Improving dementia services in Southwark - engagement results 2015 16

NHS Southwark Clinical Commissioning Group
Summary of engagement methodology

1. Survey
2. Semi-structured interviews
3. In-depth case studies
4. Patient journey mapping
5. Community asset mapping
6. Persona of Sam
7. Focus groups
8. Tea Party
In total 63+ surveys were collected from various sources:

- 29% people with dementia
- 47% from carer/family/next of kin
- 24% from General Practice (64% GP, 26% practice nurse, 10% practice manager)

A high proportion (67%) of respondents found it useful receiving a diagnosis.
More than 60% of respondents want access to more:

- Information and advice about dementia
- Befriending services
- Dementia training and awareness raising
- Financial support
Survey (Q2 2015/16)

Average weighting for national dementia ‘I’ statements was consistently low at under 3 (5=agree strongly)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I have personal choice and control or influence over decisions about me’</td>
<td></td>
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<tr>
<td>‘I know that services are designed around me and my needs’</td>
<td></td>
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<tr>
<td>‘I have support that helps me live my life’</td>
<td></td>
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<tr>
<td>‘I have the knowledge and know-how to get what I need’</td>
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<tr>
<td>‘I live in an enabling and supportive environment where I feel valued and understood’</td>
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<tr>
<td>‘I have a sense of belonging and of being a valued part of family, community and civic life’</td>
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<tr>
<td>‘I know there is research going on which delivers a better life for me now and hope for the future’</td>
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### Survey (Q2 2015/16) demographics

#### Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - British</td>
<td>50%</td>
</tr>
<tr>
<td>Black or Black British – Caribbean</td>
<td>37.5%</td>
</tr>
<tr>
<td>Black or Black British - Black British</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

#### Marital status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Single</td>
<td>50%</td>
</tr>
<tr>
<td>Living alone</td>
<td>0%</td>
</tr>
<tr>
<td>Separated</td>
<td>12.5%</td>
</tr>
<tr>
<td>Widowed</td>
<td>25%</td>
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</table>

#### Sex

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>25%</td>
</tr>
<tr>
<td>Female</td>
<td>75%</td>
</tr>
</tbody>
</table>

#### Age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>19-64</td>
<td>12.5%</td>
</tr>
<tr>
<td>65-84</td>
<td>62.5%</td>
</tr>
<tr>
<td>85+</td>
<td>25%</td>
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</tbody>
</table>
Survey (Q2 2015/16)

- 91% of practice staff knew how to refer patients to the memory service
- 36% of practice staff did not feel confident in referring patients to dementia support services
- 73% of practice staff felt they did not know what services are available to people with dementia and their carers in Southwark

0% of practice staff refer patients to the Alzheimer’s Society

45% did not feel confident that such support services are available
The biggest barrier to providing good quality dementia care was due to a perceived ‘medical model with no social care support’ – 80%
Survey (Q2 2015/16)

- 70% of practice staff did not know that all patients diagnosed with dementia in Southwark are referred to the Alzheimer’s Society for support

- 64% of practice staff were not aware that Southwark recently commissioned a Dementia Nurse Specialist in Primary Care

- 50% of practice staff would be interested in delivering a dementia pilot in their practice and 50% responded ‘maybe’
Training requirements:

- How to make a diagnosis in primary care
- How to refer to the memory service
- Information on advice and signposting to support services
- How the pathway will be improved
- How to become a Dementia Friendly Practice
- How to become a member of the Southwark Dementia Action Alliance (DAA)
‘More education ... utilise ICM role/Better Care Fund - don’t waste time and effort - shared info and planning... utilise care managers more in primary care... a lot of duplication happening and patients still don’t get what they need e.g. TeleCare/daily living support’

‘there are gaps in trying to create meaningful care packages especially with personal budgets for people with dementia’

‘...more openness and more dialogue - help with making life easier instead of trying to resolve and diagnose’
Semi structured interviews

Key themes:

1. Acute
2. Care Homes
3. Care at home and in the community
4. Support for carers
5. Personalisation
6. Issues facing all older people
7. Culture around receiving support
8. Living Well

‘I don’t want social services interfering in my life.’

‘Carers are losing their lives to caring. They need some me time; otherwise they are going to lose themselves.’

‘Where’s the community vibe gone? ...where is everyone? ...people don’t care.’

‘The challenge of change becomes more real as you get older. You don’t recognise yourself as an older person, you think, oh goodness, I’m elderly. But having a bike helps!’

‘We need to be encouraging people to access services as it isn’t charity, it is something that people are eligible to utilise because they have worked hard all their lives and contributed, now it’s time for them to have their support.’

‘Communities are not as they were... and people don’t want to get involved... it’s very sad.’

You can see it running through her mind as she’s thinking, ‘what’s happening to me?’
In-depth case study

Isobel witnessed the onset of dementia symptoms of a neighbour, Mrs Davies living in Dulwich - the lady’s daughter lives abroad and so was limited in the level of support she could provide.

‘She would wake in the middle of the night in a confused state and would call 999, despite having a care package in place. On one occasion, the carer turned up and she wasn’t at home; she had gone to A&E. The hospital had no records of her condition and no collateral history. Mrs Davies was in a very confused state. Luckily I was able to provide the hospital with the background of her dementia symptoms.’

‘On other occasions, I recall Mrs Davies had a small fire in her home as she left her radio in her oven... she once fell at home unbeknown to me or the family. Her newsagent actually called her and they called me to check on her.’

