

# Improving Experience of Care through people who use services

How patient and carer leaders can make a difference –  
Appendices

August 2015

# Appendix A

# Membership of the

# patient leadership

# programme

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## Oversight and delivery of the programme

A Programme Board oversaw the delivery of the programme. The Programme Board had the following members:

Name	Role
David McNally	Deputy Director, Patient Experience, NHS England
Steve Sharples MA	Patient Leader, NHS England
Paulette Johnson	Delivery Support Manager, Patient Experience, NHS England
Louise Fowler	Improvement Manager, Experiences of Care Team, NHS Improving Quality

The programme was delivered by an EY team led by Vicky Whelan (Partner) and Dr Anita Goraya (Director) who worked with Georgina Craig, National Programme Manager, of Experience-Led Commissioning and Roz Davies, Chief Executive, We Love Life.

## Patient Leaders Expert Advisory Group

The programme was advised by a Patient Leaders Expert Advisory Group (PLEAG).

Name	Role
Steve Sharples MA	Patient Leader, Chair of PLEAG
Philippa Brannigan	Patient Leader
Louise Fowler	Improvement Manager, Experiences of Care Team, NHS Improving Quality
Elsie Gayle	Patient Leader
Charles Goody	Patient Leader
Paulette Johnson	Delivery Support Manager, Patient Experience, NHS England
Andy Matthews	Patient Leader
David McNally	Deputy Director, Patient Experience, NHS England
Pauline Mountain	Patient Leader
Carol Munt	Patient Leader
Carol Pearson	Patient Leader
Liam Phipps	Patient Leader
John Taylor	Patient Leader
David Trigger	Patient Leader
Michael Vidal	Patient Leader

The PLEAG met on two occasions:

- On 5 February 2015, the PLEAG selected five areas to progress to detailed case-studies
- On 24 March 2015, the PLEAG discussed suggestions for next steps

Colleagues at the Point of Care Foundation and the King's Fund provided further insight when they reviewed the emerging findings in March 2015.

<b>Name</b>	<b>Role</b>
Catherine Foot	Senior Fellow, Policy, King's Fund
Joanna Goodrich	Programme Manager, Point of Care Foundation
Allison Trimble	Senior Consultant, Leadership Development, The King's Fund

# Appendix B

# Learning from

# Phase 1

# Appendix B Learning from Phase 1

We have themed the feedback from the Phase 1 Twitter conversation (Tweetchat) and the workshop under three main messages.

1. Invest in patient leaders
2. Put robust feedback mechanisms in place so that organisations listen
3. Develop the culture and systems to act on feedback

## Main themes emerging from Phase 1

The quotes are verbatim from the tweets posted before, during and after the scheduled one hour Twitter conversation (Tweetchat) and from the table-top post-it notes written by participants during the November 2014 workshop. A hashtag (#) after a quote shows that it came from Twitter.

### Invest in patient leaders

There was a broad sense that the concept of the 'patient leader' was helpful. However, people said that diversity was important and that patient leaders needed to be representative of the community and not an exclusive group in their own right:

- *'Patient leaders are the norm (in 2017)'*
- *'To be honest I don't like the term 'patient leader'. I find it off-putting and not inclusive – that's a problem'*
- *'Training for selected people who have the right values and personal behaviours'*
- *'A bold step would be helping less heard patients become leaders, with extra support where needed'*
- *'I find that sometimes patient leaders don't represent their constituency. Go into community and find energy for change #P4LEC'*

Patient leaders could influence the system positively but needed support to do that:

- *'Most NHS Trusts don't encourage creativity that's where patient leaders come to the forefront we can think outside that box #PL4EC'*
- *'What I've found as a patient leader is you can sneak in and change things from the bottom up that's where the best ideas come from #PL4EC'*
- *'#PL4EC Improving experience of care isn't always top of commissioners and providers agendas – patient leadership can help change that'*
- *'Getting those who don't listen to their patients to listen (active, empathic partnership)'*
- *'Patient leaders need access to health data, support to understand if necessary to build confidence and knowledge'*

Some participants argued that the role should be developed into a full-time role, working alongside NHS managers:

- *'Patient leaders are most effective when solution focused, working with professional as partners. Mutual respect essential'*
- *'Patient leaders become employees with a service redesign or commissioning remit – a full time proper job'*
- *'I would welcome a programme from the Leadership College for patients who want to develop leadership skills, like influencing skills, listening, communicating, and knowledge of NHS structures. This should be selected people who have the right values and personal behaviours'*

- *'To employ the people who the service is for to lead (or co lead) the service, e.g., ex-carers leading the service for carers. People are seen on a par with and paid on a par with other staff'*

There were different views about whether the NHS should pay people who give their time for extended feedback:

- *'#PL4EC A trust manager was surprised when I asked for an honorarium for spending five hours at a meeting. Did I feel valued? I will get my expenses, but it was five hours of my time'*
- *'I agree about expenses for volunteers but I am not sure about payment #PL4EC'*

Patient leaders could also help fellow patients in navigating the system and taking responsibility for their own health:

- *'An ability to negotiate the barbed wire of the system'*
- *'Peer support to others who can't negotiate the system'*
- *'Patient leaders can encourage personal responsibility for 'own' health/lifestyle, treatment options and after care'*

### Put robust feedback mechanisms in place so that organisations listen

There was a clear sense that organisations should seek feedback and thank people who gave it.

- *'People should be asked 'how was it for you' routinely rather than ever waiting for feedback'*
- *'#PL4EC go to where the patients are don't expect them to come to you'*
- *'Patient Participation Groups a valuable resource to be tapped. Some much more effective than others at the moment though, best practice needs sharing'*
- *'My experience is that patients don't understand the ways to become involved. Focus groups, surveys, conferences need to be better promoted'*
- *'Key we acknowledge/thank/feedback results to those that invest time to improve care/services'*

Participants felt the NHS needed to commit to learning from qualitative data, e.g., storytelling as well as quantitative data, e.g., surveys:

- *'(In 2017) Patient led story telling programmes are in place and are making a difference – shaping services, developing boards, understanding behaviour change'*
- *'We talk about stories and we've stopped using numbers and percentages to measure things'*
- *'It's not that data is unimportant. It's that sometimes people don't want to be treated like data #PL4EC'*

The NHS sometimes duplicated listening activity, which causes confusion:

- *'Any other sensible business would do market research. Patient = customer. No 1 problem – lack of communication and insight leading to duplication left right and centre'*
- *'The real risk that such initiatives for patient participation will not bear fruit because there are so many groups and initiatives actively being encouraged and supported by NHS England without any apparent common learned themes being shared'*

New media increased the opportunities for patients to give feedback:

- *'Well, 77% of the UK population are online at least daily – that's a start #PL4EC'*
- *'Promote a range of different options for involvement. Face to face, social media, written, spoken and visual mediums'*

People said that organisations should reach out to groups who are considered 'hard to help':

- *'There are no such things as hard to reach groups, only people who we haven't asked an interesting enough question yet. Go, ask! #PL4EC'*

