REVEALING REALITY

LCN Ethnographic Engagement

Summary of findings
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Please note, all quotes in this report have been anonymised.
Introduction and executive summary
Executive summary

This project brought together a multi-disciplinary team, using ethnographic methods to better understand the needs of those in Southwark and Lambeth and bring their voices to the centre of LCN development.

- With this aim in mind, we collaboratively developed our research objectives and conducted 30 2-3 hour depth with people with 3+ long-term health conditions (aged 52-90, 50:50 Southwark and Lambeth residents)

- Interviews were conducted in the respondents home to understand the context of their lifestyle and behaviour, and centred on experiences of health and social care services – types of support, ability to cope, and challenges

- Process of working with staff and residents from Southwark and Lambeth was largely successful, with many embracing ethnographic techniques to explore further, and seeing the team as a safe space in which to analyse findings and identify shared hypotheses

- There was a real need for care-coordination amongst our sample, with many suffering with challenges that were often easy to overcome but were not identified by professionals

- Poor wellbeing was a vast problem, with many feeling a lack of control and purpose in their lives – this was often due to loneliness and poor knowledge of how to change this or where to seek help

- Going forward, there is a real opportunity for care planning to bring real change, provided professionals endeavour to understand the real challenges and issues in a person’s life, and get beyond the superficial responses that may ultimately leave someone struggling
The importance of learning from local people

This project brought together members of staff and residents from Southwark and Lambeth with researchers from Revealing Reality. Ethnographic methods were used to better understand the health and social care experiences of local people:

✓ Enabling us to put the voices of local residents at centre of LCN development

✓ Using ethnographic skills and techniques to uncover new insights around the barriers to health and wellbeing and care-coordination in the boroughs

✓ Partnership approach allowed for a multi-disciplinary team that could draw on different strengths and knowledge to develop a shared understanding
A collaborative approach to research

Together we developed research objectives, conducted fieldwork and analysed our findings.

- **Project briefing workshop**: 2 hours
- **Fieldwork prep workshop**: 2 hours
- **Fieldwork & feedback**: 2 hours + 30 minutes
- **Analysis workshop**: 2.5 hours
- **Reporting**:
What did we achieve?

Together we conducted 2-3 hour interviews with 30 people who lived with 3+ long term conditions across Lambeth and Southwark

- Interviews conducted in the respondents home to understand the context of their lifestyles
- Questions centred on experiences of health and social care services – types of support, ability to cope and challenges
- Exploring lifestyles and behaviours that impact their quality of life and health

Sample:
- All respondents had a spread of 3+ health conditions
- Spread across Lambeth & Southwark
- Aged between 52 – 90
- Demographic variation – gender, ethnicity
- Most lived in social housing – with some in private renting and others who owned outright
Key questions and research objectives

During the initial stages of the project, the team (from a wide range of backgrounds) came up with the following objectives:

- Better understand people’s experiences of services / care across the 2 boroughs
- Clarify residents’ level of knowledge around their health & conditions
- Explore what impacts peoples’ wellbeing – either positively or negatively
- Unpick people’s ambitions and goals for the future and how they could be supported to achieve them
Why ethnography?

Ethnography is a research tool that is widely used in social innovation and enables us to get beyond ‘stated behaviour’ to truly understand individual priorities and needs

- Engagement happens in the ‘real world’ (i.e. in homes) to better understand the context of peoples’ lives
- Researchers build trust with respondents, taking time to understand life from their perspective
- Data collection includes stated testimony, but also includes observation & visual documentation

During the interviews, we collected the following data:

- Quotes / what people say
- Body language
- Personality & character
- Décor & objects
- Atmosphere of the home
- History & past experiences
- Places they go
- Paperwork & letters
- Beliefs, stories and myths
- Observation of movement
- Observation of tasks
Training process: Key Takeaways

What went well...

• **Meeting people in context:** Ethnographic skills and speaking to people on their own terms can be extremely valuable in understanding the factors influencing their health and ability to cope.

• **Breaking down professional boundaries:** Analysis and training provides a safe space to talk openly and identify shared ways of thinking.

• **Taking ownership of the findings:** Opportunities for local volunteers and staff to present back to their organisation in order to aid the dissemination process.
Watch outs and opportunities

- **Core teams struggled to get staff involved:** It’s not easy to prioritise something like this

- **Managing different levels of knowledge and ability:** Challenging and can delay progress

- ‘Avoiding ‘just stories’:** Work can feel unrewarding if it doesn’t have a direct application — really important to have a tight brief & research objectives

- **Lots of assumptions about ethnographic engagement vs. ‘normal engagement’:** Important to demonstrate the different skill sets and outputs generated

- **Challenges managing ethics and safeguarding in a partnership environment:** Different parties have different procedures (and the changing landscape of DBS checks)
Background to the work
Background: About LCNs

Local care networks (LCNs) bring together a range of health care professionals working together as a team in the community including doctors, nurses, social workers, housing support workers, home care workers and therapists who work with a patient to achieve the goals that are important to them in a clear, jointly agreed way.

In 2016/2017 local care networks across Lambeth and Southwark are prioritising the delivery of co-ordinated care to people with complex needs; i.e. those people with three or more long term conditions.

The ultimate objectives of LCNs are resilience and efficiency – aiming to integrate services, whilst empowering patients to self-manage, and prevent illness.
Background: Why we need care co-ordination

- Better patient experience
- Increased chance of patient engagement with their own health
- A better sense of trust amongst patients towards the health / social care system
- Providing better joined-up care through multi-disciplinary working

Jack was exercising multiple times a week as it was on prescription, however he stopped going as it came to an end. He stopped going and has struggled to find a way of doing exercise since, although is really keen to. If someone had noticed, it may have prevented him from stopping exercise altogether.

