



SOUTHWARK & LAMBETH
INTEGRATED CARE

Southwark and Lambeth Integrated Care - Citizens' Forum

Thursday 4 February 2016, 6.30pm – 9.00pm

Shepherd Hall, South Wing, St Thomas' Hospital, London

The Citizens' Forum has been set up to provide updates on the work undertaken by Southwark & Lambeth Integrated Care, to get people and communities fully involved in how integrated care develops in Southwark and Lambeth and to ask people for their views on specific aspects of the work.

More information

We welcome your involvement in the development of integrated care in Southwark and Lambeth. If you want to bring your skills, knowledge and experience to help design the new services, or if you have things that you want to tell us about that are important to you, please do let us know.

Contact:

Engagement Team

Southwark and Lambeth Integrated Care

Tel: 020 7188 7188 ext 55290

Email: info@slicare.org

Website: www.slicare.org

Address: 200 Great Dover Street, London SE1 4YB

Twitter: [@slicareorg](https://twitter.com/slicareorg)

Southwark and Lambeth Integrated Care - Citizens' Forum

These are the notes from the 10th Southwark and Lambeth Integrated Care Citizens' Forum, held on Thursday 4th February 2016, at Shepherd Hall, St Thomas' Hospital. Over 90 people attended.

Southwark and Lambeth Integrated Care is the partnership that brings the health and social care organisations and citizens of Southwark and Lambeth together to improve care for local people, so they can lead healthier and happier lives. Our partners include Southwark Council, Lambeth Council, Southwark Clinical Commissioning Group, Lambeth Clinical Commissioning Group, GPs, King's College Hospital NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust, South London and Maudsley NHS Foundation Trust, voluntary organisations, citizens and communities.

Welcome and introductions

Nicola Kingston (Citizens' Board Chair) welcomed everyone and introduced **Jonty Heaversedge** (GP and Chair, Southwark Clinical Commissioning Group, and co-chair of Southwark and Lambeth Integrated Care), who would be speaking this evening.

Nicola gave feedback from the previous Citizens' Forum saying that the discussions around the pledge had been really fruitful and that more work would be done to develop this and to ensure the opinions of the less heard voices were included. She described this evening as a momentous occasion as it was the last Citizens' Forum, as part of Southwark and Lambeth Integrated Care. She said that there will continue to be citizens involved, and further public meetings, and explained that what comes next will be designed together.

Jonty Heaversedge presentation

Jonty started by saying that there was a fantastic group of people in the room. We have some significant challenges ahead. There is some fantastic world class care locally but there is also recognition of the financial pressures and the need to get best value. But we'd still want to do things radically without this imperative. We need to ensure people receiving care have a seamless service. A huge amount has been done to help frail independent people stay independent at home. Locally, emergency admissions have plateaued, whereas across London they have increased.

He said that one of our local GP surgeries now has access for the first time to acute care records with the introduction of Local Care Records. This will now be extending across other GPs in the two boroughs. This work has happened because we work collaboratively for the benefit of the population.

We have to incorporate all of that learning into our day jobs as commissioners and providers and make sure we are pulling in the same direction. We have created a Strategic Partnership to ensure we make a

commitment to bring about the changes needed. We need to make that commitment tangible to one another and to citizens. There are things we could do together that would improve the quality of care people receive. This includes Local Care Networks to bring care together around the populations they serve and link up information around patients with Local Care Records. We also need to be thinking about our workforce and also those people who support and care for individuals, and the voluntary and community sector. The process of developing a pledge will be in close collaboration with our citizens. The importance of parity of esteem between physical and mental health will be important especially as those experiencing the latter often have the poorest outcomes. We have asked Local Care Networks to focus on people with multiple Long Term Conditions; and we have to start thinking about our population, not just the services we deliver, to help us focus on inequalities.

Jonty's slides are on the following pages.



NHS
Southwark
Clinical Commissioning Group

Citizens' Forum

Southwark and Lambeth Strategic Partnership

The best possible health outcomes for Southwark people



NHS
Southwark
Clinical Commissioning Group

Vision- new Strategic Partnership

Southwark and Lambeth Integrated Care will end in March 2016
The decision has been taken to create a Strategic Partnership

Vision

- To increase the value of care for the people of Lambeth and Southwark

Objectives

- **improve health and wellbeing** through effective prevention at all stages of life,
- **enable individuals, families and communities** to be well, and to enable people to manage their health, both mental and physical, and link with other services - employment, housing and financial advice;
- **significantly improve people's experience of care** and ensure quality, reflecting the diversity of different groups to ensure fair access; and
- **live within resources available**

