



SOUTHWARK & LAMBETH  
INTEGRATED CARE

## **Southwark and Lambeth Integrated Care - Citizens' Forum**

**Thursday 22 October 2015, 6.30pm – 9.00pm**

**Cambridge House, 1 Addington Square, 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.

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## Southwark and Lambeth Integrated Care - Citizens' Forum

These are the notes from the 9<sup>th</sup> Southwark and Lambeth Integrated Care Citizens' Forum, held on Thursday 22<sup>nd</sup> October 2015 at Cambridge House. 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 people and introduced the speakers for the evening; David Quirke-Thornton (Strategic Director of Children's and Adults' Services, Southwark Council) Mark Kewley (Director of Transformation and Performance, Southwark CCG) and Debbie Sorkin (National Director of Systems Leadership, Leadership Centre)

**Nicola** gave feedback from the previous Citizens' Forum. We heard that citizens warmly supported the idea of Local Care Networks and linking together services. However, we must ensure we are designing services which work for all our communities, including people with learning difficulties, those who don't attend meetings, or English isn't their first language. She explained that we work closely with Healthwatch Southwark, Healthwatch Lambeth and the Southwark and Lambeth Integrated Care Engagement Team to ensure we capture the less heard voices. The Citizens' Board members use feedback from citizens' and put them to the health and social care decision makers. 'We are your representatives driving this work forwards'.

**David Quirke-Thornton** said he was delighted to see so many people interested in coproduction at the meeting. He explained that it was going to be difficult in this time of austerity and huge funding cuts to deal with the challenges we have. He has been encouraged by conversations he has had with colleagues in Europe who have had their own devastating cuts, but who have worked closely with their citizens to find solutions. We don't have all the answers - that is why it is so important to hear your stories and opinions. He praised the work the Citizens' Board had done representing local communities at meetings. He said that if together we continue to engage, have honest conversations and challenge each other, we can make real changes.

**Mark Kewley** spoke about the recent and future work on integrated care. There has already been work between hospitals, GP practices and social care to make sure services are more co-ordinated, and as a

partnership we are trying to understand better what is needed and work in collaboration.

Mark said that unless we begin to work as a partnership across the whole of health and social care we cannot bring about change. We need to stop talking about aspirations and genuinely change the way we work. This has been a time limited programme, but integration does not finish here. Mark went on to say we're part way through a journey of integration and your views are critical as we really want to hear what you think should be included in the pledge between organisations for the future.

**Debbie Sorkin** Debbie explained that system leadership is about how you lead when you are not in charge, when you are working across networks or across boundaries. Debbie said that together we can change the way organisations think. It is based on relationships and building trust. It is about power that you can bring and the influence you have. Change is never easy, it takes time, but it is worth it in the end. This is important for citizens as leaders as well as organisations. She then gave examples of 3 projects in North West London, Cheshire and Gloucestershire which have had service users at the centre of the design as 'lay partners'.

Debbie ended with some important advice - '**Start anywhere, go everywhere and never ask permission**'.

**Zoe Reed** (South London and Maudsley) told people of an Equalities Event which SLaM were holding on 17<sup>th</sup> November. 'We want to hear your views on how we deliver services to people in relation to age, disability, ethnicity, gender, gender re-assignment, pregnancy and maternity, religion or belief and sexual orientation'. Details of the event were being advertised.

**Nicola** informed the group about an event taking place on 18<sup>th</sup> November regarding the Local Care Record to which citizens would be invited to find out more.

## Questions

Q: What about people with mental ill-health in communities that are socially isolated or have problems with their neighbours. We are told that everyone is poor, everyone is needy, and everyone is depressed, because of the high level of need in some communities, so it is not possible to get support.

Comment: We significantly need to change how we work with people with mental ill health and more importantly the social issues around it. There has been a significant increase in numbers of young people presenting with Mental Health issues. Child and Adolescent Mental Health services receive greater investment. There are people who are struggling and it is an enormous challenge. We have to urgently address Mental Health issues. We're spending a lot of money already and not getting it right. Once someone ends up in a hospital bed, services have already failed by that point.

Q: It costs around £500 for each person in an acute bed. Let's stop talking about it and do something.