“I was going 3 times a week on prescription, but it stopped and I can’t find anywhere else to go”
- Jack, Southwark

“I can’t keep going to the GP. If he wants to see me, he can contact me.”
- Phil, Southwark

Phil travels to the Anticoagulant Clinic to get a blood test, then to the GP to show them the book with his results, who contacts the pharmacy to change his dose of warfarin. He has great difficult walking and feels it would be easier if the clinic communicated directly with the GP to save him the journey.
Mary, 79, Lambeth

“They showed up the day before [the cast came off], and luckily I’d had some help from a lady at my housing unit”

When Mary broke her arm after a fall, she requested some social care to help with her washing and household chores. Someone from social care showed up 6 weeks later, when her arm was healed. She felt like a professional could have better communicated her need for social care.
Care co-ordination: *What it includes*

- Named professional
- Non-clinical information
- Care planning
- Multi-disciplinary teams
- Self-management
- Sharing records

This is a diagram created by Revealing Reality showing elements of care co-ordination, identified through conversations with Southwark and Lambeth.
Background: Related engagement work

During the end of 2016, Southwark CCG undertook a complementary project, during which they used the same methods to speak to a further 10 respondents. Whilst patient stories from this project have not been included explicitly in our analysis, we worked closely alongside this project team to develop our findings. The report can be found at the link at the bottom of this page.

Southwark CCG also commissioned the creation of a film of patient stories, to be shown at a Protected Learning Time event for practitioners & patients in October 2016. This can be seen on the CCC YouTube channel.

Understanding experiences and needs
Case Study: **Roisin**

**Lambeth**  
**Age: 74**

**PROFILE**
Roisin is originally from Ireland and has lived in Lambeth for 30 years. Her son lives with her and helps to care for her, and her daughters live nearby and help to co-ordinate her care.

**HEALTH CONDITIONS:**
- Bad back
- Mobility issues
- Diabetes
- Heart problems
- Kidney problems

**HEALTH TOUCHPOINTS:**
- GP: Twice a month
- St George’s Diabetic Foot Clinic: Once a month
- Guy’s Hospital: Recent trip due to heart palpitations

**WHAT DID WE LEARN FROM THIS STORY?**
- We learnt the extent to which her mobility was constrained by living on the 3rd floor with no lift.
- We discovered she had unsupported MH issues when we asked her about her autobiography – prompting her to tell us about abuse she faced as a child.

‘I couldn’t manage on my own – without my son here.’

‘I would do anything to come off some of that medication.’
Case Study: Azra

Southwark  Age: 62

PROFILE
Azra came to the UK from Turkey in the 70s. She is a widow and now lives with her 3 sons, who help to look after her.

She knows she has to take a lot of medication but is not sure why. She is tired all the time and quite lonely – sometimes she spends all day crying.

HEALTH CONDITIONS:
- Diabetes
- High Cholesterol
- Back problems
- Recent liver operation

HEALTH TOUCHPOINTS:
- GP: Rarely
- Nurse: Once a month for injection
- Social services: Never came to fit her shower
- Home care: After liver operation – great job, loved having company

WHAT DID WE LEARN FROM THIS STORY?
- We witnessed how socially isolated she was, despite the fact that documentation would have shown she lived with her sons
- She was not formally diagnosed as depressed, however we discovered she spent whole days crying. She had no idea there might be support for issues like this
Case Study: **Gavin**

**Southwark**  |  **Age: 52**

**PROFILE**

Originally from Scotland, where he was cared for in a foster home, Gavin came to London with his partner in 1990. They now live in a rented apartment with their 3 dogs.

Currently, Gavin takes 80 tablets and 6 injections per day. He struggles with depression.

**HEALTH CONDITIONS:**
- HIV
- Hepatitis C
- Diabetes
- Grade 2 Kidney Disease

**HEALTH TOUCHPOINTS:**
- GP: 24 appointments per year, main point of contact
- Guys and St Thomas’ hospital: 50 appointments per year
- Diabetes, cardiac, gastro and pain clinics

**WHAT DID WE LEARN FROM THIS STORY?**
- We saw how some hospital cancellation policies could be detrimental to self-management.
- Gavin felt that he was being ‘punished’ for missing appointments when he was pushed back down the waiting list.
- He felt this was unfair as he often couldn’t make appointments due to ill health.

‘I’m constantly looking for solutions’.

‘If I go to the doctor it’s because I can’t manage’.
Case Study: James

PROFILE

Originally from North England, James moved to London in his mid 40’s. He is separated and lives with his three children. Due to COPD he is linked up to a ventilator at all times, and so is mostly confined to his newly converted bedroom.

James receives supported living services, although he struggles to communicate with his carer who does not speak good English.

HEALTH CONDITIONS:
- COPD
- Schizophrenia
- Depression
- Severe breathing problems

HEALTH TOUCHPOINTS:
- Guy’ and St. Thomas’s Hospital
- GP: regular home visits
- Ventilator and breathing mask service support

WHAT DID WE LEARN FROM THIS STORY?
- We saw the extent to which James’ condition limited his mobility – comprehending how limiting life is within the 4 walls of his apartment
- We understood the huge difference James’ recently installed shower conversion had made to his quality of life – prior to this he had gone weeks without washing
- We learnt how language barriers with his carer were causing him anxiety and distress

‘I didn’t realised how depressed I had been when I couldn’t wash.’

‘A big part of caring is conversing – if I can’t understand my carer it’s a problem’.
Case Study: Red

Southwark  Age: 62

PROFILE
Red was born in Cornwall as one of 9 children. After moving to London, he was homeless for 13 years. He now lives in an apartment with his 6 cats, who he adores. Red helps to care for two elderly neighbours, but apart from this, he confesses to having no social life and prefers to stay in his apartment due to severe anxiety.

HEALTH CONDITIONS:
- Bad back
- Mobility issues
- Diabetes
- Heart problems
- Kidney problems
- Anorexia nervosa
- Asbestos poisoning
- Emphysema
- Blackouts and panic attacks

WHAT DID WE LEARN FROM THIS STORY?
- We learnt how important it is for Red to have the same doctor for consistency. Red himself would like to be at the centre of decisions around his healthcare.
- We learned how Red’s past experiences living on the streets had impacted his current perceptions of healthcare and general ability to cope.