How can we achieve this

- Southwark and Lambeth Strategic Partnership Board will
 - Have an independent chair
 - Meet in public after a development phase
 - Choose key issues to work on together- our key area is to develop Local Care Networks
- To do this effectively we need to
 - Ensure organisations are all committed to working together
 - Work to provide person centred care
 - Align contracts and funding
 - Improve information sharing
 - Develop the workforce - paid and unpaid



Southwark and Lambeth Strategic Partnership Board

Working in Local Care Networks

We heard you say we must work better with you to maximise our workforce - paid and unpaid. We will be working with you on this

We heard what you said about the Pledge and I will be working through your views with the Citizens' Board

We also heard that we must ensure we have parity of esteem for mental and physical health

We know we must also ensure we address the inequalities in our different areas

We must use partnership forums, open meetings, social media, and more ...

- The role of citizens will be crucial
- Let's work together!



Nicola Kingston Presentation

Nicola then talked through the following slides and explained the continuation of the role of the Citizen in the new strategic partnership.

Developing a citizens' movement

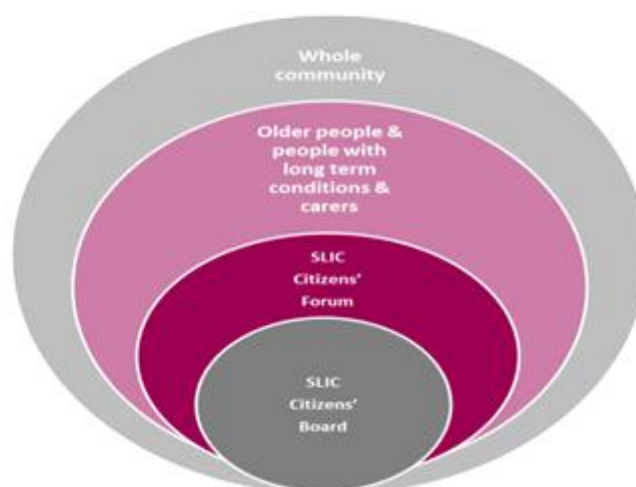
Nicola Kingston

Southwark and Lambeth Integrated Care

Citizens' Board

4 February 2016

Current citizen engagement in integrated care



Citizens' Board

- Made up currently of 19 people from Southwark and Lambeth
- Includes Healthwatch Lambeth and Healthwatch Southwark
- Includes co-opted CCG Lay Member
- Meet monthly as a Board with presentations and discussion
- Members attend all Integrated Care Board meetings and working groups
- Report to each monthly Sponsor Board meeting
- Agree key messages and statements
- Ensure that the voice of citizens is heard at meetings

Citizens' Forum

- Quarterly public meeting
- Usually 80-100 people attend
- Regular attendees, plus new ones
- Range of attendees - citizens, voluntary & community sector, statutory sector
- Ethnicity probably mirrors population
- Age is usually older
- Good mix of men and women
- Evaluation is positive
- Mix of workshops and presentations – on topics including workforce, local care records, systems leadership, service development including hospital discharge, falls, nutrition, care at home, and more ...

Citizen engagement

- Citizens involved in different aspects of service development
- Some describing their experience
- Others being members of the working groups to develop more integrated services
- Taking a lead to put workforce on the table
- Developing a 'passport' for people who use catheters
- Interviews and workshops with people who use exercise classes to help prevent falls
- Interviews with people discharged from hospital
- Workshops & outreach to develop "I statements" to underpin outcomes commissioning
- And much more ...

Greater citizen involvement in future Citizens' Board view

- Greater accountability needed to address democratic deficit
- Greater levels of involvement and engagement and voluntary & community sector throughout programme
- Sponsor Board meetings should be held in public
- Need to have a clear published overall project plan and budget
- Need each partner to be bound together
- Need to have a public pledge to work for all

- Aim of integration must be to produce improved patient experience and clinical outcomes and greater value for money
- Integration must be person centred and place based
- Citizens must be seen as equal partners
- Integration must work for whole population NOT for institutions

Developing a citizens' movement – initial ideas



Citizens' movement – initial ideas (1)

Citizen leaders' council

- Made up of people who are active in the health and social care system – including councillors, CCG lay members, Trust governors, Healthwatch, PPG Networks
- Will have two seats on the Strategic Partnership Board
- Role in governance and accountability

Strategic Partnership Assembly

- Open public meeting for people to hear what is happening
- Influence decisions
- Do-ers, active in communities, making things happen

Our challenges and opportunities tonight

Challenges

- Challenge - to think differently
- Challenge - for **all** citizens to work together
- Challenge - for citizens and partner organisations to work together as equals

Opportunities

- Opportunity - to develop a strong citizens' movement
- Opportunity – to create a strong new strategic partnership
- Opportunity - to improve health and social care for people in Southwark and Lambeth

Recommendation for a model for a citizens' movement to Sponsor Board on 25 February – discussions tonight will influence that.