(Isobel, aged 70, lives in East Dulwich, retired part-time volunteer at a residential care home in Southwark - carer, advocate and neighbour)
The dementia pathway
Mary’s dementia journey

Onset of symptoms
‘With Mary, it came on really quickly in 2012 and in the last 3 months it’s been progressing quite quickly and we’re not sure really what to do. She doesn’t know what dementia is, we never told her.’

Diagnosis
‘We went to the Maudsley twice and she was on a drug trial but this stopped because she had a viral problem. In between appointments they would review and say there hasn’t been much change in brain activity but behaviourally, we noticed a lot of change/deterioration.’

Care at home
‘She has a carer to come and help her to prepare a meal between 5pm and 6pm. She repeatedly asks ‘are we going home’ and I have to tell her that we are home. She wears a panic alarm system around her neck.’

Respite and day care
‘On Wednesdays and Thursdays 10-4pm Violet attends Stones End Day Centre. She did used to go on a council funded coach holiday each year but she stopped going because she was so confused when she got home that it took her a while to get back to normal and she couldn’t cope with the change.’

The Future for Mary
‘I’m thinking what the next stage is... I mean I get 30 calls every evening, ‘it’s only Mary.’ She doesn’t want anything. So I don’t know where we go from here. I’m thinking the next stage is that she’ll be calmer, more withdrawn and not be able to do anything.’

The outcome for Mary
‘I waited 10 weeks for day centre respite and it is now too late as Mary has now had to go into a care home which is something she said she didn’t want. I feel like our situation was not taken seriously or treated as a matter of urgency. Edith ended up crying on the phone to social services and still, nothing happened.’
Community asset mapping and personas

- Alzheimer’s Society dementia café and carers group/peer support
- Blackfriars Settlement (befriending)
- Memory Clinics
- Stone’s End Day Centre
- Age UK
- Link Age Southwark
- Dementia Action Alliance
- Forget me not group

‘She gets jealous’

‘Transport is difficult to access’

‘I feel as if I’m betraying him’

‘For those who need it, there should be more options’

‘How does Sam access the outside world?’
Tea party

‘The ‘I’ statements do resonate with me but they aren't worded in a way that I would like in terms of how I experienced the system.’
(Dementia carer, 65)

Key themes: benefits of diagnosis, stigma, workforce development, co-morbidities

‘It must cost a lot of money to get diagnosed…that money would be better spent on getting people the help and advice they need’
(Ex-carer aged 55)

‘There is stigma within the closer family and within the service itself. People can’t even say the ‘D’ word to people with dementia for fear of upsetting us. We need people to talk about it and not feel so scared about saying it.’
(Person with dementia, aged 76)
Tea party

‘Mindful narrative with integrity… their life is in your hands… too much compartmentalisation and turbulence.’ (Carer)

‘There is nobody to help me understand why I feel this way.’ (Person living with dementia)

‘The worst thing is that staff don’t get to know their patients so they really didn’t understand him… so if I could change anything, it would be that.’

(Carer to husband with dementia, aged 90)

‘What about alcoholism and depression and the impact that has on dementia… my mum was an inpatient at SLaM for 6 months. Dementia might not be the primary diagnosis or concern’.

(Son and carer of person with dementia in Southwark)

‘We need to make the advantages of diagnosis clearer, not only to professionals but to the community’

(Voluntary sector professional)

‘Doors don’t necessarily open’

(Person with dementia 76)
Key Themes

What patients and carers want:
- Receive a timely diagnosis, delivered in a sensitive way
- Feel listened to and able to make decisions about their own care needs
- Feel valued and understood
- Supported to live well
- Know that everything will be taken care of
- Know that loved ones will be supported

What do professionals want:
- Information and advice / training / awareness raising
- Clarity over the right pathway
- To understand the benefits of diagnosis
- Understand what support is available

1. Understanding dementia in the context of the whole person
2. Receiving care at home
3. Opportunities to participate in the community
4. Living well throughout life course
5. Improved acute care
6. Improved care home provision
7. Increased support for carers
8. Deliver personalised care
9. Challenge the culture around receiving support
10. Tackle issues facing all older people
Integrated Pathway Workshop
5 November 2015

Solutions:

- Develop central community hub linked to specialist OA/Dementia hub
- Develop integrated IT systems across organisations
- Encourage Southwark business to incentivise staff to contribute to community (develop more corporate social responsibility)
- Reduce thresholds for support services
- Encourage career paths for care assistants
- Commission admiral nurses within Southwark for carers support
- Apply living wage for care staff
- Commission more carer support
- Emphasise importance of ‘humanistic’ care
- Commission more dementia advisers to provide on-going support
- Implement dementia primary care service
- Extend provision of care navigation services
- Develop Extra care and sheltered housing provision
- Loosening of eligibility criteria
- Expert patient & care programme
- Provide tailored training for care staff & professionals
- Provide formal/structured support for carers
- Promote healthy lifestyles
- Produce a local offer/dementia services in Southwark hand-out/guide
- Mobilise our community assets & tap into new money coming into Southwark
- Allocate support at the point of diagnosis
- Improve pathway for discharged patients to get rapid access back into memory/SLAM services
- Set a performance indicator from referral to diagnosis
- Develop one care plan for older people that is shared across organisations
- Commission more weekend opportunities
- Integrate commissioning budgets