HEALTH TOUCHPOINTS:
- GP: regular visits
- A&E
- Kings College Hospital eating disorder clinic

‘Helping to look after my neighbours takes my mind off my own problems sometimes.’

‘I’ve been through a lot in my life. I don’t like to remember it all.’
PROFILE

Born in London, Ivan has been living with his wife in a flat for the last 22 years. Their two daughters are in their 60s.

Ivan does not leave the house as much as he would like. His biggest struggle is securing transportation when his daughters are busy.

HEALTH CONDITIONS:
- Diabetes
- Coronary thrombosis heart attack
- Angina attacks
- Aneurism on aorta

HEALTH TOUCHPOINTS:
- St Thomas’s Hospital: RRS and New Cancer Centre
- GP

WHAT DID WE LEARN FROM THIS STORY?
- After returning home from hospital, Ivan was visited by social support workers who felt the need to fill their official time quotas, but for Ivan were completely unnecessary.
- This was a huge waste of time and resources.

‘The only problem we have had is with the transport’.

‘The aftercare team fall a bit flat sometimes’.
WHAT DID WE LEARN FROM THIS STORY?

▪ Margie had severe depression, and suicidal thoughts, but was unclear on where to go for support with this.
▪ She felt that the only person to whom she could explain this was her community psychiatric nurse.
▪ She found it difficult to spend long times waiting in public spaces, owing to her mental health difficulties.

Case Study: Margie

PROFILE
Margie moved from Burma to the UK at 18. She had a very hard life at home and describes her two consequent marriages in the UK as very turbulent and violent. Margie has no contact with her 3 adult children.

She now lives alone in a flat she bought about 30 years ago, mostly staying in the bedroom; and occasionally has suicidal thoughts.

HEALTH CONDITIONS:
▪ Diabetes
▪ High cholesterol
▪ Severe depression
▪ Breathing difficulties

HEALTH TOUCHPOINTS:
▪ GP: once a month
▪ CPN
▪ Chiropodist
▪ Psychiatrist
▪ Keep Fit sessions at Brixton Recreation Centre

‘I might look nice but inside I don’t feel nice’.

‘I could talk to my community psychiatric nurse – no one else would listen’.
Case Study: Anand

Lambeth  Age: 72

PROFILE
Anand was born in Kenya and moved to England in 1984. He currently lives with his wife. They have 4 children, all married, and 6 grandchildren – family being hugely important to him.

He tries to look after himself well, exercising each day in his son’s self-built gym in his garden.

"Sickness comes, everyone has to go through that'.

'I was aware – medication can harm health'.

HEALTH CONDITIONS:
- Heart attacks
- Frozen shoulder
- Diabetes
- Blackouts

HEALTH TOUCHPOINTS:
- GP: every two months
- St George’s hospital: several times a year

WHAT DID WE LEARN FROM THIS STORY?
- Anand is clearly well supported by his family, and experiencing relatively good health and wellbeing due to this support
- However, he is largely unclear on how the healthcare system in the UK works, and with limited English struggles to know how to find this out.
Case Study: Derek

Lambeth Age: 90

PROFILE
Derek has been married for 74 years and has 3 sons. One of them stays with him during the week and is referred by Derek as “his pillar” and “his rock”.

His wife has recently moved into a nursing home after being diagnosed with dementia, which has been a huge shock for Derek, and he is unsure how to cope.

HEALTH CONDITIONS:
- Prostate cancer
- Depression
- Diabetes

HEALTH TOUCHPOINTS:
- GP surgery
- Local chemist
- St George’s hospital

WHAT DID WE LEARN FROM THIS STORY?
- Derek was a relatively healthy and resilient person, however since his wife moved into a nursing home had suffered a huge shock to his emotional wellbeing.
- He was reluctant to admit to having depression, but had recognised he needed support and had started taking medication.

‘My wife and I lived for each other and lived for the kids’. ‘I’ve starting taking ‘hose happy pills’ recently.’
Case Study: Pete

Lambeth  Age: 75

PROFILE
Pete has lived in London all his life and has been married to his wife Marsha for 44 years. Their only son died of cancer 11 years ago.

The couple both worked for Lambeth Council for over 20 years. They are relatively sociable, and consider themselves the surrogate grandparents to their neighbour’s children.

‘I don’t feel my age at the gym’.

‘If she goes first, I’ll go on a cruise and never get off it again.’

HEALTH CONDITIONS:
- Non-hodgkin lymphoma and myloma
- COPD
- Tinnitus

HEALTH TOUCHPOINTS:
- King's College Hospital: 2-4 appointments per year
- GP
- SELDOC
- Gracefield Gardens Drop-in Centre

WHAT DID WE LEARN FROM THIS STORY?
- Both Pete and Marsha exercise regularly at their local gym, having been inspired to go following a local diabetes management class
- They are both trying to keep it up, but are aware they may find barriers with attending as they age
Staff Case Study: Community Matron

PROFILE
Conducts in-home visits to help deliver care, and signpost to any relevant services. Some key skills listed on the National Careers Service website include:

- Carrying out physical examinations and treatments
- Referring patients to a specialist
- Managing the care and support patients receive
- Identifying patients who may be at risk of being admitted to hospital when they don’t need to be
- Managing services to make sure the focus of care is in the home and community for as long as possible
- Teaching patients, carers and relatives to spot changes that could lead to conditions getting worse
- Organising extra support, like home care or respite care
- Making sure policy guidelines and procedures are followed
- Maintaining patient records

What data could she help to collect?
- Information on patients’ general circumstances, e.g. accommodation, finances, ability to maintain their standard of living; carers
- Data on wellbeing- e.g. physical appearance & mood
- Any changes in circumstances

When does she interact with patients?
- During in-home visits
- When treating/ examining patients
- Talking to them about their care
- When signposting on to other services

What expertise can she offer?
- Reflections on appropriateness of care delivered
- Insight into what changes could most improve quality of life for the patient
Staff Case Study: Pharmacist

What expertise can he offer?
- Thorough understanding of medication taken and potential side-effects
- Alternative medications and treatments

What data could he help to collect?
- Prescribed medication
- Any reflections form patients on their medication
- Other measures of health and wellbeing – e.g. appearance, mood
- Details about ability to self-manage – e.g. noting if respondents repeat the same questions

When does he interact with patients?
- When they drop in to his pharmacist
- When they are picking up new prescriptions
- When they call up with inquiries about taking their medication

What key points did you take away from the training overall?
Large and varied holistic approach to someone's health and wellbeing

Q. What skills do you plan on using from this point on?
I think I will try an ask the patient what they would want to happen and what they want to achieve with their health rather than just me telling them what I want to happen.

