Introduction

The best possible health outcomes for Southwark people
Purpose of patient and public engagement guide

This guide is for commissioners and CCG members of staff planning engagement activities

The purpose of this guide is to:
• Promote best practice of different methods of patient and public engagement
• Support staff to develop engagement throughout the commissioning cycle
• Remind staff of legal duties around engagement
• Help staff fill in the engagement plan template for submission to the Engagement Advisory Group for further advice and comments
• Provide ideas, examples and case studies of previous NHS Southwark Clinical Commissioning Group engagement
• Provide resources to develop your knowledge on engagement methodologies

You can find the ‘engagement plan’ template here.
## Engagement as an empowering process

### I want to know what’s going on
- **Inform**
  - Published plans
  - Bulletins
  - Newsletters
  - AGM
  - Website
  - Social media
  - Outreach
  - Advertorial in Southwark News

### I want to tell you what I think about your plans/services
- **Consult**
  - Formal consultation
  - Published options
  - Views asked on options via surveys

### I want to be involved in your work
- **Involve**
  - Engagement meetings
  - Telling my story
  - Ethnographic studies

### I want to actively work with you to help shape what we do
- **Co-design**
  - People with lived experience co-designing proposals as equal partners
  - Co-design workshops to develop outcomes

### I want to make formal decisions
- **Empower**
  - People on procurement panels
  - Lay members on Governing Bodies and Committees
  - People setting up peer support groups

### Providing services
- **Engagement activities**
  - Factsheets
  - Directories
  - Care navigators
  - Patient experience data: PALs, Friends and Family Test, complaints, surveys,
  - Audits of patient records

### Commissioning services
- **Engagement activities**
  - Published plans
  - Bulletins
  - Newsletters
  - AGM
  - Website
  - Social media
  - Outreach
  - Advertorial in Southwark News

- **Consultation**
  - formal consultation
  - Published options
  - Views asked on options via surveys

- **Involvement**
  - Engagement meetings
  - Telling my story
  - Ethnographic studies

- **Co-design**
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**I want to make formal decisions**
The commissioning cycle

How participation can support the commissioning cycle

Engagement in governance:
- Ensure lay people / those involved in co-design or mystery shopping are part of performance management structures

Engagement to assess and decide priorities:
What do we already know?
- Insight from previous engagement
- Joint Strategic Needs Assessment
- Service data including quality reports, patient experience, PALS, complaints

Engagement in feedback:
- Use quality data including PALS, complaints
- Mystery shopping
- Healthwatch enter and view

How can we find out more?
- Engagement meetings
- People’s stories
- Surveys

Engagement in tendering:
- Patients as part of procurement decision-making process

Engagement to design:
- Co-design workshops with people with lived experience and their families
- People with lived experience / their families in working groups
NHS England have developed 10 principles for participation:

- Reach out to people
- Promote equality and diversity
- Seek participation from people who experience health inequalities & poor health outcomes
- Value people’s lived experience
- Provide clear and easy to understand information
- Plan participation, budget for it and involve people early
- Be open, honest and transparent
- Invest in partnerships and on-going dialogues
- Review experience of involvement
- Recognise people’s contributions & feedback
What is co-production?

The Coalition for Collaborative Care describes co-production as a “way of working that involves people who use health and care services. Carers and communities in equal partnership, and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with lived experience of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives.”

The collation also describes five values and behaviours that need to be addressed to create the culture where co-production can happen:
Public engagement legal duties

Section 14Z2 of the NHS Act 2006, as amended by the Health and Social Care Act 2012 sets out the legal duties for CCGs around engagement:

CCGs must make arrangements to involve service users in:

- The planning of commissioning arrangements
- The development and consideration of proposals for changes in the way those services are commissioned (where implementation of proposals has an impact on
  - the manner in which the services are delivered
  - or the range of health services available)
- Decisions affecting the operation of those commissioning arrangements

How we involve and to what extent will depend upon what is fair and proportionate in the circumstances.
Don’t forget the Gunning principles!