If you want to go fast, go alone. If you want to go far, go together.

Questions and Answer Panel

Nicola asked the members of the panel to introduce themselves :

Adrian McLachlan, GP and Chair, Lambeth Clinical Commissioning Group: “We are now live in one practice with Local Care Records. It works. It will be rolling out really fast. It is important for safety and for quality”

David Quirke-Thornton, Strategic Director, Southwark Council: “We are on the cusp of significant change. There is more work to be done with citizens. It is no small feat that the partners have come together”

Therese Fletcher, Managing Director, Lambeth GP Federations: “The GP Federations have a seat at the table of the new Strategic Partnership and are active members of the Local Care Networks”

Elizabeth Rylance-Watson, Citizens' Board: “We are at a critical and wonderful moment. There needs to be a commitment to the workforce both paid and unpaid. We need to work together”

Questions & Answers

Q: They told us we'd be cut out of Supported Housing without giving us any information

A: Supporting People ended in 2010. We are making changes. We're working with Family Mosaic to make sure people with Learning Disabilities get that support. Vulnerable people who need our support will have it.

Q: With all of the cuts we still need to maintain a positive approach. We need to carry on and be very supportive. We want both boroughs to be aware of deaf people's needs and Southwark and Lambeth working together with a united approach so that we can improve services for everybody. We know about Lambeth but what is going to happen with the deaf community in Southwark?

A: We can put you in touch with the PPG network who can give you more information.

Q: Cuts are coming from government not the councils. There are lots of good ideas in the plans for the Strategic Partnership but all those phrases were used twenty years ago with Community Health Councils. I don't believe we can provide better quality with fewer resources.

A: If we did it separately it would be even worse than if we do it together. When we do we make decisions and spend money in a way that makes sense and produces better results. What money we do have we can spend better for the outcomes we all want.

Q: Why are you closing care homes? Are you caring for people at home? The way some of these carers treat elderly people they are not looking after them or giving them the care they deserve.

A: We need to make sure vulnerable people get dignity of care. We have moved away from a public care system to an independent system. We, in Southwark, are one of two local authorities in the country to pay the Living Wage and pay for travel between house-calls. Two care homes have closed because private funding reform was put back undermining their business model. Our focus is on care at home and in the community.

Q: Big organisations cannot do the job of caring. That is human to human. It has to be based on a partnership and facilitating the patient voice. I'd like to hear a strong commitment to quality, care and outcomes so that the citizen voice is at the heart of creating services, at the table and able to adjust and design things as they go. I'd like a commitment to excellence.

Q: Why don't the two CCGs amalgamate?

A: We have also been asked this question by some of our members. Some have asked this of their Councils too. There is a future in which that might happen. Legislation and forms of practice put limits on it. There is a strong commitment to work together where it makes sense. We work at different levels together – London, SE London, etc. The system needs to maintain the benefits of being both big and small. Working separately sometimes helps to get things done, and we learn from each other. Hospital care has

to think about a bigger geographical area. It is about recognising where we can get the most traction. Trying to make change happen has to start with individuals. Occasional competition is helpful. We need to be challenged on a regular basis. This is something we should talk about again and again.

Q: Why did you close all the mental health Day Centres in Southwark?

A: It is a long journey for mental health to get into parity with physical health. There has been a three year transition plan – we've been providing providers with funding and people with personal budgets. There was a massive consultation plan. We spend almost twice as much as other London boroughs on people with mental health problems. We have 200 people in permanent care homes. We can do much better. We are the third largest social housing landlord in Europe. We need better outcomes. Many people are voting with their feet and taking direct payments, and using those to pay for other day services.

Q: What can you tell us about the recent news regarding GPs refusing to treat people in care homes?

A: Many GPs are feeling close to the brink of what they can do and are asking can they safely deliver care in care homes. I don't think that is happening here but the breadth of the workforce are feeling under strain.

Nicola explained that the notes from this Forum will go to the next Citizens' Board. We will then come back to you with details of the first post-SLIC public meeting, and tell you what's happening with the pledge and how we have taken forward your suggestions.

The next forum is scheduled for Thursday 19th May 2016.