- *'And for every 'hard to reach' group is an ignored voice 'cause it wasn't saying what we wanted to hear #value #PL4EC'*
- *'Use Easyread and simple language'*

## Develop the culture and systems to act on feedback

There was a strong view that organisations needed to act on the feedback they received:

- *'We sometimes forget that hearing and listening are different'*
- *'It seems easy now, with social media, for patients to have a voice, but still not easy to be heard or make a change #PL4EC'*
- *'There is no point in being involved as lay person unless you have impact, either improvement or maintaining services #PL4EC'*

NHS staff should be supported to work in different ways. Participants recognised that effective listening was resource intensive:

- *'Be honest and realistic about time and resource needed to engage with patients effectively #PL4EC'*
- *'Train NHS staff and the public to work together'*
- *'Invest time up front in relationships that will support co-production. Great dividends returned #PL4EC'*
- *'This requires culture change, not easy. Staff need to be supported, encouraged and helped to change behaviour'*
- *'Need to identify best practice and spread it around'*

Participants suggested that NHS organisations should be obliged to and be held accountable for involving patients in commissioning and designing services:

- *'Becomes totally non optional – NO service redesign or change approved if front line staff and patients haven't been involved from the start'*
- *'Every CCG must complete a significant service re-design led by patient and staff insight'*
- *'True power-sharing – patients and professionals. People buying the service have specific knowledge of that condition/service – follow models from other countries – put your money where your mouth is'*
- *'Influencing commissioning decisions – e.g., CCG patient sub groups, lay members, etc.'*
- *'50/50 membership of NHS Boards, patient leaders and NHS leaders'*
- *'Change NHS contract. Have a new contract that holds everyone to account for improving care experience with measures that will influence providers'*

## Definition of feedback

One of the main conclusions from Phase 1 was the importance of feedback. This was the most mentioned word from the Tweetchat and the workshop and therefore formed the scope of the subsequent phase. The programme team collated the verbatim points that Phase 1 participants made on organisational behaviour around feedback. These points are set out below.

### Getting feedback

The organisation:

- Has a single point of entry for anyone who wants to feedback about their NHS care experience. People say it is easy to feedback and find out how to do that
- Uses simple, jargon free words in its workshops and surveys including easy read formats
- Makes its feedback events and ways of working with people fun
- Collects not just numbers (surveys); collects stories and values qualitative data equally too



- Runs feedback work as a continuous conversation rather than 'one off' events and surveys
- Focuses less policy tick boxes; more on using feedback to improve its care/management decisions
- Has a range of ways to listen to and hear what matters to people and families, including:
  - Patient leaders gathering ideas, feelings and feedback from people and families who use services, e.g., community researchers; patient assessors
  - Real time feedback systems/questions
  - Using stories to understand care experience
  - Going to where people are, e.g., school gate
  - Providing new, creative 'spaces' where groups of people can work and design together, e.g., people, families and front line staff and special interest groups
  - Online conversations and online feedback platforms like <https://www.patientopinion.org.uk/>; <http://www.peblfeedback.com/>
  - Webinars
  - Surveys
  - Analysing complaints and compliments
  - Ways of providing feedback that suit different communication preferences, e.g., the needs of people with learning disabilities, visually impaired and hearing impaired communities
  - Different times of the day so people who work can participate

### **Making sense of feedback**

The organisation:

- Uses feedback from many sources and pulls it all together so that feedback from different sources creates a rich picture
- Sees feedback as being about more than numbers; values stories and qualitative data equally as sources of insight
- People who use services are involved in making sense of feedback
- People who use services work with and alongside researchers

### **Responding to feedback**

The organisation:

- Uses patient leaders (people and families) to assess and decide how to respond to feedback
- Measures different outcomes; ones that are designed by people and families and reflect what matters to them. This means that outcomes that not only about the medical things
- Has contracts and purchasing processes that measure these different outcomes so that medical people and organisations are only paid if they do what matters to people and families really well
- Involves people and families. This includes:
  - People and families being paid for their input
  - People and families helping to provide services. This is sometimes called 'coproduction' of services
  - People and families helping decide how services should work, be designed and/or be commissioned. This is sometimes called 'co design' of services
  - People and families jointly commissioning services with the NHS management people – 'true power sharing'
  - People and families having and using personal budgets; pooling of personal budgets to commission together
  - People and families being more in charge and signing off changes in services or contracts

**Feedback to people and families**

The organisation:

- Prioritises making feedback to people and families a 'MUST DO' or ALWAYS EVENT
- Involves people and families in the running of the feedback process; encourages people and communities to hold the organisation to account for feeding back
- Uses online really well and as an efficient way to feedback (77% of people in UK are online every day)

The research team took these points into Phase 2 and worked with the case-study sites to develop this feedback model further.

# Appendix C

## Examples of good practice

# Appendix C Examples of good practice

In Phase 2 of this programme we considered examples of NHS organisations in England that are carrying out good practice to improve patient experience of NHS care. Participants in Phase 1 highlighted over 50 NHS organisations that were involving patient leaders or working to improve care experience with people and families. NHS England local Area Teams added further examples to the list.

We investigated further and 27 of these organisations were specifically working to use feedback and feedback systems to improve care experience in partnership with patient leaders. Of those 27 organisations, 17 organisations were willing to participate in this research and could demonstrate that they had made progress on improving care experience by working with patient leaders using feedback.

We carried out telephone interviews with the key system leader or leaders within the 17 organisations and produced a two page summary for each example. There were 18 examples in total as one organisation produced two examples. Four of these organisations were subsequently selected for a site visit, resulting in a detailed case-study review.

The 14 organisations which provided a telephone case review are listed below.

Reference	Organisation	Contact
C1	NHS England: Devon, Cornwall and Isles of Scilly (DCIOS) Area team	Nikki Thomas <a href="mailto:nikki.thomas@nhs.net">nikki.thomas@nhs.net</a>
C2	NHS England: Arden, Hereford and Worcestershire Area Team	Claire McWilliams (Quality and Patient Experience officer) <a href="mailto:claire.mcwilliams@worcestershire.nhs.uk">claire.mcwilliams@worcestershire.nhs.uk</a>
C3	NHS England (Thames Valley)/ Oxford Academic Health Science Network leadership programme	Kathryn Davies (NHS England Patient Experience manager) <a href="mailto:kathryn.davies13@nhs.net">kathryn.davies13@nhs.net</a> Julian Hendy (Hundred families) <a href="mailto:julian.hendy@btinternet.com">julian.hendy@btinternet.com</a>
C4	North Lincolnshire CCG	Jane Ellerton (Senior Manager Commissioning) <a href="mailto:jane.ellerton@nhs.net">jane.ellerton@nhs.net</a>
C5	East Riding of Yorkshire CCG	Sally Ann Spencer-Grey (Lay Member, Public and Patient Involvement) <a href="mailto:Sally.spencer-grey@nhs.net">Sally.spencer-grey@nhs.net</a>
C6	Slough CCG	Jacky Walters (Prime Minister Challenge lead) <a href="mailto:jackywalters@nhs.net">jackywalters@nhs.net</a>
C7	Herts Valleys CCG	Dr Marianne Essam (GP, Clinical lead for Integration and Partnership) <a href="mailto:marieanneessam@nhs.net">marieanneessam@nhs.net</a>
C8	North Somerset CCG	Mary Adams <a href="mailto:mary.adams@northsomersetccg.nhs.uk">mary.adams@northsomersetccg.nhs.uk</a>
C9	Northumbria Healthcare NHS FT	Annie Laverty <a href="mailto:annie.laverty@nhct.nhs.uk">annie.laverty@nhct.nhs.uk</a>
C10	King's College Hospital NHS FT	Jessica Bush (Head of Patient and Public Involvement) <a href="mailto:jessica.bush@nhs.net">jessica.bush@nhs.net</a>