These were confirmed by the Court of Appeal in 2001 and apply to all public consultations that take place in the UK.

- Don’t leave it too late
- Be open with the public
- Allow enough time
- Take responses on board

Recent case law:
- give sufficient notice of consultations
- information needs to be accurate, comprehensive and sufficiently detailed
Planning your engagement

You will need a minimum of two months to plan and execute your engagement depending on the level of engagement you require. An information giving/feedback event such as a health fair would take around two months. Finding out what people’s lives are like (ethnographic work) to develop outcomes would take much longer.

You will need to have a budget for your engagement and this could range from £500 to £20,000 depending on what level of engagement you require.

You will need a project team including Clinical Leads to get the most from your engagement. Members of the engagement team can support you.

How will you be engaging people throughout the commissioning cycle?

You will need to seek advice from the Engagement Advisory Group & provide updates on your engagement as part of your reporting to the Commissioning Development Groups, the Primary Care Commissioning Committee and / or the Commissioning Strategy Committee.

You will need to seek assurance from the Engagement and Patient Experience Committee on your engagement before any decisions are made.
Committee / Board identifies an area of work which requires engagement

Commissioner discusses with engagement team who provide initial advice

Commissioner drafts engagement plan based on this guide and plan template

Commissioner discussed draft plan at Engagement Advisory Group meeting

Engagement activity carried out by commissioner and engagement team

Report of engagement written and discussed at EPEC for assurance

Committee / Board takes decision on proposal which includes report on engagement

CCG assurance for engagement
Writing your engagement plan
Section one: outline proposal and purpose of engagement

- What is the title of your plan / proposal / commissioning activity?
- Provide a brief overview including key objectives
- What are the aims and objectives of engagement?
- What do you know already? Consider:
  - Insight from previous engagement - talk to the engagement team
  - JSNA data
  - Service level data
  - Quality / patient experience data – talk to the quality team
- What do you not know and need to know in more detail?
- What can be influenced and what is fixed?
Section two: who are we engaging

Six questions for stakeholder mapping:

1. Who is directly impacted by this initiative?
2. Who is indirectly impacted by this initiative?
3. Who is potentially impacted by this initiative?
4. Whose help is needed to make the initiative work?
5. Who knows about the subject?
6. Who believes they have an interest in the subject?

You may find it useful to map your stakeholders regarding their interest and influence:
Section two: who are we engaging

To reach people with lived experience and other stakeholders and generate interest in your project you could use a range of methods including:

- Write to patients via GPs and secondary care health professionals to access patients and public with lived experience

- Email to the CCG engagement database

- On the CCG website and promote via Twitter – talk to the communications team

- Use local online forums

- Attend meetings that are already happening e.g. patient forums, Community Council meetings, mosque services, tenants and residents associations

- Attend CCG meetings – north and south Locality Patient Participation Groups

- Community and voluntary sector organisations
Section three: Equalities Analysis

When identifying stakeholders for engagement you will need to think about ‘seldom heard’ voices – this includes looking at the nine protected characteristics plus carers and people who are socio-economically deprived.

Alongside your engagement plan you will need to undertake an equalities analysis to ensure that any changes in provision does not negatively affect any one group more than another in regards to the nine protected characteristics.

You should do this at the beginning of your project and update it after the engagement has taken place and it should form part of your business case.

To ‘reach out’ to these seldom heard groups you may need to ask for support from:

- The engagement team
- Healthwatch
- Community Southwark
- Other voluntary and community sector organisations, including:
  - Forum for Equalities and Human Rights in Southwark
  - Southwark Disablement Association
  - Faith groups
  - Dragon Café
  - MIND
  - Southwark Carers
  - Advising London
  - Speaking Up Southwark

The CCG Engagement database can help you identify which groups you will need to work with.
Section four: how we can engage

**Inform**

**Social Media** – a good way to get information out to the public, linking to web pages. The CCG has over 7,000 followers on Twitter.

**Website** – we have a public website that you can add information about upcoming plans.

**CCG Newsletter** – we have a quarterly engagement newsletter that goes out to over 700 stakeholders.

**Outreach** – A good way to give out information. Piggy backing onto existing events means less resources needed. You can also get people’s email addresses for further involvement!