Workshop – The role of citizens' in the new strategic partnership – some draft ideas



Citizen leaders' council

- Made up of people who are active in the health and social care system – including councillors, CCG lay members, Trust governors, Healthwatch, PPG Networks
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Strategic Partnership Assembly

- Open public meeting for people to hear what is happening
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Citizens with experience

- Patients, service users, carers
- Giving views on services
- Continuous and real time use of feedback
- Co-design and co-develop services
- Self care

Citizens and communities

- Everyone in Southwark and Lambeth
- Involve people who have wider skills to bring to health and care developments
- Local communities and neighbourhoods

Each table were given the above diagram and explanation, and asked to give their opinion of the following questions;

Q1. What are your initial thoughts on this model as a whole?

Q2. What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

Q3. How can we create a movement that works for all citizens?

Q4. How could this model work with Local Care Networks?

Q5. What support would be needed to create a citizens' movement?

Workshop – full notes

TABLE 1

How do we create a movement that works for all citizens?

- Organise meetings
- Forum is well attended
- Could use email
- Doesn't matter if you don't reach everyone
- Need to be representative
- Easier to meet at a neighbourhood level / local level

Children

- Give them incentives and they will come
- Have music
- In doctor's surgery
- Use social media
- Have to be trendy
- Drugs/smoking/diabetes
- Go to where young people are – clubs
- How to involve people with dementia

Adults

- Decide what you want to change
- Sometimes you don't want to be at home
- Cuts are the big problem
- Might not all agree what is wrong
- Go to put culture in it

- How to help each other
- Meet to help each other
- Solve problems
- Start small and local
- More volunteers
- Befriending
- Offer friendship
- Train volunteers
- Needs facilitators and venue at different times
- Volunteers at home and not just in hospital
- Exchange volunteering 'I can offer talking'
- I could offer to help to people just arrived in this country
- 'I will invite people to my church'
- Shopping and theatre
- Could match people
- Men are lonelier
- Gym and badminton
- 'I do lots on my own and would like to do more with other people'
- Language is important
- We need matchmakers for loneliness

Recommendation

- Can we have a meeting just about developing a citizens' movement?
- Can we meet to make connections with each other?

TABLE 2

Thoughts on the model as a whole

- Leadership of Citizen Council and of Healthwatch reps on it needs to be high quality
- Council needs to be responsible, do what it says and be accountable
- It needs to go out and see the people –see what's happening on the ground
- There needs to be a strong link between all parts of the "onion"

Key roles

- Planning together
- Listening to patients and giving feedback to the system – act to improve the system
- Scrutiny

- There needs to be trust between members
- There needs to be care at the end of a phone – someone people can dial in to...

How to create a movement

- Feedback from what Citizen Council members hear in the community and also Council members need to feedback what is heard in meetings back to the community

Local Care Networks

- LCN's need to be aware what's out there – challenge how does the council connect to the community
- Felt that a community connectors model could achieve this – see Project Smith being run as part of the Resilience Programme.
- Needs to be visible points of contact for the Citizens Council at LCN level
- Felt that LCN meetings should start with members saying who they are as individuals who live in a community rather than I'm a doctor, nurse etc...

Support

- There needs to be a network of citizens groups. Community hubs built around LCN's that can connect and feed into each other as part of the citizens' movement.
- Resources for a community connector model in order to fully reach communities
- Workforce support – Training on basic health needs and what is available in local community and training to be a carer and to offer caring skills so that people can help each other
- Somewhere to meet – i.e. a forum but also smaller meetings too so that we can feed back what's happening in communities to the forum

TABLE 3

Thoughts on the model

- Good starting point
- How do each of the layers realistically link in with each other which allows tangible feedback/input/influence into the Strategic Partnership
- What is the power of the leaders' council in terms of the wider partnership model? This needs to be clear so that engagement is meaningful and not tokenistic and people in the outer rings can see the outcomes of their engagement.
- What is the accountability of the leaders' council? How are they held to account?
- Is there a need for quarterly? What about twice a year?
- Can see that it's wide and ever reaching but how can you meaningfully engage with group that are so broad and there are several of them (i.e. PPGs)?

Workforce

- There is a feeling that healthcare professionals spend more time in meetings and less time with patients
- Junior staff in hospital don't get exposed to the good things/services happening out in the community which may help them provide a better discharge for their patients
- How are LCNs going to ensure volunteers are kept up to date?

Engaging with groups

- How do you get the views of everyone and then push it up the next level?
- All groups have a different way of engaging with their target group, how do we work with all them to ensure we are feeding it all into the process?
- Getting young people involved – schools, colleges, awareness raising, talks in schools from patients/volunteers rather than leaflets that get lost
- Carry out a huge awareness raising campaign
- Need to be clear on what local peoples impact can be, this will lead to more people showing an interest
- Use technology to engage with certain group – valuable way to connect with everyone

Methods

- “you said, we did” – very powerful way of showing the impact of people's feedback
- Gain the views and opinions of a cross sector of the population
- Local people should be invited to tell their story – powerful of engaging healthcare professionals and an incentive for change
- Local people's voices is the most valuable way of getting healthcare professionals to listen
- Patient stories are powerful...verbal, written, video, case studies, training puposes

TABLE 4

What are your initial thoughts on this model as a whole?