Reference	Organisation	Contact
C11	Blackpool Teaching Hospitals NHS FT	Fiona Jones (Patient Experience Officer Child Health and Neonates) <a href="mailto:Fiona.Jones@bfwhospitals.nhs.uk">Fiona.Jones@bfwhospitals.nhs.uk</a>
C12	Royal Berkshire NHS FT and Berkshire Healthcare NHS FT	Carol Munt (patient leader) <a href="mailto:Munt12@aol.com">Munt12@aol.com</a>
C13	University College Hospitals London NHS FT	Julie Lewis (patient leader) <a href="mailto:judemlewis@gmail.com">judemlewis@gmail.com</a> Hana Ibrahim (Macmillan) <a href="mailto:Hibrahim@macmillan.org.uk">Hibrahim@macmillan.org.uk</a> Dan York (General Manager, Orthopaedics and Head and Neck) <a href="mailto:Dan.York@uclh.nhs.uk">Dan.York@uclh.nhs.uk</a>
C14	NHS England Thames Valley Area Team	Kathryn Davies (NHS England Patient Experience manager) <a href="mailto:kathryn.davies13@nhs.net">kathryn.davies13@nhs.net</a>

The research team carried out detailed site visit case-studies for the following four organisations:

1. Birmingham CCGs
2. Ipswich Hospital NHS Trust
3. Midlands and Lancashire CSU
4. Shropshire CCG.

Further information on these sites is set out in Appendix D.

## C1: Devon, Cornwall & Isles of Scilly NHS England area team

### Brief description of programme:

Funded from NHS England Compassion into Practice monies – part of 6Cs Programme 2013/14 and in response to i) individual requests for Patient Participation Group (PPG) development and ii) GP practices in the area receiving over £1mn from the PPG Direct Enhanced Service (DES) payment. This programme sought to:

- Explore new and improved ways for patients and the public to work with primary care and its commissioners
- Provide commissioners with different information and support – beyond numbers and from independent sources (Patients Association/Devon Health & Social Care Forum/Healthwatch) where people feel safe to be more honest
- Ask the independent sector to lead developments as they have existing embedded and vibrant community networks
- Involve everyone at once – scale up from day one
- Achieve improved patient/public outcomes from the DES including improved involvement and engagement in primary care

The Programme began in 2013 and has four phases:

1. **Patient Participation Group (PPG) development:** This phase is close to completion. The Patients Association has worked with its ambassadors who have supported 229 patient participation groups and 230 GP practices to develop PPGs. The programme steering group is 100% patients. NHS England does not attend nor influence programme delivery. 8 workshops are complete; 3 more are planned. 58% of GP practices have attended a workshop. 95% have been contacted by phone – including practices that did not receive or submit a PPG DES payment. Practice managers are using their newly-found connections to engage and support PPGs. Large numbers of patients have been mobilised and supported to get involved.
2. **Patient Leadership development support for 75 patient leaders:** Transition to Phase 2 has begun. The Centre for Patient Leadership will deliver the first of three training events in June 2015. Training is now likely to be oversubscribed. As a result, the Area Team has approached the local independent Leadership Academy to sustain and expand patient leadership support. An important element of training is building a network of patient leaders across the health system who can work with each other to develop an understanding of whole patient pathways.
3. **Patient Experience 'Rate and Review' Feedback Online Platform:** Led by Heathwatch Torbay the Area Team invested some of its grant money to spread this local innovation across all 5 local Heathwatch organisations. The Academic Health Science Network agreed to seek additional funding to develop the platform. This tool now provides a way to leave feedback about all services in the area through a single access point. There is a paper as well as electronic version. Once every 24 hours, the tool automatically does a 'social media sweep' that identifies comments about care in the area on various social media platforms. All data collected is subject to 'Sentiment Analysis', which identifies positive and negative experiences. Feedback is published online. Insight is available on a Dashboard that is reviewed by the Area Team's Quality Surveillance Group. The Group is now looking at how it can provide an early warning system around care quality locally. Currently individual providers cannot access bespoke reports. This is a planned future development.
4. **Patients Assembly for Primary Care:** the PPG patient leaders trained in Phase 2 will take this forward. The ambition is to explore how to involve patients in co-commissioning of primary care in light of current developments and Area Team is open to how that might happen – and wants patients to decide how best to do it. It may not be an 'assembly' as imagined by the Area Team.

### Impact and changes the programme has created

- NHS England has stepped back. Patients have led the PPG Development Programme themselves, supported by Patients Association = big change in NHS behaviour
- Engaged 3 CCGs, 229 PPGs, almost 230 practices, 5 Healthwatch organisations
- Supported PPGs to connect with their practices and identify shared support needs and common areas of focus, e.g., PPGs and practices say they want training – not toolkits; to focus on health improvement – not raising money for the practice; a different name
- Toolkit designed and created by patients
- Relationship with Plymouth university – student nurses & PPGs pilot
- PPG conference in July 2015
- Creating sustainability in the future
- Built a vibrant community of engaged primary care patient leaders
- Supported development and spread of a whole new way of gathering feedback, led by Healthwatch, that overcomes patient experience being ‘hard to measure’

All three initiatives have been rolled out across the Area Team’s patch from the start. This programme is about system change. It cannot demonstrate change in care experience yet.

### Key learnings

- Co-production takes more time. Patients work at their own pace and this needs to be understood by the NHS. The system needs to work at that pace too if work is to be patient led
- The organisation supporting the change needs to be clear about its vision and the principles it is championing – then step away from controlling how change happens and the solution. This requires bravery and ambition
- Scale from the start – or you will never scale
- Get everyone involved in building one local feedback system to avoid duplication and everyone asking patients about the same thing
- Time pressure about spending money can drive the wrong behaviours. One solution is to pass the money on to external organisations with a co-design mentality. They will ensure the work is done well and in the spirit of co-production

### Replicable?

*‘Yes, if you are brave and ambitious’*

## C2: Arden, Hereford and Worcestershire NHS England area team

### Brief description of programme:

This area team started developing its NHS Patient Leadership Programme in 2013, driven by NHS England's Everyone Counts Programme in 2012/13. The area team and 7 local CCGs established a Patient Forum which first met in 2014 with a view to members getting involved in:

- Commissioning decisions and procurement processes
- Story-sharing events, including webinars
- Providing feedback to influence redesign

The Forum now has 16 Patient Leaders. They meet 2-3 times a year to gain peer support. They are passing on their learning to a new generation of Patient Leaders to sustain involvement locally.