Examples include International Youth Day in Peckham Square and a programme of engagement for the Extended Primary Care Service.

**Engaging on our joint draft mental health and wellbeing strategy**

NHS Southwark CCG and Southwark Council are seeking feedback on their draft mental health and wellbeing strategy. Since October 2016, we have been working with Southwark Council, NHS organisations, the voluntary and community sector, users of services, carers, and local residents to talk about mental health and wellbeing and what matters most about the services we deliver.

We are now engaging with the public on our draft strategy and as part of this, we will be holding an event on the evening of 11 September. Further details will follow, but if you are interested, please contact us at inquncp.southwark-ccg@nhs.net.

**Southwark News** – article in monthly CCG advertorial.
Section four: how we can engage

Consult

**Document:** production of a document setting out the proposals and options in everyday language. You will need to send paper copies out to partner organisations including voluntary and community sector.

**Survey:** you will need to develop a questionnaire asking people for their views of the proposals and also asking for monitoring data. This will be sent out with paper copies of the documents and also be on the website. The CCG has a Survey Monkey account and is a good way to collect quantitative and some qualitative information.

Outreach – A good way of promoting the consultation. Examples include presentations and discussions on the proposals around NHS prescriptions at Community Council meetings, the Diabetes Forum and VCS organisations working with people from Latin America and Africa.

Website – we have a public website that you will need to advertise the consultation and outcomes of consultation.
Section four: how can we engage

Involve

Patient Participation Group meetings – the CCG organises north and south Southwark Patient Participation Group meetings which you can attend to discuss ideas.

Story telling – this could include but is not limited to:
• open ended interviews / discussions
• photos boards
• films – the CCG has a YouTube channel
• story telling

These approaches provide a rich source and understanding of what is important in peoples lives to inform the commissioning and development of services

Engagement meetings – the CCG organises engagement meetings on specific topics. Examples include engagement meetings on developing the mental health and wellbeing strategy, as part of the community dermatology procurement. The CCG has also put on joint events with Healthwatch. It is good to identify clinical leads who can present the proposals

Patient stories

“I would do anything to come off some of that medication.”

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

“I wish I could do more exercise, but I just don’t know where to go or how”

“I once took the wrong pills and ended up in hospital.”

“IBS is by far the worst – I have to spend hours in the morning preparing before I can leave the house.”

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

Case Study: Azra

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.

“I liked my carer because we could laugh together.”

“I can only talk about one problem but I have so many.”

HEALTH CONDITIONS
• Diabetes
• High Cholesterol
• Back problems
• Recent liver operation

HEALTH PROBLEMS
• GP Band
• Make Over a wish forIncontinence
• Social services Home care to fit her needs.
• Home care After liver operation – greatly, loved having company.

WHAT DID YOU 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, or depressed however we discovered she spends whole days crying. She had no idea there might be support for issues like this.
Section four: how can we engage

Design Workshops – This could include but not limited to:
- Personas
- Pathway mapping and design
- Appreciate inquiry / roots and fruits

The CCG has used these approaches to help plan where services are in the new Dulwich Health Centre, the healthy weight pathway and the are coordination approach with people living with multiple long term conditions.
Section four: how can we engage

Design Workshops – personas

Personas are fictional characters that could be real and are developed in conjunction with clinicians.

Personas should include the persons likes and dislikes, their networks, their hobbies and their thoughts and feelings as well as their medical conditions. Personas should also include a photograph and a name to promote empathy.

The aim of using personas is to help your group to empathize with another person, put themselves in their shoes and begin to think about what life is like from their perspective.