- Noble aspiration
- Improve on what we have. We're now doing better than we used to – ‘continuous improvement’ comes to mind.
- How to get from outer circle to inner circle
- Are the Citizens' Board elected? Are they a cabal? Nobody knows who these nineteen people are. How would I find out who they are? It's an old pals' act. It should be open. People should know why they are there.
- I think it will work. Those driving it forward are truly dedicated to it, not withstanding obstacles and lack of finances.

- One wonders how effective it might be at the end of the day. It can't afford to fail.

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

- It is less clear how influential citizens are going to be other than providing information and feedback
- I feel my PPG is largely a talking shop
- The PPG is one way of publicising it and making it known
- Active/inactive citizens – what about those that aren't physically able?
- The Citizens' Board should be open for people to attend it. It ought to be in public. If it's open for people to be there you can't get away from it.

How can we create a movement that works for all citizens?

- 96% of the population are not going to know anything about it
- People who come here take a real interest
- People generally don't care until the time comes that they have to worry about their care
- Develop a local caucus and make the collective voice heard
- I wasn't interested until I was diagnosed as a diabetic. That sort of incident in your life you are not going to forget. 35 year olds playing rugby aren't going to get involved. But my road to diabetes started at that age. Nobody challenge me about being overweight.
- Communication – it takes years

How could this model work with Local Care Networks?

- What about the social services side of things?
- PPGs – responsibility for implementation should lie with GP practices
- If they do network that would be a means of influencing
- Trying to pump up effectiveness of PPGs
- GPs used to send a letter saying come to a [PPG] meeting
- Our PPG has a permanent advert up – zero response
- I would say its apathy

What support would be needed to create a citizens' movement?

- Communication, education, awareness
- CCG allocated funding for Lambeth PPG network to make it more effective and improve feedback
- The locality PPGs in Southwark get expenses. That wouldn't motivate me.
- What about people who have to have a childminder?

TABLE 5

What are your initial thoughts on this model as a whole?

- SPA a bit wordy. People won't understand what it is.
- Didn't think the Citizens' Forum is effective. People at front throw things at you. Then ask questions but there is no real engagement in the process. Balance of interaction is wrong. People need time to read and digest.
- People with time need to be involved. People want to know what is going on.
- Why can't lay people be on the Citizen Leaders' Council
- Ensure all statutory organisations are in place e.g. PPGs
- How would you engage younger people? Have a separate younger people's forum? Do we want to engage with the transient population?
- Engagement costs money. Consultation costs money. Front load resources to involve harder to reach. What is in it for them?

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

- Not just 'professional patients/citizens'
- How to be a fluid/adaptable system. Lot of people with knowledge and skills that can be shared with others.

How can we create a movement that works for all citizens?

- Need to make sure you have a representative group with a range of experiences
- Provide information to people – knowledge is power – allow people to make a choice about whether or not to engage.
- Build the community around people to support them, to help prevent problems arising How to engage those that can't come to the meetings
- Engage different ages to identify all the problems and show how they can contribute to solving them.
- Engage with the Youth Mayor – invite them to be involved. They will know how to engage the younger population.
- More analysing of the data to see trends and work out needs of patient groups

How could this model work with Local Care Networks?

- Need to ensure there is clear representation

What support would be needed to create a citizens' movement?

- How do you sustain the Assembly going forward? Who will organise/facilitate?
- What can the system do for you / what the community needs to do?

TABLE 6

What are your initial thoughts on this model as a whole?

- Not sure about the language of 'movement'
- Has heavy political connotations
- Could we call it citizen participation?
- Movement implies forward progress
- (Circles) Implies a them and us
- Agree with the structure. Important point is how representation is effective at every level
- 'Citizen' – still query whether this is the right language

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

- Educators – on day to day, on ground

How can we create a movement that works for all citizens?

- Need to make sure you have a representative group with a range of experiences
- Need to find a way to activate under-represented groups
- Need to find a way to reach out to these groups
- Needs to be inclusive of everyone. Need to find a way to collect stories, evidence issues from wider group to feed in.

How could this model work with Local Care Networks?

- Need to ensure there is clear representation

What support would be needed to create a citizens' movement?

- How do you sustain the Assembly going forward? Who will organise/facilitate?

TABLE 7

What are your initial thoughts on this model as a whole?