Q. What skills are useful for your team?
Maybe more about listening and understanding patients aspect of their long term condition and how it affects their daily life.

Q. What skills are useful for your team?
Large and varied holistic approach to someone's health and wellbeing.
Most people relied on a **key trusted professional or family member**; over-reliance on one person could be detrimental in the long-term

- Most respondents had a good ongoing relationship with one professional (normally their GP) – who was something of a ‘go-to’ for a whole range of issues
- Most also had contacts within their wider social circle who could be powerful allies and support in maintaining health and wellbeing
- In some cases this was a family member or friend, on whom they heavily depended for support
- Whilst this was largely positive, it often meant that they lost some control over their own health
- The potential loss of these people, especially prevalent among a sample of older respondents, also highlights a risk to both parties left by bereavement or unexpected changes in circumstances
Trusted people: Patient stories

They know me

“For those for whom illness has become a part of their life, it is important they have a relationship with someone they can trust. This doesn’t have to be a GP – it can be a care worker, a volunteer, or another professional.”

“Weekly a GP are like this. He knows everything about me”
- George, Southwark

“My community psychiatric nurse was the only one I told about my suicidal thoughts.”
- Margie, Lambeth

The person at risk

“Within a couple, there is often someone that is currently the ‘stronger’ one and may be the sole carer of the two. There is a danger that if this person gets ill, or if the person they are caring for dies, they may slip under the radar and become at risk as the focus has not been on them.”

“I’ve been really depressed since my wife has been taken into care. I don’t know what to do with myself.”
- Derek, Lambeth

“I went on a course to do his dialysis so he can have it at home. I set it up every night”
- Harry, Lambeth

“Although I have COPD I can move about better than my wife. I have to help her a lot”
- Peter, Lambeth
Most people wanted to do more physical activity, but faced **barriers to this**, and most could do with some signposting or support

- Respondents were often enthusiastic about physical exercise, but struggled with various barriers to engagement (including: knowing what’s available locally, anxiety and worry about abilities, fear of judgement by other participants)
- Most recognised the benefits, both physically and mentally, and felt they needed more support or signposting to engage
Physical activity: Patient Stories

Jim, 74, Southwark

Jim was going to the gym and doing exercise but stopped (it was on prescription). He struggled as they were doing chair-based exercises, but the chairs were too small and they wouldn’t change them. He was going to go to Peckham to exercise, but he was too worried he would end up at the pub.

“Jim was going to the gym and doing exercise but stopped (it was on prescription). He struggled as they were doing chair-based exercises, but the chairs were too small and they wouldn’t change them. He was going to go to Peckham to exercise, but he was too worried he would end up at the pub.

“I tried to go to the gym but when I got there it was busy and they didn’t have anyone to help me” – Margie, Lambeth

Anand, 80, Lambeth

Anand took his exercising seriously, and felt it was an important source of emotional, as well as physical wellbeing. His routine was to run for 20 minutes each morning whilst being spotted by his son. Without his son’s support it is unlikely he would have done as much.

“My family set me up a gym in the garage. I exercise 3 times a week” – Pete, Lambeth
Some people were living in **unsuitable accommodation**, which was not something they thought of talking about with healthcare professionals.

- People with declining health also spoke of a decrease in everyday activities and tended to leave their home less often.
- Some were no longer doing activities that had previously been important to them.
- Most barriers to taking part in hobbies and socialising more generally related to mobility issues and their housing situation.
- For example, some respondents were living on a first or second floor, without a lift to get down to the ground floor. This had a significant impact on their growing tendency to stay at home.
Housing / mobility: Patient Stories

Getting out and about

Roisin was living on the 6th floor in a block of council flats with no lift. She walked with a stick and struggled to get out of the apartment if she needed to go shopping or for other errands. This is something that could become a serious issue as her health deteriorates.

‘Sometimes I have to stop 6 times on the way down the stairs’
- Roisin, Lambeth

On the way to the GP I caught the wrong bus - it took me hours to get home” - Margie, Lambeth

Patricia was living on the 3rd floor of a block of flats. It has become hard for her to go out, so she has stopped going to Church or even to the GP, as she is now telephoned. Her family bring her food over, and although it is easier for her, it means she never gets to see the outside world.

“I used to go to my GP but now they call me so I don’t have to go out”
- Patricia, Lambeth

“I try to make sure I leave the house once a day, otherwise it gets you down” — Marsha, Lambeth

“I have to get a bus everywhere and the stop is so far to walk. If I am caught in the rain I get soaked” – Phil, Southwark
Many respondents had a limited, and declining, **social network**, which often brought about loneliness and reduced wellbeing

- The majority of our respondents were socially isolated, and for many this was having a negative effect on their mental health
- This was often due to poor mobility and no longer being able to do the things they wanted
- Some were depending heavily on a limited social network in order to manage their health conditions.
- Most were seeing their social networks reduce, either through bereavement (especially for older people) or reduced mobility causing people to stay at home
Social network: Patient stories

Margie, 79, Lambeth

‘I used to talk to the neighbour, but nowadays the only person I talk to is my community nurse’

Understanding how a person’s social network functions can be crucial to understanding their health and wellbeing. Margie was experiencing suicidal thoughts and the only person she felt able to tell was her community psychiatric nurse. As an immigrant estranged from her family, she was especially vulnerable.