You can use forum theatre to bring personnas alive if working with children or young people, which the CCG did at its joint CYP engagement event with Healthwatch.
Section four: how can we engage

Co-design

Design Workshops – pathway mapping and design

Once you have developed your personas you can then begin to map and design your new pathway or service. You will need to ask your group questions such as:

1) How does your persona access the service?
2) What motivates your persona to access the service?
3) What does the service look like? Including what professionals and elements make up the service
4) What changes/improves once your persona has used the service? This is to look at outcomes
Section four: how can we engage

Co-design

Design Workshops – appreciative inquiry / roots and shoots

AI is a style of workshop that looks at assets instead of deficits and solutions instead of problems using creative methodology such as story telling and art!

The five elements of AI are highlighted in the diagram below.

The CCG used this approach with the Local care Networks when working with people living with three or more long term conditions on person centred care coordination approaches. We used a roots and shoots approach to help people identify what is important in their lives (the fruit) and what they need to be in place to help them achieve this (the roots). This then forms the basis of person centred care coordination.

Appreciative Inquiry 4-D Cycle

- Discovery
  - "What gives life?"
  - (The best of what is)
  - Appreciating
- Positive Core
  - "How to empower, learn and adjust?"
  - Sustaining
- Dream
  - "What might be?"
  - (What is the world calling for)
  - Envisioning Results
- Design
  - "What should be - the ideal?"
  - Co-constructing

My goals and what is important to me

- **Affirmative Topic Choice**
- **Destiny**
- **Dream**
- **Design**

What I need to help me achieve my goals

- Need support for people to have assistance to go out
- Need to find services that would help if people get to a point where there are barriers - this includes transport
- Need support for people who have mental health needs and their needs to look after their needs
- Need to have easy access to services to support
- Need to work with people to identify how to support people with mental health needs
- Need to be able to develop a more efficient appointment system
- Need to work with people to understand how to support people with mental health needs
- Need to have access to services to support
- Need to work with people to identify how to support people with mental health needs
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- Need to have access to services to support
- Need to work with people to identify how to support people with mental health needs
- Need to have access to services to support
The whole process of engagement can be very empowering for people if done well. This can result in:

- Local people with lived experience on procurement panels
- People setting up their own support groups
- Local people with lived experience on steering groups of the project

The above is in addition to:
- Lay members on Governing Bodies and Committees
- Healthwatch on committees and the Governing Body

Empowered people are more likely to:
- Access health services and health advice
- Be more confident in giving feedback to service providers
- Understand the need for self care
- Understand the need to use health services appropriately
- Have a sense of being cared for
- Understand the need for compliance with medications/treatments etc.
Section five: what is the plan for letting people know about the outcome of the engagement

**Report** – write a report of the engagement. You will need to send this to all people who took part in the engagement (if you have their contact details) and publish on the CCG website on the engagement page which you set up.

**Social Media** – you can arrange for links to the report to be tweeted.

**CCG Newsletter** – links to the report and outcome of the engagement can be included in the CCG newsletter.
Top tips and resources
Top tips …

• Use plain English and clear information:
  • Be personal - use ‘we’ and ’you’
  • Use everyday language and not jargon
  • Think about how you might explain your proposal to a friend or a family member
  • Use pictures that reflect the people you want to talk to
  • Make sure your words and pictures are inclusive of all communities

• Be friendly – this includes being welcoming, talking to people and providing some refreshments

• Try and make the room you are engaging in look colourful and welcoming
Involving people...
 Jacinta & Janelle  
**Single, teenage mum with obesity & her toddler**

### Background

- We live in temporary accommodation and would like to find a more permanent solution
- I’m anxious about Janelle being ready to start school next year – I’m not sure Janelle is ready
- I get left out of activities with my friends – I think it’s because I have a child. This sometimes makes me resent having Janelle in my life
- I have little contact with my family outside of my brother and occasionally my mother
- I sometime feels isolated, lonely and unsupported
- I sometimes regret having Janelle and feel like I’m missing out on life and some of the opportunities that my friends are taking advantage of

### Day to day life

- I like to head out drinking with my mates on the weekend - when they invite me, and I’ll generally leave my daughter with a friend or my brother, or occasionally with my mum – I struggle being a single parent fulltime and not having time to myself
- I communicate with the outside world via social media. I also watch a lot of television with my daughter. I use the internet on my smartphone but don’t have a laptop or computer
- Me and Janelle spend a lot of time together - 6.5 out of 7 days per week