Q: I've had a Mental Health problem for 11 years which has resulted in me being sectioned. The work by Community Support Network, South London, they are doing some very valuable voluntary work, instead of the numerous art projects in church halls (which do not help).

Q: I welcome you talking about integrated housing in your plan. Invisible disability can deteriorate so then you need services. They don't know how to manage and keep going. It's not just people who come to you when it's too late – within housing I am having to repeat and repeat that people need help.

Q: I've been a carer for many years - people are messed about when they apply for something and need someone else to help them. I've had to deal with a friend who has been provided with services for dialysis and heart bypass but then for things to be taken away. He is fighting against the system and it is causing a lot of mental distress.

Q: I do welcome the idea of listening to citizens but it needs to be in an inclusive way. It needs to include homeless, older people, people with Mental Health problems, BME – the different strands of each group will have certain challenges – that will not affect the other strands.

Q: In the Guardian there was an article around people with mental ill-health as a national issue and how much of a difference we can make. I think people have a wish list that isn't possible.

Comment: We must look at what is happening with our neighbours and it is all our responsibilities to play a part.

## Workshop - Pledge for Southwark and Lambeth.

We want to make sure that everyone involved in integrated care – health services, local councils, voluntary and community groups, citizens, patients, service users and carers – can develop and agree a joint public statement about how care will be provided in the future. We are calling this a ‘public pledge’.

Each table was given examples of pledges to read (East London pledge, Leeds pledge, North West London pledge, Royal College of Physicians pledge and Solihull pledge) and asked what works and what doesn’t work, and to share any other ideas that would help develop a public pledge for Southwark and Lambeth.

A pledge has to be more than something written on paper. It must be real and fully owned by the people and organisations signing up to the pledge – and owned by the citizens in Southwark and Lambeth.

The feedback from the groups shared a number of recommendations, the most common being that the wording of the pledge should be simple, plain English, short, transparent and jargon free. It should also be translated, printed in large print and available to everyone. Some also suggested that not only should all organisations involved sign but also citizens’. One group proposed a separate citizens’ statement “We, as citizens’, pledge to work with the system to...”

The areas which people felt were the most important to be included in the pledge were:

- Proactive and preventative care.
- Timely help in a crisis.
- Accessible and flexible care with informed choices.
- The mutual importance of physical, mental and emotional wellbeing.
- Support for social integration and prolonging independence.
- Everyone treated equally. Reduction in health inequalities.
- The importance of facilities and resources.

They also felt that organisations should promise to:

- actively encourage public involvement in meaningful decision making. Citizens’ should be respected, listened to and heard.
- ensure better coordination between services including the sharing of information (but concerns were raised by some regarding confidentiality)
- involve wider services such as housing and education

Some of the preferred phrases were: ‘we are responsible’, ‘we are committed’, ‘we are coordinating services’, ‘we will put you first’ and ‘we will work together’.

## Workshop – full notes

### Group 1

#### What we like

- A signed pledge, with people and organisations – makes it real
- Good to have a central place – simple point of access, to take any problem – health, social care, housing
- People need to listen to you – not be talked at all the time – we need to be heard
- Being heard is different to being listened to – reflective listening
- The person who can make decisions – GP – hard to get an appointment
- People need help to navigate – system like a maze – we can't just keep getting referred on

#### The pledge needs to be

- All embracing – buy in from all parts of the system. Signed by organisations with public buy in
- Stop professionals saying 'that's not my area'
- More accountability – but what does this look like?
- Don't confuse us – explain things to us simply
- Don't confuse us to the point of confusion that we get exhausted and ill. We don't want politics and medical jargon
- Want language to convey pledge to people, not protect institutions, eg 'only possible if we work in partnership'
- Don't make promises you can't keep
- What are consequences of not committing to the pledge?
- Want words like 'we are responsible', 'we are committed', 'we are coordinating services'
- We want language that conveys change – like 'moving forward'
- Commitment to being heard – all citizens, especially those vulnerable and isolated
- Actively encourage public involvement