In July 2013, the area team facilitated a successful bid for 3 CCGs to become a Friends and Family Test (FFT) pathfinder for FFT with stroke survivors. The Area Team and the Stroke Association wanted the work to cover the whole stroke survivor pathway. The CCGs agreed with this approach. The Area Team set up a Programme Board, including key decision makers: ambulance, A&E, ward teams, GPs, social services, community teams and the voluntary sector as well as survivor champions. Four stroke survivors got involved and worked with The Stroke Association and CCGs to deliver the 8-week programme. Bringing everyone together to focus on understanding the patient's story for FFT opened up a broader redesign conversation. As a result, the CCGs agreed to extend the programme funding to 12 months to cover project leads' time.

Supported by the area team, the CCGs redesigned FFT in collaboration with a group of 20+ stroke survivors whom Stroke Association brought together. They included young and black and ethnic minority survivors. The CCGs worked with stroke survivors and these four champions through a series of co-design workshops. They created bespoke FFT questions; guidance for health professionals on using FFT with stroke patients (making sure people's true meaning is understood). The Stroke Association trained 7 volunteers to test FFT questions. The learning from FFT work is available for all to use on NHS England website.

After the FFT pilot, the CCGs further analysed free text FFT comments. They brought this together with existing insights and data from NHS, social care and The Stroke Association. The patient champions also shared their experiences and helped to make sense of the feedback. The insights showed that when people have a stroke, services are not connected – especially around key transitions like from going into the ward; coming out of hospital and back home in the community. At 8 weeks, people said they often find out they cannot return to work and have financial worries. At 6 months people were reflecting and often got depressed. At 12 months, people were starting to live life as a stroke survivor, which is like living with a long-term condition. People need access to physiotherapy. The Area Team identified a significant group who were diagnosed as 'not had a stroke'. They were discharged with no follow up nor support to make lifestyle change. They championed this group to ensure services were commissioned to meet their needs.

The Area Team was already organising workshops for GP practices to launch FFT. They invited the four champions to attend and tell their stories to raise awareness of stroke and how to tailor FFT to their needs. Feedback from the event showed that this session was useful. The champions also got involved in The Patient Forum. Over a year down the line, the three CCGs have responded to the insights and modified service design to improve experience (see below). The Area Team has shared the learning with its seven CCGs and beyond. Work is happening in all seven CCGs as a result.

### Impact and changes the programme has created:

- **Developed a responsive FFT for stroke survivors:** wording and font size; in built quality assurance test to check accuracy of response; specific questions for stroke survivors
- **Engaged patient leaders:** starting to take control and build sustainable patient leadership through peer support, training and mentoring
- **Improved service design:** receive a discharge pack automatically; GP informed immediately; GPs offer counselling routinely; patients get financial advice at 8 weeks; open door physiotherapy; proactive lifestyle support linked to acute provider to catch people who had 'not had a stroke'



**Key learnings:**

- Walk the whole pathway in the shoes of patients. Involve patients with relevant lived experience. Use their stories and insights to engage hearts and unite different stakeholders across the pathway around shared purpose
- An area team can play an important role, facilitating, supporting and bringing people together and can join things up and enable collaboration
- There are lots of insights out there already. People often do not share them. A focused, connected piece of work can encourage data sharing. Working with existing data brings better insight for less investment
- Language is big issue when working with stroke patients. They sometimes say yes and mean no so it is important to keep checking back using simple tools
- Eight weeks is not long enough to do a pilot like this well and across a whole pathway, which is what needs to be done, CCGs extended the investment to improve the findings
- Learning does not always cascade up quickly or well so spread happens by chance – and only if local teams make the effort to talk about it
- It is amazing what you can achieve when you all work together

**Replicable?**

*'Yes and we are. We have shared the learning across 7 CCGs. We are using the model in COPD and end of life. We have spread stroke work to all 7 CCGs. It has been adapted so non clinical lead organisations like Healthwatch can use it. I am really proud of everyone's hard work'*

## C3: Thames Valley NHS England area team/Oxford Academic Health Science Network

### Brief description of programme:

In 2012 this Area Team responded to the increase in homicides carried out by people with a history of mental health by building a partnership with the charity Hundred Families:

*'it seemed to me, after supporting many similarly affected families, that the NHS dealt very poorly with those left behind (either through fear or institutional blindness) and that if anything was going to change, we needed to engage constructively with the NHS to try and secure lasting improvements and embed real learning after these tragedies.'*

The experts say 20-35% of homicides are avoidable. After the NHS reorganisation, this Area Team recognised that things had to change and the NHS had to listen to the victims' voice. Working together with Hundred families, they created an overarching vision to:

- Engage with and learn from bereaved families whose loved ones had died in this way
- Co-create an NHS support service that is user sensitive and responsive to the needs of the families of both victims and perpetrators
- Make families integral in NHS investigations
- Embed learning into practice
- Translate policy into practice by learning from families in order to prevent further avoidable deaths
- Ensure the NHS hears families' voices throughout investigation and that they get full answers to their questions
- Educate and inform commissioners using 'conversational methodology' that captures stories and uses the power of film to get key messages across to wider audiences
- Run learning events, facilitated by families that bring the experiences of victims to life and move away from statistics to real people
- Make feedback work continuous; not a one off to show that the NHS has engaged with families; it is a high priority that the NHS keeps learning and improves the investigation process for families
- Look critically at action plans and ask what has actually been done to improve things, and what has changed in practice on the ground?

### Impact and changes the programme has created:

- Access to senior people at CCGs for families
- Victims are treated as an equal with a valid view
- Victims have contributed to consultations around preventing avoidable deaths in the future
- Victims have helped develop a single operating model for the 'serious incident framework'. The framework is used to investigate serious incidents
- Investigations have got quicker (something important to families) and almost all now have some involvement and feedback from victims' families
- The NHS is hearing families' voices – although it is a bit too early to say there has been lasting change

*'I can't tell you how valuable yesterday's session was. Yet again, new pieces of information for me to personally digest and work into our programme, but also for my new team. For them to hear first hand, objective feedback on the current state of play, at the very start of this work, sets us up in exactly the right mind-set in a way that I don't think anything else could.'*

**Key learnings**

- Strong NHS leadership has driven the programme
- Patient leaders' impact increases when they get to know key people who can make change happen
- You need to have real and meaningful conversations with people
- There has been good uptake in some parts of the system. It is unclear why there is uptake in certain 'pockets' of country and not others; do not yet understand the dynamics of spread
- It is important to be able to evidence efficiencies or cost savings due to better use of feedback from families of victims. But this is more than a financial saving. You need to measure and value financial benefits and emotional and psychological benefits equally
- Decisions made by busy professionals can have terrible consequences in terms of both homicides and patient suicide

**Is this replicable?**

*'This should and could be easily replicated around country. We need real leadership and the will to make it happen. Some resource to assist families volunteering for these roles would be very welcome'*

## C4: North Lincolnshire Clinical Commissioning Group

### Brief description of programme:

Right from the start (2011), the clinical leaders within this CCG felt that patient and public engagement should underpin service design. The CCG has two main approaches to engaging people and getting feedback:

1. **The Experience Led Commissioning (ELC) Programme.** Patients and their carers come together with health professionals in facilitated events to co-design what the CCG will go on to commission. The CCG has been using this approach for at least two service re-design projects each year since 2012, including services for dementia, long term conditions, mental health and end of life.
2. **The Embrace Patient Network.** Set up in April 2014, this currently has 120 members; people who have registered interest in being involved in shaping local NHS services. This work is at an early stage of development. As the network expands in the future, it will create a larger database of people to be invited to share their experiences and thoughts on relevant topics – by whatever means suits them, e.g., by mail, email, surveys, focus groups or events. People will receive feedback on how their contribution has helped to change patient experience in the way they prefer.