### Well-being attitudes

- I have always thought that because I am young I won’t have health problems
- Last week, my GP advised me that I am obese and need to lose weight, and that my daughter is overweight as well. My GP quizzed me about our diets and said it is not healthy
- I don’t think there is a problem with eating sweets and takeaways regularly

### Well-being

- I have borderline obesity
- My daughter is in the upper weight limits for a child of her age
- Other than that we do not have any current health issues
- We will attend the GP or A&E when we get ill
- I am a smoker but I try to walk most places to save on the bus fare

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**Example of persona**

**Ages:** 19 and 4  
**Ethnicity:** Black-British  
**Relationship:** I’m single, Janelle’s father is known but is not in our lives and doesn’t pay child maintenance  
**Occupation:** I’m a Tesco checkout operator (part-time), I also receive a combination of income support, child tax credits, housing benefits, and a council tax reduction to boost my income  
**Income:** A total weekly income of about £170  
**Housing:** We are living in temporary accommodation in a 1 bedroom flat  
**Education:** No GSCE’s, I left school at 15  
**Languages spoken:** English
Alice
Young Carer

Background
- Alice is a carer for her mum who has Multiple Sclerosis. Her mother has been sick for as long as she can remember, but in the past two years gotten a lot worse and is now stuck in a wheelchair and needs help with normally everyday things like showering and getting dressed
- Alice has been missing school more and more to help her mum and is normally behind on her homework. Her teachers are getting concerned and the deputy head mistress came and visited Alice and her mother a couple of weeks ago to talk to them about it
- Alice’s mum refuses to get full in home care as she doesn’t think it is necessary, and says that they can’t afford it. She thinks the part-time help they currently have for 4 hours per day is enough
- Alice has noticed her mother’s behaviour is increasingly erratic and thinks that she has issues like depression or anxiety, however her mum hasn’t told her GP about how she feels, and Alice doesn’t want to bring it up with her mum
- Alice doesn’t have any family members or friends that can help her with her mother. She struggles to relate to a lot of girls her age and thinks that they are pretty immature

Age: 14
Ethnicity: White British
Occupation: Student
Income: None
Housing: Lives in a two bedroom flat in Denmark Hill
Education: She is registered at her local academy, but has been missing a bit of school because she needs to help her mum and is falling behind
Languages spoken: English

Day to day life
- Alice wakes early and helps her mum get out of bed and get dressed
- She will make them both breakfast and will normally head off to school around 8-8.30am, her mothers carer arrives at 10am normally
- Even when she is at school she finds it difficult to concentrate because she is worrying about her mum and thinking about what she needs to do when she gets home
- She has some friends at school but feels like she isn’t really part of the group because she can’t go out with them at weekends, and she has to rush home after school to make dinner for her mum
- She enjoys reading books as it helps her relax and not think about her troubles

Well-being attitudes
- Alice thinks that the staff she sees at the hospital with her mum are really helpful and nice
- Alice would like to do more exercise and activities that make her happy but doesn’t see how she will be able to find the time to do that
- She tries to cook healthy meals but often it is easier and cheaper to just put a pizza or some chicken nuggets in the oven
- Alice’s health is important to her but she feels that her mum is her priority at the moment

Well-being
- Alice has a lot of stress in her life, most of which is caused by her mum’s illness
- She often gets upset when she’s alone, and she finds that she doesn’t have people she can talk to who can help her
- She has asthma and has been getting breathless more often, she hasn’t been to GP about it as of yet

Example of persona

‘I’m worried all the time, mum is really sick, I’m missing school and getting behind, I’m only 14’
“I would like to commend the ambulance staff and paramedics for their endless patience when Mrs S, my neighbour was going through her ‘ring 999' period.

Although I have no doubt that at some stage they had her flagged up as a 'serial 999er' they never took chances (after all, there was always the possibility that on one occasion, her fears would be justified) and always turned up, checked her out with kindness and good humour (usually in the middle of the night) and gave her reassurance.”