### Group 2

#### What to include when designing a health pledge

- Widen the remit to be applicable to all of London not just Lambeth and Southwark as this may have a greater appeal to people
- East London health pledge has the closest fit to what the final pledge could look like; build on this pledge with some additional text covering resources and other issues
- 'Independent' is a problematic word because this is not always attainable for severely disabled people, 'inter-dependent' is more inclusive
- Independence should be about maintaining dignity, we're not all the same, what is it that you need to make your life independent?
- 'Compassionate care' is very important
- 'Inequality' remains a huge problem
- We need to take into account the amount of care already happening in the home which is different to the type of care provided by the council

- Include all groups, for instance harder-to-reach such as homeless people
- Be positive about our well-trained healthcare workforce
- 'Time to listen', people are given less and less time by health professionals, for example, some GP surgeries request that people do not go over their 10 minute appointment
- Produce a video of our citizens reciting the pledge

### **What not to include in the pledge**

- 'Co-production' is an off-putting word, it doesn't sound authentic
- The word 'quality' has been debased, the pledge says we expect quality but the definition of what quality is can be difficult to define.

### **Other considerations**

- Communication another area to think about which isn't exclusively about what's being said, it can be about being silent and use of body language; both are forms of communication
- Southwark Carers are now receiving the London Living Wage and are paid for travel time between visits
- Once discharged, people used to be surrounded by a multi-disciplinary team covering all their needs – where has this gone?
- Care Workers aren't given much time to do their tasks, by the time the patient has said 'hello' the carer has gone, but carers have lots of people to look after and it's not that they don't want to help
- Organisations are running at a profit in private care, it's got to be part of a public care system
- Nothing about funding of care. Resources are important
- System isn't able to be as responsive to the harder to help, it can be fatigued by some individuals
- We all play our part for the benefit of all
- 'Partnership' is this word positive or negative?
- Time to care and time to listen – there is too much rush
- Can we use the word 'happy'?
- Consistent consistency
- Ethical care charter – a public care system
- 'We pledge to work with our cultural.....'

### **Group 3**

- Coordinated. As equals. Inclusive.
- Promise not pledge
- Services available to all without discrimination. Enable to live with dignity.
- Close the gaps between hospital, GP, Social Services
- Professionals promise to work better together
- 'Nothing about us, without us'
- Need to get examples of good integrated care so we can see what good looks like
- More investment in Community Services

- Every citizen in the borough must be cared for and provided with health and social care they need
- One size does not fit all – services need to be flexible so services fit individuals needs/wishes
- Information – we pledge to try and ensure that information is available to everyone
- Promise to get the balance right between data sharing and confidentiality
- Respect and listened to what people say they need
- Disconnect between those making the decisions and those on the ground
- Too slow and cumbersome
- Feels we don't achieve anything in the Citizen Forum meetings
- Training of carers. Increase pay and training
- Want to be able to help pledge makers to account
- Flexible
- Dignity
- Not just clinical
- Confidentiality – only share relevant information
- No one forced to go into an institution without consent, except where no capacity to make own decision
- Provide information about health and wellbeing for people to make their own decisions
- Make sure community services are effective
- The pledge should be short, clear and punchy, but supported by a set of specific promises
- No jargon
- Concise
- Simple
- Plain English
- Not just complex needs
- Large print and translated
- More proactive and preventative
- Public health strengthened
- Offering information
- Informed choices around, food, smoking, lifestyle, alcohol, exercise

#### **Group 4**

##### **Citizens' Pledge/Promise**

- Putting resources together to improve care and take early action
- Holistic approach
- Early action to stop people tipping over the edge
- Involvement of wider services – welfare rights, education, housing as well as social care and health
- Housing and social security – big issues that impact on health
- Bottom up
- Prevention is better than cure
- Better joined up care in community to help stop people from ending up in hospitals – example of isolated older people and falls
- Social security/benefits system linkage to address poverty and impact on health



- Safeguarding / escalation issues

### **Organisations need to:**

- Listen
- Work together
- Have realistic times for home visits (social care, district nurse etc)
- Link in and plan care with families
- Take a flexible approach to fit around people and family needs
- Need welfare rights services linked into GP services
- Signposting to a wider range of services
- Patients and citizens can be politically active to effect change
- Can we as an integrated care programme evaluate impact of poverty on health and wellbeing especially mental health
- Can we also gather evidence
- MPs and local councillors should sign pledge and Mayor of London
- Can we invite local MPs to Citizens' Forum? Jeremy Hunt too
- Need services within hospital to join up better like the new outpatients at St Thomas'