Other ways that the CCG is gaining feedback from patients and carers includes:

- A 'talk to us' email and a telephone contact point
- Patient representatives join working groups and help specific projects, e.g., continence service redesign
- Engagement events to support development of the local commissioning plans for example a specific Lesbian Gay Bisexual Transgender engagement programme
- Attending regular meetings such as Carer Advisory Group to gain an understanding of people's experiences
- Delivering specific events to seek views of patients and public

### Impact and changes the programme has created

- Members of the End of Life ELC Programme co-designed the CCG's advance care planning process and record – now in use across the whole CCG
- Members of the Dementia ELC programme developed patient and carer information for people with dementia
- Many people with long-term conditions were unhappy with some of their experience within outpatient services. Co design work, insights and ideas led to the development of a volunteer network to help and support people in out-patients and implementation of a pager system so that people can sit in the hospital café while they wait for their outpatient appointment if they wish
- The Quality Group of the CCG Governing Body collates patient feedback data in its monthly meetings. This means that service performance measures are brought together with stories showing people's experiences of the service. The CCG uses this information to challenge its providers about patient experience
- The ELC process is delivered by local staff, trained in this method. The team comes from a variety of stakeholder organisations, including: the CCG, the local authority, local hospital Trust, Healthwatch, Commissioning Support Unit and the voluntary sector. This has helped gain their engagement in these change programmes as well. These organisations help to develop the proposals and then are part of delivering the changes that people want to see
- There has been a culture change across the CCG and its partner organisations about how people's involvement can help effect the changes that matter to people. This is now the way we do things around here

### Key learnings

- Strong clinical leadership from the outset helped create the change in culture and mind-set needed for this work to happen
- Engagement and co-design with patients and carers take time and expertise
- If it is done well, engagement and co-design can really support commissioning things that matter to people rather than focusing purely from the health professional's perspective
- Patients and carers very much value being involved in service design
- Even what seem like small changes can sometimes take a long time to actually translate into action. Identifying what people want sometimes exposes the bureaucratic challenges in the system
- Some people may not see themselves as Patient Leaders, but they are willing to engage on topics that are of interest to them. Other people identify themselves more clearly as Patient Leaders and may have a wider understanding of the health and social care system and how it works. Both groups are very important in improving patient experience through feedback. They may have different training and engagement needs and preferences which need to be taken into consideration
- The CCG continues to work towards inclusion of patient centred KPIs into contracts based on its insights – partly because service specifications for new models are still in development, and partly because translating patient feedback into formal performance measures can be difficult. The CCG takes learning from all its programmes into account as it develops service specifications for new services. There are some common themes from the programmes around access and support that people say would help them stay well and reduce the need for hospital admission. The plan is that these common themes will be reflected in future contracts

### Replicable?

*'Yes, this is very easily replicable. ELC is a recognised programme for patient, carer and staff engagement and experience based co-design is widely used. The Embrace Network is similar to approaches used by other local CCGs too. The CCG drew on the experience elsewhere when developing the Embrace network'*

## C5: East Riding of Yorkshire Clinical Commissioning Group

### Brief description of programme

The CCG carried out a review of its research practices and found that i) there is not always sufficient research evidence on which to base its decisions and ii) that insights of both patients and clinicians should be taken into consideration in commissioning. The CCG therefore adopted a knowledge, learning and project management approach which values three domains of evidence equally:

- Published evidence, e.g., research evidence/evidence from literature
- Practitioner and clinician wisdom – lived experience and expertise
- Patient and carer wisdom – lived experience, preferences and behaviours

As part of decision making, the CCG takes into consideration evidence provided against all three domains.

The CCG appoints a 'patient champion' in every commissioning programme delivery team. The 'patient champion' ensures that patient and frontline team involvement is timely, robust and proportional – with evaluation built in. Patients, the public, carers and clinicians are equal members of programme delivery meetings. Every programme tracks involvement, communication and engagement and scrutinises how those insights gained are informing programme development.

Future hospital design: Local concerns about clinical safety led to the temporary suspension of medical admissions in a key hospital provider. This became a permanent situation in November 2013. The CCG set up a Stakeholder Liaison Group which includes: Patient Participation Group members from local GP Practices; Healthwatch; Health and Wellbeing Overview and Scrutiny Committee members; town councillors; the local MP; The Courtyard (a local voluntary sector organisation) and local patient representatives. GP practices and members of the hospital's clinical teams are also involved. Together, the group has:

- Developed the evaluation criteria and assessed existing and potential future models of service delivery based on a set of core principles: 'centralise where necessary, localise where possible'; optimise access; meet local health needs
- Created 'principles of engagement' to inform development of future consultation or enhanced engagement work as well as on-going engagement around four working groups: Minor Injuries Unit (MIU), Health Campus, Medical Inpatient Beds and Elective Care Services
- Assessed how the hospital development programme fits with the wider whole system transformation programme so the two align
- Influenced programme governance and the set-up of the Programme Board

The group has also used insights gained from hospital staff drop in sessions to inform planning.

CCG engagement, involvement and communications strategy: The CCG worked with: CCG and provider employees; the Disability Advisory and Monitoring Group (DAMG) and East Riding Equalities Network (EREN) to review its draft strategy. The group provided feedback – in particular on how to make the engagement strategy easier to read and engage with. The CCG launched the engagement, involvement and communications strategy at its Annual General Meeting in June 2014.

### Impact and changes the programme has created:

#### Developing future hospital design

- The community has felt part of the journey and its relationship with commissioners and the provider has changed. The community is challenging providers about things that the CCG cannot, e.g., car parking policy. The community is supporting tough CCG decisions with local people
- CCG now takes a more 'blank sheet' approach to planning because that leads to more creative solutions developed from within the community
- A greater emphasis is placed on transport and early repatriation and local re-ablement support when someone has to go to a hospital some distance away for treatment
- The CCG has more information about existing community services

**CCG engagement, involvement and communications strategy**

- Is only three pages long (reduced from 60 pages) with one strap line
- Uses simple language and includes a glossary of definitions; has a written easy read version and a video with audio and British Sign Language narration. These are all available on line
- Has a re-drafted, positive equality and diversity section
- Amended its strategic goals so that they are: clear, measurable and achievable.