- Circles not working
- Not confidence – not empowerment
- Want to be taken seriously
- Don't understand circles – very top down
- No connection top to bottom – need connection
- Need different model. It cannot be managed, it must emerge. Build on needs of people.

- Circles doesn't work / not right. Layers. No connections. Not integrated.
- Me and them – still distinction in the circles vs. co-owning
- Great examples elsewhere – NHS Citizen, Better Together – come share best practice
- CCG – on website next week – belongs to us
- Circles – not equal. It's tokenism
- Need to be transparent and accountable
- Need to know our rights – what constitution says is it belongs to me
- 20 year cycle – must break it
- Must be equal. Must connect.
- UK has history of citizens' movements. It created NHS. Aids movement. Built around need. What learn from this.
- Come down to our level and talk to us – sit with us
- Structure is wrong. It's a regression and worm hole.

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

- Educators – on day to day, on ground
- In practice – peer support, illness/condition support
- Patient self-management at scale (1,000?)
- Buddy system – hit brick wall with calls
- 'Movement'

How can we create a movement that works for all citizens?

- 96% of the population are not going to know anything about it

How could this model work with Local Care Networks?

- Bring young and old to tea parties
- Motivate, engage young folks
- Stop the lip service – get everyone on board before. Do it – put money where mouth is.
- Recruitment – all sectors
- Real people not polished – provide training
- Being seen to be heard but isn't
- Need to see results. Feel the change
- [Pledge] – could have power to share decision-making

TABLE 8

What are your initial thoughts on this model as a whole?

- Layers look fine but they need to integrate into each other
- We could do this better, it's going to be challenging. Need to have these sorts of events but also other ways/structures to get this sort of information to feed back to each other. Needs to be representative to everyone.
- Technology - needs to be accessible
- Blog/reports all on the internet. So all can access.
- Needs to be more deaf awareness
- Need to share information and then it can be spread
- Often in English but needs to be in all languages so people can understand
- Doctors should come to these things and listen to us
- We need to invert the pyramid – 'us' and 'them'
- Paid (doctors etc) come to learn from VCS/citizens/people
- Assembly – info going up and down
- Make sure people actually understand the information
- Lots of different groups – faith, peer support, carers
- Councils need to be able to access these groups so feedback can go back and forwards

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

- Local information
- Borough-wide information
- Who should hold all this information – Council?
- GPs need to provide accessible services for all – only 20% are good
- Deaf group good place to distribute info to their people and work with other groups
- Most people go to GP or hospital at some point – they could be signposted there to where they can get info
- Area in waiting room – video with signer / very powerful way to communicate with lots of people

How can we create a movement that works for all citizens?

- On the grand scale
- We need to put a bid in for money to support the idea. We came up with videos, websites, events
- Sign-language/disabled accessible; audio – for sightless/visually impaired, different languages/training
- All variety of exercises, creative things for wellbeing
- Needs to be a personal approach – human touch
- People want face-to-face – someone to discuss with
- No one in A&E do sign language
- Get remote interpreter via Skype on iPad but needed in clinical areas/appointments

How could this model work with Local Care Networks?

- Public meetings for local areas in each borough
- LCN in 5 groups (GP feels the same) – should we work like that?
- They get to know their own actual area better – good local knowledge
- Deaf problems need to be at the top level in Southwark and Lambeth
- Some issues big and some local
- Lots of energy can be driven at a local level – PPGs etc
- Articulate specific goals to give leverage at higher levels
- Dual approach for local and borough level
- Top-down and bottom-up
- Need local meetings with engagement from all levels
- GP Federations need to be told we need citizen involvement at local level which then skills up those that are Federations/LCN – need engagement
- GP Federations/LCNs skill up small and then this will spread

What support would be needed to create a citizens' movement?

- Facebook/Twitter/Websites
- Important topics from deaf groups would need to be interpreted into English from BSL. British Deaf Association could distribute info for us.
- Deaf have links with Councils – also visually impaired, LTC, Stroke networks, all need to be accessible. They can gather and disseminate info.
- Bring all together – citizens, carers, councillors, Trust etc
- Needs to be a joined up approach – co-leads, positive outcomes
- 21st century you'd think we could get communication to work well

TABLE 9

Is this a good approach?

Key points:

- People generally thought it was a good approach – one excellent, another said along the right tracks.
- People identified themselves as Citizens with Experience.
- Some people wondered if they would be able to fully commit to being in the Assembly.
- In terms of what had happened so far – people felt it had been successful because of the admin support provided. Having admin support was considered extremely important for any continuation of the board/forum to be successful.
- People said they were impressed that professionals were willing to come along and take part in SLIC.
- There was some discussion around self-selection of forums etc. It was felt that this was part of social capital and should be accepted. It should not be looked upon so much as a negative.