### **Other thoughts**

- Accountability for output and not just collection of statistics
- If you cannot influence government policy, who can and why are we bothering?
- Welfare rights is integral to integration – GP services
- Evaluate impact of poverty and feedback and how it affects change
- Joined up services within hospitals too
- Real joined up services
- Involve politicians
- Flexible care to fit around lives of people and families
- Address poverty – as impacts on health, especially mental health
- Early action

### **Group 5**

#### **Leeds Pledge**

- Too much
- Needs to be understood quickly

#### **Solihull Pledge**

- Don't like first paragraph
- Structural – no impact on individual population
- Final paragraph should include 'wellbeing / prevention / staying well'

#### **North West London Pledge**

- Too much – so what?

## **Royal College of General Practitioners**

- Good but simplify, plain English

## **East London Pledge**

- Add: We seek to provide equal access to all people needing care which delivers adequate standards of care to improve the quality of life of the recipient and the community as a whole

## **Group 6**

We the citizens of Southwark and Lambeth want an active involvement in our care, which covers both health and social services and for which we are paying.

We the health and social care partners across Southwark and Lambeth pledge to integrate members of the community into our systems of care and involve them meaningfully in decision making.

We pledge to put you first – your health, your wellbeing, your community. We will work together, we will listen to you, we will.....

Our pledge to you – who is ‘our’ and ‘you’?

Agree acceptable terms (citizens/client)

Short pledge, easy to understand

## **We want**

- Seamless
- No join between primary/secondary/social/any care
- To be heard not just listened to
- Care to be an active dialogue - not being done to – listened to and responded/acted on
- Treated equally regardless of differences
- An equitable system (not multi-tiered system)
- To include staff in the pledge
- Care to be near where I live and be aware of local facilities (neighbourhood basis)
- A coordinator who works across the whole system and ensures it is seamless
- Services to keep me well and to coordinate when I need input (right place right time)
- Flexibility, personal, trustworthy, local, joined up

## **Using the 4 areas of the Leeds Pledge**

- Holistic – supports social integration, physical, mental wellbeing and emotional wellbeing, prolongs independence
- Clear signposting
- Want activities that are enjoyable and increase social interaction
- Reduce health inequalities
- Specifics – hospitals same premises housing, therefore facilitate easy access to all elements of integrated care
- We want to replace the nebulous mission statements with concrete fixed proposals

- We want to protect community assets and ensure use for most vulnerable (eg housing, we want timely repairs)
- We want property repairs to be facilitated and supported where necessary by low cost loans
- Key issues – Older housing, older vulnerable people/families in cash poor and asset rich homes unable to afford repairs. Very poor municipal housing
- Needs innovative incentive/financial schemes to support
- Need dedicated barinstorm for each issue like this
- Involve us (citizens) in all aspects of integrated care (eg GP pilots) not just pledge

### **Group 7**

- A citizen statement should be included – ‘we as citizens pledge to work with the system to...’
- Get as many citizens’ as possible to sign. Can we get at least 50,000 citizen signatures?
- Citizens’ should sign if they really believe in it
- All signing parties should make a statement
- Sign in public – could we all sign it?
- A signed pledge is really important
- Signatory form all partners including housing, voluntary, citizens etc
- ‘Spiritual’ needs should be included
- Information is shared across all services
- Where I can take part in and control my care
- A friendly pledge with one number/email as a contact
- A pledge that is short and punchy
- Accessible and timely care
- One point of contact for each patient
- We need services to reduce not cause stress
- More appointments available and at the right time
- Person focused care
- Everyone is listened to and heard
- Better coordination between services