“I don’t trust the outside world any more – the only person I see is my son” – Tyrone, Southwark

Roisin, 74, Lambeth

“I tried to sign up to community activities - but they didn’t happen in the end”

Some respondents were really eager to take part in activities, but not sure where to look to find these, and unable to travel too far afield to get to them. Better signposting to local activities would boost the quality of life of many, who would have enjoyed the opportunity to take part.

“One neighbour comes to check on the dogs when I’m too ill to look after them – I couldn’t manage without her.” – Gavin, Southwark
Most respondents had **different health concerns** and priorities to the professionals supporting them

- Almost everyone had one of their 3+ conditions that worried them more than the others
- Often, this was not necessarily the one that professionals would assume or prioritise on the patients’ behalf. More often, they were embarrassing (IBS) or more difficult to manage on a daily basis (bad back)
- Being able to identify these concerns is key for gaining trust; as well as helping to deliver appropriate advice and support.
- Ethnographic insight can help to reveal what would have the biggest impact on the life of the individual
Health concerns: *Patient Stories*

*Janet, 65, Southwark*

‘If someone could help me find adult nappies I would be able to go out more’

Some conditions have a great impact on the quality of life of a respondent, even though they may not be considered to be medical priorities. In some cases there may be a relatively simple solution that could improve the overall wellbeing of a patient if these issues are identified.
The majority of respondents have a low level of **wellbeing**, and diagnosed mental health issues were prevalent

- Levels of poor wellbeing were not surprising given that many were isolated and extremely ill
- Wellbeing and overall happiness was often linked to small things that could be changed, as well as larger obstacles, such as ability to wash or leave the house for small periods of time
Wellbeing: Patient Stories

‘The thing you’ve stopped doing’

People had often stopped doing the thing they used to enjoy or that was important to them, and this was often the first of many things that began to stop in a person’s life. That one thing can often be a lifeline to the rest of the world so stopping it can be really damaging to a person’s wellbeing.

“I used to go to Keep Fit but my friend passed away, so I don’t go to that anymore” – Florence, Lambeth

“It was lovely for you to come round. I’ve really enjoyed it, as I didn’t have much on today” – Mary, Lambeth

“We found a lot of loneliness, and a need for human contact. Small interactions such as a smile, or a 2-hour visit every 2 weeks from a carer, can mean a lot and the long week can often stretch ahead when people barely see or talk to anyone else.

“When I came out of hospital I had a carer. We had such a good time, we laughed”

“I used to cook but I can’t really anymore as I can’t stand up for that long” – Phil, Southwark
Some had long-standing bad habits they were *unwilling to give up* when these were seen to improve quality of life in other ways

- Some respondents admitted to lying or exaggerating when talking to professionals about diet, smoking or drinking in order to sound more responsible
- Others had habits they would struggle to kick because they were part of an important bond with friends and family (e.g. a curry on a Friday night with a friend)
- Noting down any of these *consumption habits* could give an indication of any simple ways a patient could improve their health
- It could also enable HCPs to have an open discussion about *some indulgences* that patients feel improve their quality of life day to day, and for whom sacrificing would mean a reduction in quality of life
Health / diet: Patient Stories

Derek, 90, Lambeth

“My son taught me how to cook – before that I used to eat quite unhealthily”

Most respondents could do simple things to improve their diet – such as changing small habits. Some, however, had indulgences they weren’t prepared to give up, as these were considered ‘treats’ that made them feel better.

“Hiding or obscuring ‘bad habits’ such as drinking or smoking was common across the sample. James suffered from COPD and did not stop smoking until his doctor showed him an X-ray of his lung and he realised how badly he had damaged it.”

James, 66, Southwark

“I used to tell the doctor I didn’t smoke any more because I didn’t want to listen to another lecture”

“We eat well. Steak salads, and that kind of thing. Not too many carbs” - James, Lambeth

“We eat out 2 or 3 times a week. Pizza Express is our favourite. The cheesecake” – Peter, Southwark

“We buy meat from Waitrose – our neighbours make fun of us, but for some foods you should get the best” — Marsha, Lambeth
Some people had difficulties self-managing their care as they had trouble understanding and remembering advice from professionals.

- Understanding of conditions and care pathways was inconsistent across the sample, with some patients very clear on their circumstances and others with a much more limited understanding.
- Some relied heavily on family members and others in order to manage their condition and healthcare.
Barriers to understanding care: Patient Stories

Eralia, 86, Southwark

“I miss my home and I’m not sure what I’m doing in the care home”

Some respondents were too ill to make big decisions, and depended on family members or HCPs to look after them. For example, Eralia struggled to understand why she was living in a home, and could make only basic needs understood to HCPs.

Roisin, 74, Lambeth

“My brain doesn’t work as well as it did when I was 64”

Many respondents found that they were struggling to stay engaged and organised as they aged. Some found that they were increasingly forgetful, and tended to rely on family members to remind them about appointments and medication.

“I once took the wrong pills and ended up in hospital” – James, Southwark

“I find it hard to follow the TV programmes – I get distracted and my mind wanders” – Addisu, Lambeth

“You find when you get older you forget things” – Patience, Southwark

“Sometimes I go to cashpoint to take out money and walk off leaving the cash” – Addisu, Lambeth
There are a number of topics that could be on a care plan, however gaining valuable information can be a challenge…

- Across these categories, some of the information could be relatively straightforward to access – with simple questions within appointments
- Information that is more challenging often comes from: memory and recall, reporting bias & truthfulness, cognitive capacity, and ability to self-reflect on behaviour
- Some questions may be made difficult by the fact they are being asked by a health professional – at which point the relevance needs to be made clear

