In Camden we have been interviewing people from African and Indian backgrounds. The main themes coming from all the interviews were about:
- Lack of information on choices
- Poor communication
- Not involving family and friends
- Lack of understanding about cultural and religious issues
- Not enough caring or empathy
- Dislike of nursing homes as an option

There were also specific comments on:
- Lack of holistic care
- Doctors and other healthcare professionals being patronising
- Needing more support with facing the reality of death
- People being left alone to deal with difficult and painful issues
- Being 'got rid of' to a nursing home.

"It's worse when people want to go and die at home, they are neglected, it just seems so complicated to put a care package together, so the person does not get the care they desperately need, not pleasant, very sad."

"Even though I knew my loved was going to die, I still had hope."

"There isn't a lot of freedom (in the nursing home), it is really routine based, and switching things up could've improved quality of life rather than having to do the same thing every day or follow the same procedure."

However, the biggest issue was on attitudes and perceived lack of respect and empathy. "(Some of the staff behave) as if they are better than everyone else especially the people they find."

"They are not taking what the patient is saying seriously, the patient and Doctor relationship is like student and teacher."

"I felt as if I wasn't valued and that I was just a product. I felt emotionally neglected at times as there wasn't great support or communication."

When asked about feeling supported in the last phase of life, a key theme from the interviews was about older people feeling written off, being treated as useless or a drain on resources - with comments such as *"Giving up on the patient and showing it"*.

Similarly, there was a theme about older people feeling they are a burden to others, with comments that staff are too busy, and have no time to listen until it's too late.
Support for religious beliefs was another theme, one suggested that issues of religion are too complicated for staff to be bothered to understand them. Another said the attitude encountered was *"that's not my belief why should I bother"*.

There were also specific comments on:
- Not respecting the wishes of the patient e.g. in terms of confidentiality
- Trying to communicate to the patient even though they were not compos mentis when they could easily speak to the family representative.

Religious and cultural differences

A community worker said that the key message is that *"staff need to be open minded and willing to learn that they will encounter situations that they did not learn in their training and not being judgemental"*.

One case study illustrates this:
"My cousin believed she was cursed and that she had a demon in her stomach. Instead of the staff getting the right help in, speaking to family members, even if it's just picking up the phone to call someone from the person's community to advise the staff or to help the client they instead frowned on the patient. She later died because she refused to take the treatments and was harming herself by taking unconventional medication to deliver herself from the demon. She ended up damaging her liver. What would have been helpful would have been to speak to a spiritual specialist. This may sound unreal but it is real for some people."

We have also had comments about specific religious practices, especially relating to the cleaning of bodies after death, and the removal of traces of death – different communities have different expectations and beliefs, so the key message is to ask, not assume. When people had died at home, it could be difficult to find someone to remove medical equipment (e.g. catheters, T-lines) from the body after death; this was distressing for family members.

This work is continuing, further reports will follow.

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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