### **Group 8**

- Social integration – community support for whole families
- Support guidance – navigate a complicated system (and make system simpler)
- Impersonal research and treatment V’s Care for me
- Whole life/person beyond health and social, eg. financial, etc
- Care should be personal, see me as a person (not a patient)
- Cultural understanding and background of individual
- Time and space with someone you trust, who listens and guides
- Systemic/causes/reasons why mental health
- Not a victim, not done to me
- Timely help in a crisis (not a year later)
- Early intervention (prevention) before becomes complex, long term

- Care/nurturing
- Partnership – solve together (not alienated)
- Carers need care too
- Language needs to be common, easy to understand (not research/medical)
- Ban words like ‘mad’, ‘demented’
- Listen, talk, communicate, dialogue with us
- I don’t see myself as complex
- Equality for all

## **Group 9**

### **The Pledge should contain**

- Mental health equally as important as physical
- Permission to challenge decisions
- Community spirit is important but it’s missing
- Isolated people are vulnerable
- People need shared spaces. It’s good to meet and mix with a big mix of people. Staying active makes you feel better.
- Sharing information is most important. Letting people know what there is for them to get involved with. What opportunities there are and what help they can get.
- Connect young and old (mutual benefit)
- Connect – fast
- Love & care
- No delay between signposting and contact

## **Group 10**

### **What is important?**

- Decisions and plans – how will it happen? Transparent plan or how/why it’s going to work
- Measured outcomes – what does it achieve?
- Joint decision making between organisations and citizens’ (communication)
- Value for money
- Real commitment
- It should be coproduced decision making with citizens’ at the heart, not separate bodies
- Accountability
- Independent citizen led scrutiny, representative of the population
- Transparent rules/guidelines

## **Citizens' Forum Feedback –Thursday 22nd October 2015**

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

- People attending that are able to listen and put change in action
- Brought up some interesting questions
- Very interesting, educative , informative and people orientated
- The facilitators were quite experienced and very good
- The workshop
- A good discussion on my table and we came up with a revolutionary way forward to improve care
- The conversations and involvement
- The variety of people. Ideas and topics discussed. Refreshments
- Some good points in the talks
- Lively and progressive discussion in the group – very good humoured
- Excellent food and drink
- Good turn-out. Accessible venue, close to public transport links
- Excellent and inspiring third speaker
- How complex and difficult managing the terrain of Health and Social Care is and yet there is a willingness to engage people
- Only 6 of us on the table workshop, we could all hear each other and contribute

### **What do you think could be improved?**

- More time to communicate as a group together so helps to understand differing difficulties
- Microphone
- Some of the room was cold as the windows were open
- Some of the speakers were difficult to hear as they didn't use the microphone properly
- A bigger room and more time for more workshops
- Better sound
- Involve more people to get more ideas of different age groups and backgrounds.
- More variety of sandwiches. Organisation of transport, cab didn't turn up
- A pity one of the discussions had to left out – can't we start on time
- Encourage people to genuinely ask questions rather than make long statements
- Time keeping of each section of event to prevent over running and work shop opportunity
- Prevention of agenda being over taken by vociferous minority
- Reduce the number of speakers
- Choice of speakers and their language/concepts that are accessible to users! (few had context)
- Time keeping to agenda

### **Do you have any further comments?**

- Good session and hopefully bring forward further ideas
- Lots of questions – we need answers
- Centralised, coordinated care and services for all
- The facilitators on table 7 were amazing
- I look forward to the next meeting

- I hope to be at the next one
- It was an opportunity to share ideas and voice areas of concern
- Explore the effects of mental health and music. YouTube 'Alive Inside'
- Coordinated, centralised, person focused care and services envisaged please
- Very good atmosphere.
- Do we need all that food?
- Keep going
- 9.00pm is a bit late for older people
- Please no more mission statements/pledge exercises! Too remote from people's lives. Subjects should be ones related to lives of audience members that they have personal knowledge/experience of, ie housing/access to GP, so that they can contribute and feel involved
- Having requested a gluten free diet this was not fulfilled, I do hope there was either a reduction in payment for a discount for future, an apology from the supplier, I hope the supplier is made aware of breaches
- More time should be allowed for the public – it felt very much like being talked to and told what was going on rather than being included. Either less speakers or break up the agenda items between
- Explore the effects of mental health & music, everyone should check out YouTube "alive inside"