Examples include:
- **Wellbeing**: A simple answer may be someone saying they are fine, however someone may be hiding important information due to embarrassment or fear of causing a fuss
- **Physical activity**: People often overstate their level of physical activity, however deeper probing may uncover barriers that can be overcome to exercising
- **Health concerns**: If asked in an appropriate way, people may discuss the biggest concern or difficulty for them, that may not seem the most obvious condition
Drawing on our conversations with trainees, feedback from an online survey we set trainees after the training, and overall experience delivering training for similar projects, we can make the following recommendations.
Training process: Key findings

Key points

• The ‘hypothesis brainstorm’ worked well to warm participants up to the process and start to think about potential findings
• Learning about different styles of work was beneficial to attendees
• Sessions built rapport between the team, leading to more collaborative analysis and better findings
• Everyone was extremely enthusiastic and engaged

Watch-outs & opportunities

• Managing mixed levels of understanding and skills
• When rolling out, there must be a tight brief with a clear question to answer by the group
• More could be done to introduce people to sampling, as it is harder to balance a sample in real world settings
• Recruitment can be labour intensive
• Standardised project materials are an option
Training process: Key findings

Key points

• Saying things out loud really worked - we created a safe space to practice techniques
• Participants valued being introduced to key questions for the fieldwork

Watch-outs & opportunities

• Trainees were often nervous before doing fieldwork, so need reassurance beforehand
• Ethics and consent can be confusing and challenging landscape that caused anxiety
• Important to emphasize the journey and sense of progression (training and then engagement) to avoid feelings of being overwhelmed
## Key points

- Generally very good and proactive in taking part, especially the professionals
- Everyone really embraced the ethnographic method, noticing and gathering information other than quotes
- Those that did two interviews showed vast improvements
- Field notes were really detailed

## Watch-outs & opportunities

- DBS checks are a challenge (especially in a partnership environment)
- People struggled to listen to their senses in order to spot more hidden data e.g. smell
- Assumptions were often made about what people are comfortable with, e.g. photos
- Important that people are supported in being pushed from their comfort zone
- Good to build in opportunities for repetition & reflection
Training process: **Key findings**

**Key points**
- Everyone seemed to enjoy the chance to discuss their respondents to the team – sharing their general observations and not just key findings
- Team dynamics led to a safe space with critical and realistic discussion
- Professionals were often able to reflect on things they personally could change

**Watch-outs & opportunities**
- Some people dropped off towards end, so worth keeping that in mind
- Facilitating comparisons with other respondents is important for developing thinking
- Clear questions to begin with are key to ensure practical thinking and keep people on the right track – although diverging is, of course, important too
Training process: Key findings

Key points

• **Share with everyone** so everyone can see the results of their efforts

• This is a significant factor when thinking about sustainability – trainees will be able to see which data was most useful and **learn and develop skills for next time**

• Important to feed in input from the **whole team** to ensure all of the stories and data are reflected

**Watch-outs & opportunities**

• Opportunities for local volunteers and staff to **present findings** back to their organisation in order to take ownership of findings and the dissemination process

• **Divide up reporting** duties in order to ensure that everyone gets to contribute their story and observations

• Opportunities for **feedback on final draft** in order to take amendments from wider team
Thinking about future sustainability

Training objectives for a sustainable project:

In order to ensure that stories are embedded and that the approach can be replicated on an ongoing basis

• Ensuring stories are focused around a relevant and tight brief – with a clear question that needs answering

• Ensuring engagement captures stories and lived experiences from a wide range of residents / patients – going out to target those who are relatively ‘hard to reach’ in order to capture new perspectives

• Efficient processes for collecting stories in ‘real life’ – rather than clinical / professional environments

• Ongoing training and feedback to ensure staff and local volunteers develop and learn and can support others – such as ‘test and learn’ style phase going forward

• Stories and deliverables that inspire action and drive change – keeping up momentum and preventing it from being tokenistic exercise
Sustainable Briefing: Things to consider

Key things to consider:

• Ensuring each piece of engagement work has a **core ambition**, focused around a tight brief and a key question

• Creating a **team environment** in order to generate a ‘safe space’ for sharing ideas and inspiring next steps

• Team members will benefit from the **chance to practice** beforehand in order to learn skills and mitigate potential stress of fieldwork

Opportunity

• Collaborative session with engagement staff to brainstorm hypotheses and engagement objectives in order to develop a **strong engagement brief**

• Creating a ‘**safe space**’ where engagement team can discuss concerns and worries before going into the field

• Opportunities to **practice key skills** with wider team

• **Group activities** create team rapport and allow a place to share thoughts and ideas moving forward
Sustainable Recruitment: **Things to consider**

**Key things to consider:**

- Important that future recruitment designs a cost effective process that captures a **wide range of residents** in different circumstances.

- Finding efficient ways for residents to **opt in / out** of taking part in story collection – to ensure there’s an ongoing stream of potential people to speak too.

- Ensuring everyone who wants to participate is **screened and spoken to** so that they can be assessed for any wellbeing concerns and to ensure they are a useful voice for the project.

- Caveating **total number** of respondents required in case more people respond than the project team are able to interview.

**Opportunities:**

- Designing a system for capturing people easily, for example an **opt out** process, or a built-in option when booking an appointment for taking part in engagement.

- Potentially an electronic system (link from GP website) where people can sign up.

- Posters in GP surgeries and community centres which explain engagement, and what taking part will mean, as well as providing contact details.

- Clearly wording engagement materials so respondents are aware the project team might not have capacity to talk to everyone.
Sustainable Fieldwork: Things to consider

**Key things to consider:**

- Scheduling is hard and time-intensive: there must be a designated person to take control of sharing the insights and managing / organising the process

- Finding a way for engagement teams and/or volunteers to speak to people in a range of different ‘real life’ environments, not restricted to ‘health settings’

- The changing DBS landscape can make securing clearance a difficult and lengthy process

- Safety is an issue for in-home visits - going in pairs with a check-in process is a good way of getting around this

**Opportunities:**

- Having a standardised format for interviews and template for note-taking will ensure that information is collected as consistently as possible

- Developing the process over time – building in opportunities for feedback and learning in order to improve the process iteratively

- Making use of community members with prior engagement skills could work well for this more sensitive kind of engagement
Sustainable Fieldwork: *Staff + Local Volunteers*

Whilst there is benefit to training up either staff or local volunteers, it may be that training staff is more likely to achieve the project objectives. We recognise that much thinking has been done on these issues, but outline a few points relating specifically to this project below.