**Key learnings:**

- Be transparent, open and honest about what is not possible and why. Keep people well informed at all times. Meet even if there is nothing new to report. Keep checking that you have correctly understood what people meant. Ensure you have gained agreement before moving on. This builds trust and sustains involvement
- The community will support tough decisions when they have been involved. Demonstrate the impact and influence that peoples' contribution has had at all stages. Producing simple to read documents shows you really value and understand what matters to patients

**Replicable?**

*'Yes. We are applying the same model to development of community hubs, embedding in service specification and route to market processes'*

## C6: Slough Clinical Commissioning Group

### Brief description of programme:

This CCG has always been a low performer in the GP Patient Survey results for satisfaction with access to a GP, making an appointment and opening hours in particular. The local population is ethnically diverse, with a high transient population, language and cultural barriers and high rates of unplanned need for care. The CCG chair provided strong leadership and started a new Patient Reference Group (PRG) in January 2014. Representatives from 14 of the 16 practices attended the first meeting. They began to discuss what 'great' primary care in the area would look like and how it could be delivered, meeting monthly and continuing to do so a year later.

By April 2014, the CCG had become one of the Prime Minister's Challenge Fund pilot sites, receiving nearly £3mn investment to support its pilot work in improving access to primary care, including this patient/public engagement work. In May 2014, every practice had an Open Day in which trained patients, CCG, local authority and voluntary staff facilitated conversations with patients about what helps them to keep well. They tested the ideas that had come from the PRG patient leaders about great primary care and generated new insights from around 550 people. The patients want to lead a similar event planned for May 2015. The CCG used an experience led commissioning process to undertake this work and analysed the data to understand how the experience of specific groups can be improved, e.g., parents with young children, people with long term conditions.

PRG members fed back the impact of their work to their practices via the Practice Participation Groups (PPGs). The CCG also use local newspapers, radio and TV communications to highlight change. The PMCF work is also fed back to the CCG Governing Body so that it can contribute to commissioning plans. Patient feedback work is also included in the weekly e-bulletin that goes to all primary care staff, including an 'insight of the week' section.

The CCG is planning an open event in March 2015 to present 'you said, we did' case studies to all interested stakeholders and members of the public. By then, there will be more tangible outcomes from the various projects and work-streams initiated throughout 2014 to feed back upon. The CCG will produce posters to show how patient feedback has been used to make a difference. Some patient leaders along with their lead GPs may record videos of their work and its impact to share on their practice TV screens in the waiting rooms, the CCG and other websites.

PRG members have been given extensive support to building relationships and connection with their individual practices and to reflect on their communication styles; how best to influence and improve their engagement with CCG, GP practices and the public. As a result they have influenced every step of primary care strategy development and have had intense involvement with specific projects too.

### Impact and changes the programme has created:

By August 2014, the CCG had started to provide seven-day access with four 'cluster hub' practices open until 8pm on weekdays and 9am to 5pm on weekends. The CCG obtained feedback from over 600 patients, using these new services through paper surveys over a two-week period in October 2014 and a further week in December. This showed that 98% of patients were either 'satisfied' or 'very satisfied' with their experience of the new service.

By October 2014, the CCG's engagement work and patient insights led to an additional 11 projects, based on what people had said would help them to keep well and use services more appropriately. These include:

- Patients work with GPs to develop a 'Simple Words' training programme to reduce the use of jargon during patient consultations and to improve the experience for doctor and patient
- GP and nurse led group consultations for a range of patients, including those with long term conditions, so they can support themselves more effectively and gain peer support
- A text service so patients receive appointment reminders and public health messages and can cancel appointments by February 2014
- GPs going into primary schools and talking to children about using health services so that they share their learning with their parents and influence their behaviour through 'pester power'



The CCG has worked closely with colleagues from the local Council for Voluntary Services (CVS). This organisation is ideally placed to reach people who do not visit their GP practice often and do not participate in PPGs or are from ethnic minority groups. Similarly, by liaising closely with Healthwatch and the Borough Council, the CCG has seen people come forward to participate in engagement events that the CCG alone normally would not have reached.

**Key learnings:**

- Truly listening to patients has generated innovation
- Patients are willing to put in enormous effort and resource to improve services
- PRG members have benefited from training in leadership skills, such as active listening and providing constructive challenge. This type of training needs to be framed carefully as not all patients see themselves as 'leaders' and may be put off by such terminology
- PRG members have come to work effectively as a group, supporting one another and functioning as a team. They are willing and able to consider their future as a group, developing formal Terms of Reference and considering succession planning
- Clinical leadership is essential. The enthusiasm of a few clinicians brings many others into the new culture of truly engaging with patients and the public

**Replicable?**

*'With the right clinical leadership and the commitment of the CCG Governing Body, this work can be replicated but it does take time and needs dedicated programme management'*

## C7: Herts Valleys Clinical Commissioning Group

### Brief description of programme:

This CCG benefited early on from a strong focus on engagement. The CCG leadership, assisted by a passionate GP patient participation lead, developed an engagement strategy to ensure patients are involved.

The CCG encourages practice patient participation groups (PPGs) to feed into locality groups. The locality groups vote two of their members onto the CCG Patient and Public Involvement Board sub-committee. Two of its members then sit on the CCG Board. In addition, two patients sit on every CCG decision-making sub-committee.

Every locality group has a GP patient participation champion. The unique strengths and passions of these GP locality leads have enhanced the CCG's ability to engage the public; notably one GP who has extensive experience in engaging people from minority ethnic groups.

Alongside this governance structure, the CCG has developed a 'People Bank'. This now has over 1,000 members who are interested in different areas of care and are available to help. This feels like, 'a huge fraternity of patients who are with us as we go'. The CCG and social care team jointly produce a colourful e-bulletin. The CCG also has a 'Readers Group' which provides comments on documents and check that they are written in a way that the public can understand.

Patients and carers are involved in clinical commissioning. Healthwatch ensures that patient opinion is assessed in an unbiased way. The CCG holds 'Conversation Cafes'. At these events, people are invited to respond to an improvement question, e.g., what can we do to make this town a healthier place to live? There is always a lively debate. Local stakeholders have 'market stalls' at these events, e.g., housing, charities, meals-on-wheels and so they have the opportunity to make connections, develop relationships and uncover 'instructive stories we can build on'.

The CCG inherited an outspoken patient group who campaigned to keep a local hospital open. The CCG has invested in patient leadership training. Through engaging with the group and individuals and demonstrating its willingness to listen, it has gained their trust and respect, and we are working together on sustainable solutions.

Early on, the CCG won a National Association for Primary Care Patient Participation Award. This made everyone very proud and was an early win.