- In terms of getting involved, some admitted that they had become involved by accident. In order to communicate to other residents – things like using local press like the Weekender was suggested.
- It was also felt that texting and email could be used to wider distribution lists ie all patients attending a GP practise instead of just members – to widen interest.
- You've not mentioned patients who are members of PPGs – that's the bit that's missing.
- Yes I've enjoyed the meeting so far, since June and have been impressed to see who attends and that professionals actually take the time to meet citizens. It gives me the chance to see the passion – that can be expressed in different ways. But I still feel there is the not knowing of what is happening next.
- The Citizens Board is a group of self-selecting people and then we have the forum. I think we need to hang on to that.
- Given that this part "Strategic Partnership Assembly" if it includes councillors, we need to make sure it doesn't become politically motivated.
- I think we should have some way of using a different model re administrative support. The reason why it has been successful is because of the administrative support. It is very difficult to keep things going without that support.
- I was a bit shocked that the Citizens Board was challenged around whether they are actually "patients". Well of course we are. We all have our turn.
- We are quite a lot of the usual suspects and that's an issue for me.

TABLE 10

What are your initial thoughts on this model as a whole?

- I don't understand it.
- Structure, it's the way it's built. Like a graduated progression.
- It's a wormhole – like Star Trek!!
- Layers, not integrated.
- Needs to be more overlapping.
- Pie-chart – would be clearer.
- Try and put it in perspective. There doesn't seem to be any connection.
- No connection between people at the bottom and at the top.
- It needs to be mandatory for people at the top to come down to talk to us.
- They have to come down – they don't know how to get feedback.
- We want to be heard.
- We invited the chairman to talk to us – he hasn't committed. He has to come and get it (feedback).
- It's not showing togetherness.
- It's not saying empowerment.
- It's not showing confidence.

- There shouldn't be a top and bottom, there should be layers.
- We should be equal.

What are the key roles for citizens in a citizens' movement – and what would each role accomplish?

Roving reporters, camera, audio tapes, notes?

- A crisis buddy: fantastic.
- My mum has Alzheimer's and I'd be happy to give up my time to help people with dementia.
- I have been saying this for years, it works in mental health and schools.
- I hit a brick wall with each phone call.
- I can't ring my doctor and say I have a problem. I have to make an appointment.
- We should have someone in a surgery or CCG to talk to.
- In other parts of the country lots of patients are involved in decision making
- In Lambeth, it is focussed on specific conditions rather than on support.
- This isn't a model for me.
- Movements of people do not fit into pre-existing management structures, they fit into human need.
- We need a different model to be understood by people who care about other people.
- A new model has to emerge. The model represented by the CCG is moribund.
- We had a citizens' movement in the 30s and 40s – we are now in a different situation.
- People are looking for a different pathway to that which is represented here, eg the AIDs movement.
- We will have argument and dissent, which can't be managed within circles.
- Have you heard of NHS Citizen?
- To be an NHS Citizen you have to know your rights and responsibilities. We have rights.
- NHS Citizen has to go onto both CCG website next week – take that as an action!
- We don't own the hospital but it is ours.
- We've already sold off the NHS.
- Quotes: 'fill the mouths of GPs with gold in order for them not to sabotage the NHS'
- We can't fire the chair of the CCG (not that I'd want to).
- I didn't have the right to take Jeff Bezos down, but I did.
- We need to learn lessons and apply them.
- 20 years ago – it's the same record.
- We need a revolution to break the record. We need a new constitution to take this forward.
- It's about evolving.
- Let it grow organically - more fluid.

So what would it look like?

- We don't need to reinvent the wheel.
- We don't need to invent solutions for Southwark and Lambeth that are disassociated with Devon.

What can we do?

- Bristol is doing something incredible.
- Educating people on a day-to-day level.
- I'm a service user of mental health. It's what we do.
- You are being too attracted by formal ways of power systems. I have 2 challenges: How to make your model transparent and of value to people in this room.

So what would that look like?

- Everyone is not represented here.
- It's if they turn up.
- You are in the wrong model. My friend Alison is the Director of Altogether Better. She helps 17,000 people in SW Yorkshire NHS Trust.
- Networks of people: well-resourced and well-funded.
- It's not new stuff.
- Use what exists, make it relevant.
- Small scale – add value and grow it.
- We are looking at a network of groups.
- 'Self-management at scale'
- Have to get everyone involved before we can make it happen.
- Put the money where your mouth is.
- Not lip-service: commitment.
- In 10 years, GP involvement is no further forward.
- They (the healthcare professionals) have to accommodate change.
- Everyone has to be on board.
- How about inviting people from high up around the country to come and talk to us?
- I want to see young people involved.
- We talked about it. Nothing has happened.
- We need to coach them. (young people)
- Great projects bringing the young and golden years people together.