<table>
<thead>
<tr>
<th>STAFF</th>
<th>LOCAL VOLUNTEERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likely to have a better <em>working knowledge of the system</em> so better able to spot areas for improvement. They will be <em>more likely to engage with findings</em> if they observed similar things themselves</td>
<td>Would need to be <em>trained with enough knowledge of the system</em> in order to understand provision</td>
</tr>
<tr>
<td><strong>More accountable</strong> as interviews can slot into and inform their normal workload</td>
<td>Would require <em>management investment</em> to marshal local volunteers, and standardise outputs</td>
</tr>
<tr>
<td>However, likely to have <em>busy schedules</em> and have less time to conduct and process fieldwork</td>
<td>Likely to have <em>more free time</em>, so better able to devote time to interviews and analysis</td>
</tr>
</tbody>
</table>
Sustainable delivery of findings: Things to consider

**Key things to consider:**

- Important to allow for **analysis time** for engagement teams to reflect on the stories and pull out the key themes / insights

- Feeding the stories back into the system is as important as collecting them. Need processes to ensure **information gets to the right people**

- Engagement teams need **to see action / change** as a result of their work – otherwise momentum will be lost

- Opportunities to **make the most of existing networks** in order to disseminate findings

**Opportunities:**

- **Collaborative analysis sessions** to bring together people with different levels of experience and expertise, to ensure knowledge transfer

- **Workshops** with key stakeholders to ensure findings are disseminated and to allow for ongoing input

- **Toolkit style** format for deliverables to create an accessible resource which can be re-used and adapted to suit the needs of multiple events and stakeholders

- Trainees could take opportunities to **present** back findings, to take an active role in results dissemination
Training process: **Key takeaways**

- It is not cheap to visit people’s houses, but extremely valuable in understanding the factors influencing their health and ability to cope.

- Engagement teams are eager to share their findings and find a way to help – if they can’t see the impact of their work, momentum and interest will drop.

- When delivering training to a range of teams, allowing time for practice and feedback can build confidence as well as skills.
Thank you

Written by George Lamb, Anna Waldie & Jenny Holland
## Appendix 1: Engagement trainees

### Southwark Staff
- Ambrose Omoma
- Erin Mee
- Aarti Gandesha
- Chithmini de Silva
- Catherine Negus
- Rosemary Watts

### Southwark Volunteers
- Rozi Premji
- Liz Day
- Helen Ogunmwya

### Lambeth Volunteers
- Natasha Blackstock

### Lambeth Staff
- Kar Man Chung
- Kate Damiral
- Anna Katirai-Jones

### King’s College Hospital
- Lucy Hamer
- Silvia Scalabrini

### Guy’s and St Thomas’
- Julie Vazquez
- Deidre Cornish-Brown

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**Southwark Council**

**Age UK Southwark**

**Healthwatch Southwark**

**Healthwatch Southwark**

**Healthwatch Southwark**

**Healthwatch Southwark CCG**

**Lambeth LCN Pharmacist**

**Healthwatch Lambeth**

**Healthwatch Lambeth**

**Engagement and Experience Manager**

**Engagement and Experience Manager**

**Adult Local Services Project Manager**

**Community Matron**

**Healthwatch Southwark**

**Healthwatch Southwark**

**Southwark PPG**

**Lambeth citizen / Healthwatch volunteer**
Appendix 2: Recruitment

All participants went through multiple levels of consent to ensure they were happy to take part, and could drop out at any point

- GP practices across the boroughs identified patients with three or more long term conditions

- Practices and/or GP federations sent a letter to the patients that they identified, which was produced by engagement leads and Healthwatch, in jargon-free English, asking if they would like to get involved

- Each person who replied was phoned to confirm their consent to take part, and again by Revealing Reality to check consent, introduce themselves and schedule an interview

- Recruitment and scheduling was a challenging and lengthy process, although respondents were put at ease and it provided an opportunity to answer many up-front concerns
Appendix 3: Fieldwork

All interviews followed a similar format, although they were kept flexible and open-ended, to allow for respondent variation and sensitivity. In general, the engagement team conducted the following:

- 2 hour structured, open-ended interview, across the key themes
- Tour of respondents’ home to learn more about them, where appropriate
- Asked to see respondent’s medicine or medical-related aids and adaptations
- Took photos where appropriate
- Spoke to family members where possible
Appendix 4: *Sharing of findings*

We believe that sharing the findings are just as important as the engagement itself—most notably to ensure that the recommendations are accessible to those professionals who can drive change. For this reason, the next steps for this project are as follows:

- Visual PowerPoint report – designed to be easier to digest and understand than a lengthy document
- Patient stories from Southwark & Lambeth
- High quality photography for use at events
- Presentation to LCN Board(s) / Programme Board
Appendix 5: Developing the care plan
Key thoughts on care planning:

- Most people were looking for all the different support they accessed to come together – especially those needing social support. This could be a way of helping them to self-manage their condition.

- A named professional could be included on a care plan – perhaps a social support worker.

- It is a challenging data-management task, so important to think about how information is collected e.g. key questions & topics.