### Impact and changes the programme has created:

- Because the CCG designed all its systems and governance with patients from the start, it has not needed to change much as yet
- Through its People Bank, within as little as 24 hours, the CCG can get people together in a room
- At Conversation Cafes, patients' issues sometime get solved on the spot, e.g., a young mum having problems with housing attended and met the housing team at local authority. They looked into her case when she shared her experience of their support at the session
- The critics are now on board. The relationship with the community has matured. Both sides have grown in confidence. Patient leaders recognise the door is open and have built their ability to influence. They speak up and are a positive force for change. 'These days, patients feel empowered and able to challenge'
- Coproduction has become the way we do things around here
- Because local conversations about local care are always close to hand, the CCG has its eye on the ball. It knows quickly if there are issues to address

**Key learnings:**

*'A good consultation is one where you find yourself in partnership with the patient. The same is true of clinical commissioning with communities'*

- Identify champions – both professionals and patients. Tap into their passion and strengths. Recognising enthusiasm and experience grows local leadership
- Asking patients to volunteer to do this work is a big ask, 'It is like inviting them into a one sided partnership. They have no protection in law if things go wrong. The law on volunteering needs to be changed so it protects people. In the meantime, CCGs need to ask, what else can we do to help and support you?'
- Patients value patient leadership programmes and say they helped them grow in confidence; gain understanding of the healthcare system and commissioning
- Invest in solid communications and an administration team to 'run the gauntlet and organise events'
- Offer a range of ways to engage. Not everyone wants to come to workshops
- Encourage GPs to have active PPGs. This may be a good place to start. At PPGs, you may identify people who are more interested in the bigger questions. Tap into their interest and show them the other work they can get involved in
- If you have people on committees, make sure they have the power to make decisions and support them with that. Otherwise it is just a tick box
- Winning awards engenders pride amongst patients and builds engagement

**Replicable?**

*'The things we do like the People Bank and Conversation Cafes and Readers Panel are things others can replicate'*

## C8: North Somerset Clinical Commissioning Group

### Brief description of programme:

This CCG has well-established community networks and relationships and a strong commitment to patient leadership:

- A very supportive chief clinical officer/lay chair
- The patient engagement manager has been working on the patch for 10 years and is passionate about coproduction
- The community services commissioning manager was deeply committed to working in an inclusive way
- When the CCG formed, it supported the Primary Care Trust's lay volunteers to migrate over to Healthwatch and provided them with patient leadership training
- Working with Patient Leaders previously to procure urgent care services

Since May 2014, the CCG has been undertaking a £23-25mn re-procurement of its community services in partnership with the local community and Healthwatch. Healthwatch's chief executive sits on the Community Services Programme Board. Patient leaders are doing the detailed work. The procurement was supported with a strong stakeholder analysis and equality impact assessment to identify key people – and in particular people who are seldom heard.

**Pre-procurement (March-May 2014):** The CCG and Healthwatch created a range of ways of gaining feedback that would be attractive and easy for people. These included a workshop tool kit comprising a standard presentation, frequently asked questions, standard feedback form, Easy Read presentation and hand out. The partners went out of their way to listen to a diverse group of people in places where people were and at times of the day convenient to them. Stakeholder workshops happened outside of office hours so that working people and family carers attended. The CCG used its existing networks and went to existing forums to meet with people. The CCG also gathered online feedback. GP practices had copies of the feedback forms available for patients. Advertising in local press raised profile of the conversation. The CCG saw that having consistent questions was the most fair and robust way to gather feedback. It asked the same questions on-line, on the paper forms and in the workshops. The CCG collected the feedback forms, put them on a database, analysed the results and published a summary report on line. There is a full audit trail of every piece of information received, which is important within procurement exercises.

**Procurement: (May 2014 – present day):** Procurement begins with a Memorandum of Information (MOI). The MOI contains all the information potential bidders need to decide whether they are going to bid. It includes background, objectives, scope and Critical Success Factors (CSFs) for community health services. CSFs are the 'must deliver' things which the commissioner believes will make the final service successful. This CCG made sure the insights generated from pre-procurement influenced both the MOI and CSFs. The CCG also trained 11 patient leaders from Healthwatch in marking bids. Their activities to date include:

- Setting two critical success factor (CSF) questions on community engagement and on social value within Pre Qualifying Questionnaire (two out of total of nine CSF questions)
- Marking bids and being part of consensus scoring meetings
- One of the Patient Leaders is a spokesperson and attends a 'consensus meeting' for final scoring

In the future, these 11 patient leaders will be involved in developing the contract outcome measures, evaluating the final presentations and making the final decision about the successful bidder. The CCG has written personally to the patient leaders to stress how important and valuable their contribution is, and an article in the local press has brought public recognition.

### Impact and changes the programme has created

- People contributing to pre-procurement came from a wide range of ages and diverse backgrounds, including working people and seldom heard groups. Involving people in pre-procurement reinforced the value of their contribution within the process. As a direct result, 11 patient leaders were trained in assessing bids
- Healthwatch and the CCG have used the feedback from the pre-procurement to shape the MOI and CSFs. What people said has directly influenced and shaped procurement
- 11 patient leaders from Healthwatch have:
  - Helped design the PQQ; directly set two of nine CSFs
  - Assessed and scored bids
  - Helped shortlist providers

The CCG's approach aims to ensure that the provider chosen is responsive to what matters to people. In the long run, this should help improve care experience.

### Key learnings

- Commitment from the Programme Board, top team and the lead commissioning manager is key
- Nurture relationships with the community. Build trust over time. Be reliable. Keep turning up
- Offer patient leaders good training, support and public recognition 'as you cannot pay them'. Keep reinforcing the value and importance of what they are doing
- Build in enough time to collect feedback. On a future children and young peoples' service procurement, the Board has extended the timeline to reflect this
- If you have few local networks, build in more time to develop them – or work with others who have the networks and connect through them, e.g., local authority; voluntary sector
- Data analysis and audit is a must do in procurement
- Start all major procurement work with robust stakeholder analysis. Identify and address weaknesses in networks, e.g., the CCG established that it needed to do more to engage with children and young people. In response, it has asked Healthwatch to set up a Youth Forum
- Listen during pre-procurement and show deep commitment to understanding what matters to people. In the subsequent consultation, the conversation is easier and you have more credibility

### Replicable?

*'Absolutely. We are doing it again on a pan-area procurement with young people and children'*

## C9: Northumbria Healthcare NHS Foundation Trust

### Brief description of programme:

In 2009 and motivated by 'doing the right thing', this Trust started to work differently in eight wards and two sites. After five years of steady progress, the Trust has developed a sophisticated approach to using feedback and involving people. It talks to over 50,000 people a year, gathering feedback in a variety of ways – everything from one-to-one interviews with people on wards through to significant redesign programmes and defining improvement measures. It would now be: 'very unusual for a clinical team to improve anything without inviting input from people who use those services'

A recent example of listening and acting on feedback was when the Trust introduced a new car parking system. The system proved very unpopular with patients – with a flood of complaints about how the new company operated the system. The Trust quickly realised this was 'threatening our relationship with the community' and took the difficult and costly decision to sever the contract; 'It was painful, but the right thing to do'.