How could this model work with Local Care Networks?

- What level of people?
- Director? So the usual level – the same.
- We should have the power to make decisions.
- It should be polished members of the community.
- It doesn't matter if they are not articulate.
- Buy in.
- Let them own it.

- Challenges locally – so may have an involvement but don't feel like it's making a difference.
- The things we have been told about – I haven't got wind of it. I haven't been informed.

Citizens' Forum Feedback –Thursday 4th February 2016

What did you think was good about this evening's workshop?

- All the discussions we had made sense. The ideas were very good
- This is a very nice evening, good and friendly turn out. Need more meetings like this
- Hearing the future direction of the citizens' forum and being able to hear and ask questions of decision-makers
- I thought the packs were of a really high quality. A very professional standard of resource
- Enabling most present to engage in development of this partnership
- Thinking about how we can engage the young
- Many people said what they wanted. People said where there is a problem
- Good mixture of people
- Discussion on the table
- Networking. Table discussions
- Then workshop – excellent discussions
- The feeling that my opinions are being heard
- An opportunity to look at the model and challenge it and look at an alternative, which will hopefully be considered and adopted
- Update on the forum activities
- Many people attending. Seeing the people in positions coming to speak directly to us. Different abilities able to have a say. Seeing the passion some through both from staff and citizens
- Good to see people from various different organisations and interests
- Good, very interesting
- The group work and discussions
- It was clearly expressed
- Well run. Clear speakers. IT worked well. Superior refreshments. Lively discussion
- Nice venue, food and facilities. Interesting topics discussed
- Excellent. Very informative. The time went by very quickly. Liked that there were representatives from all areas and sectors, including the general public
- Promotion and sharing of very interesting and diverse thoughts, ideas and concerns
- Good table work, varied views
- The communication was good. The subject was interesting. The venue was good
- Very useful
- The format is well tried and works well, especially this evening in the splendour of Shepherd Hall

What do you think could be improved?

- Nothing – but let's keep it going

- Initiate member of the young youth council for each borough to these events. Ask how they can be used to engage with young citizens
- More deaf people
- Don't use the word 'council' as gets mixed up with 'local authority' aka council
- More time for questions to the panel
- Invite people from around the UK who have already done what we need to do
- We need more information about what is happening ie the way Southwark Social Care is changing Home Care
- Needed longer to allow for deeper discussion, wasn't enough time
- Nothing – every meeting is held differently and in a different venue, so it is good
- Home Care, visit to lonely old people could be improved. The closing of Lambeth Town Hall causes people to be unable to attend some meetings
- Do not change the process too much because it is clearly working to get so many people attending. Have more time to just hear from people – by the time some pluck up the courage to speak they might lose the chance
- Don't have then tables so close together, health hazard
- More DVDs in surgeries
- Nothing – perhaps the discussion could be longer
- Next time could we have more clarity on the Citizens' Board
- I think it worked well as many of these conferences have. The venue was better than many. Initial time-keeping could be better
- Identify the problems and changes needed
- It could be a whole day event
- Limit the Q & A section to questions and not statements. Stick to timings
- Longer time for group discussion

Do you have any further comments?

- We should work together and harder
- Think this meeting was near perfect
- I would be interested in helping to form the new organisation/structure
- There is a wealth of knowledge within both Southwark & Lambeth which can play an important part in building partnerships
- We could explain to hearing people about problems with access for deaf people
- Really like the idea of joining up citizens with lay members, Councillors and Trust Governors
- Introductions to local group representatives
- Too noisy here
- Citizens' want more involvement – help us to help you to move forwards
- Catering was great

- I look forward to future meetings and an opportunity to stay involved with the evolution, next steps, future of SLIC
- The future of the Citizens' Forum, is it going to die?
- Improve all areas of care
- Keeping it non-political, without dominance and ensure, where possible, to bear in mind elections. Would like to keep it citizen focused and not become political
- It would have been nice to have a list, in the pack, of all the people attending
- It was great
- Invite speakers from the PPG to give feedback on how they are doing
- Bottom up communication (? Leaflets in surgeries). Involve maternity clinics? Schools and mums?
- Look forward to meeting in May. I hope the process will be transparent!
- Train volunteers at home. Encourage more people to attend, including youths, at a local level (children centres, schools, social clubs) to reach the majority of the community
- Food was lovely
- Please can we have the next meeting here worked really well
- Thanks to all concerned for their time and effort in pulling all this together
- Publicise more in GP surgeries