- Also important to make it shareable – and ‘skimmable’ by busy professionals and patients themselves – e.g. highlighting 3 key pieces information at the top.
Everyone we spoke to would gain a lot from a care plan, but it remains a challenging data-management task

• Every respondent could have benefitted from better integration between health and social care as well as support to help them self-manage their health
• A care plan could prove to be a useful document for keeping track of health needs and changes – and empowering patients to take control
• In order to make it a useful document for staff, data needs to be stored and shared in a systematic way
• Some data will be harder to collect, depending on the type of information and the amount of time staff have to collect it

So this is an area full of opportunity – there is so much that can be done to support clinical staff to feel more confident collaborating with their colleagues in social care and empowering self-management among patients
Where our findings & recommendations come from

• Patient stories
• Things patients have told us
• Our analysis with trainees

• Our analysis of what patients told us
• Previous knowledge (us + trainees) of health and care organisations
• Our knowledge of data collection challenges

• Our analysis of what patients told us
• Previous knowledge (us + trainees) of health and care organisations
• Previous knowledge/experience of sharing / managing data
There are 3 factors to consider when developing the care plan

What should be on it: People can struggle to articulate their priorities, so it is important to consider how questions are framed and information is gathered – exploring around different topics is one way to get around this and allows for links to be drawn between seemingly unrelated issues.

How to collect it: This leads to an opportunity to change how people are asked questions, as a change could lead to the discovery of barriers to engagement with better health or wellbeing. Ethnographic methods can be useful here, for example triangulating data or identifying visual clues that health and wellbeing may be poor.

How to share it: Professionals often saw respondents through the lens of their conditions, and assumptions were made about their priority illness, when the reality was often that their priority lay elsewhere. Better questions and clear identification of these priorities on a care plan will help professionals to share what is most important.
What should be on it?

- Finding out what is important to residents and uncovering useful information could be done in a number of ways. Asking outright could have a number of challenges (see ‘how to collect it’ section)

- Asking questions around themes would allow professionals to work out what is important to people by exploring different parts of their lives – and prompts patient’s memory in the moment

- Whilst the care plan could include many themes, we recognise the importance of prioritising a selection. We outline our recommendations for priority themes in the following pages

- Understanding future goals of patients to help understand how their health and wellbeing can be maintained despite challenges
Through our conversations with patients, experience delivering training to the engagement team, internal analysis of the data, and previous experience in collecting and managing data for similar projects across the public sector, we can make the following recommendations for collecting the data for the care plan.
How to collect it? Challenges & opportunities

How to pitch the questions

Asking an ‘obvious’ question might not get professionals the answers they expect or need. Often patients will need some prompts or support to provide useful information and recall relevant details.

Opportunity
Is it possible to design in a more structured approach to unlocking information for the care plan?
Could you speak to patients around themes / topics, rather than leaving it completely open to interpretation?
Pressure to do it all

If there are too many parts to a care plan (e.g. topics / themes), professionals could feel pressure to capture all the data in one appointment, when time is already pressured.

Opportunity
Could there be an option for some patients to ‘self-complete’ (e.g. filling in part of the care plan at home)?
Could each professional be asked to fill in just one question each over time?
How to collect it? Challenges & opportunities

Using ethnographic techniques

Sometimes it is difficult to get to the heart of the issue through conversation alone, especially with limited time.

Opportunity
Could professionals make notes about people’s appearance and hypotheses driven by this data? Could they ask people to bring information / evidence / artefacts to appointments to shed light on their life? What opportunities are there for non-clinical staff to complete?
How to collect it? Challenges & opportunities

Monitoring change & progress

Making sure the document is ‘dynamic’ and can be updated over time – reflecting changing needs – will be important but difficult.

Opportunity
Could professionals put in regular review points (e.g. annual)?
Could updates tie in with reviews / check ups of health conditions?
Could the system ‘flag’ when something needs to be updated or refreshed?
Through our conversations with respondents, experience training the engagement team, internal analysis of the data, and previous experience in collecting and managing data for similar projects across the public sector, we can make the following recommendations for sharing the care plan.
How to share it? Challenges & opportunities

Knowing what to prioritise

Care plans will likely contain a large amount of data. Some of that data will be vital to pass onto other organisations or professionals, and there is a chance it is not identified or overlooked.
Prioritising the most important data should help professionals engage with key information at appointments

• From all of these themes, it is important to identify **2-3 key factors** that have a big impact on the health and wellbeing of patients, and highlight these clearly at the **top of the care plan**

• This way, any professional can quickly identify what is important to the patient
Prioritising important data: Patient stories

“My IBS is the most embarrassing. I can’t go out” – Janet, Southwark

“I will never go into a care home – they are far too happy clappy.” – Pete, Lambeth

“My dogs are what get me up in the morning – if it wasn’t for them I’m not sure I’d still be here” – Gavin, Southwark

“I can’t clean my windows anymore and I don’t like that” – Ivan, Southwark

“I love my garden – it is so important for me to watch things grow.” – Anand, Lambeth

“My carer even washes my curtains and puts them back up how like them” – Albert, Southwark
How to share it? Challenges & opportunities

Knowing how to act

Care plans could present a whole range of opportunities for better supporting a patient with health or social care concerns. It might be challenging for professionals to know who might be able to help and in what ways.

Opportunity

Could care plans have clear action plans included?
Could the system incorporate notifications for action?
Data management is crucial to ensure the information is up-to-date, coherent and ultimately useful for the patient and professionals.

**Opportunity**

How can IT help share information between professionals? (And collect data)
How possible is it to ensure all staff have access to the necessary information?
What data sharing protocols are needed in relation to consent?
Sharing with patients

Sharing the care plan with the patient would mostly beneficial to everyone – and could help them feel empowered to take action on their condition. However, it could include uncomfortable truths and would need careful consideration to ensure it’s understandable.

Opportunity
Could there be a ‘private’ area for professionals to store notes that are less appropriate for patients?
How to share it? Opportunities

Warm referrals
Care plan can be used as a ‘central database’ for patients, which will mean that professionals can pass information easily. This will create a way of encouraging warm referrals between organisations.

Identifying important things
Identifying top 3 most important things about a patient, and placing at the top of the plan will allow professionals to be able to easily share and understand more about a patient’s needs.

Sharing with patients
On an online care plan, there is an opportunity to select certain items that should be visible only to professionals, as a flag for a risk or that action may need to be taken.

Digital sharing
Storing the information digitally can allow for search and re-organisation of information as is most useful & convenient for different HCPs. It can also allow information to be quickly and regularly updated.