The Trust uses a range of feedback methods, including: interviews, written and telephone surveys, observation by experts through experience, shadowing, mystery shopping, management walkabouts, social media, stakeholder engagement and experience-based design. It mixes and matches methods to the task in hand, considering a number of things:

- How quickly do we need this feedback and insight to support front line staff and /or management to act and do different things or things differently?
- Which method will provide the best opportunity to get to the heart of how people are really feeling e.g. when interviewed in hospital, people still feel very grateful and may be reluctant to criticise = gratitude bias
- How specific or representative do we need the feedback to be? This impacts on sample size and spread of participants

'Real time' ward interviews are used to keep staff engaged and motivated. They allow the Trust to act immediately to improve care whilst the individual is still in hospital. 'Right time' data gathered after people leave hospital provides 'warts and all' feedback.

For more strategic reviews, the Trust uses a larger sample, designed to minimise bias and produce more authoritative findings. The choice is not data or stories but both.

The Trust seeks volunteers through extensive networks within the local community, voluntary sector, Council of Governors and its large, active membership. Those who have had reason to complain about a service can act as an excellent resource to influence how things can be improved.

The Trust has over 1,000 hospital volunteers, including Age UK volunteers who support patients AND provide immediate feedback about dignity to ward teams – both positive examples and opportunities for improvement.

People with learning disabilities work as health quality checkers and have helped improve oral surgery services. Young people have helped spread 'You're Welcome' accreditation across hospital and community services. Healthwatch colleagues and volunteers act as mystery shoppers for outpatient services.

The Trust is also part of an NHS England Area Team/Academic Health Science Network programme that will see 50 patient leaders trained in 2015. The Trust will lead work on common measurement approaches across the region.

**Impact and changes this programme has created:**

- Significant culture change. Responding to feedback is the way we work around here
- Measurable difference in national results for patient and staff experience
- Many nationally recognised, award-winning examples of measured service improvement and co-design
- Patients who feel involved and listened to
- Staff who welcome feedback

**Key learnings:**

- There is no single method of feedback that gives you all you need. Match the method to the task. Understand the benefits and limitations of each approach
- Measure at different stages of the journey to understand patient experience in the round; collect 'real time' and 'right time' feedback
- Staff respond really well to immediate feedback. Patients prefer to be appreciative
- When we involve patients and carers in improvement, it happens faster and is more likely to be sustained. It often enables staff to make changes they have wanted to make for many years
- We have a lot to learn from other sectors – especially mental health
- Success comes from many things. It can be hard to know exactly why things have worked well, but important things include:
  - Having stable, committed senior leaders
  - Values-based recruitment: having the right staff focused on the right things
  - Getting to the heart of what matters most to people and families – working with them to improve care experience
  - Measuring the right things; measuring often and acting quickly
  - Sharing all results widely – transparency is the cornerstone of improvement
  - Understanding that improvement relies on enhancing both patient and staff experience
  - Celebrating the great stuff; fostering a sense of joy, pride and creativity

**Replicable?**

*'It is possible. A number of elements need to be in place. Most important is a stable Board that is deeply committed to this way of working'*

This Trust is keen to share its learning and continue to learn from others and is supporting a neighbouring trust. This neighbour has already started to feel impact and see statistically significant shifts in performance in a very short time.

## C10: King's College Hospital NHS Foundation Trust

### Brief description of programme:

This Trust runs a large-scale patient experience programme which sits under the corporate affairs directorate. It benefits from senior management buy in.

The Trust generates more than 3,000 pieces of feedback in a month (n=36,000 a year). It gathers this feedback in many different ways:

- Large scale 'How are we doing?' patient survey programme incorporating the Friends and Family Test
- A range of listening events and initiatives including:
  - The 'King's In Conversation' initiative, which gathers feedback on key issues from hundreds of staff and patients. KIC includes 'Pop Up Conversations' throughout the hospital to gain feedback from people who may not otherwise talk
  - 'Goldfish Bowl' and 'In Your Shoes' events which bring patients in to share their experiences with staff and action plan for improvement
  - **Patient Video Stories:** initially funded by the NHS Institute's 'Patient Feedback Challenge' fund in 2013, this programme continues. Stories are used in training and at staff meetings on a regular basis and teams are supported to develop collaborative approaches to improving healthcare
- A nationally renowned **volunteering programme** specifically designed to improve patient experience with over 1,700 volunteers working across the trust in wards and outpatient clinics and also supporting vulnerable patients when they go home. Volunteers are another valuable source of feedback. The programme has secured significant charitable funding

Patient feedback is an intrinsic element in:

- The Trust's 'cultural change and integration' programme
- Performance framework with patient experience metrics on trust, division and ward/ specialty scorecards
- Monthly Patient Experience Reports integrating feedback from How are we doing?, complaints and PALS
- Including patient stories as part of key trust meetings from Board to Ward
- Sharing feedback with patients and staff through the trust's website and posters that use headline results and patient quotes in a 'You said. We did' format

The Trust is keen to enhance its current feedback with a greater emphasis on 'patient stories' and to focus on making more sense of the information it gathers. To support this, it has recently begun working with a new electronic feedback platform provider, which includes a sophisticated tool for analysis and theming of free text comments. In tandem with this, the Trust has launched new shorter How are we doing? surveys and will have an increased focus on making sense and better use of free text, qualitative feedback. This will provide more insight into the themes which are emerging for improvement.

### Impact and changes the programme has created:

- **Cardiac team:** introduced 'intentional rounding' on wards at night as well as during the day to increase opportunities for patients to talk with staff and share concerns and queries
- **Rehabilitation Unit:** introduced patient and relative diaries to improve communication, particularly out of hours and at weekends. Patients and their relatives note down questions and queries. The diaries are checked each morning and the team take action in response
- **Discharge:** pilot of post discharge phone calls to patients; increased use of volunteers to support patients after discharge through the 'Hospital to Home' scheme
- **Medical team:** ward teams focus on finding opportunities to smile and joke with their patients as they recognise this makes a real difference to patients' spirits
- **Surgical team:** in team meetings, the ward sister encourages staff to be approachable and make time so that patients and relatives feel able to ask questions and feel listened to
- **Emergency Department:** increased use of volunteers across the department, including in reception, to support patients through their journey



**Key learnings:**

- Continue to encourage staff to make patient experience and involvement part of business as usual and to dispel some continued fears about engaging with patients
- Get feedback to front line teams as they are the ones who make change and improvement happen
- Don't just focus on the negatives which can be disheartening for staff; share positive patient experience to boost staff morale and spread good practice
- A well developed volunteer scheme with a clear focus on improving patient experience can attract additional funding
- In times of change and pressure, ensure you keep responding to feedback and that patient involvement and leadership remain on the agenda
- Look for innovative ways to keep patient involvement and leadership on the agenda, for example Goldfish Bowls and video stories
- Always share and encourage spread of good practice

**Replicable?**

*'... completely replicable and people are welcome to talk to us about our programmes'*

## C11: Blackpool Teaching Hospitals NHS Foundation Trust

### Brief description of programme:

In 2010, this Trust was approached by the local council's youth service about undertaking a 'Hear by Rights' audit that reviewed the active and meaningful participation of children and young people in organisations. On the back of this, the Trust began to work with young people through a scheme called 'Victoria's Voice' in 2010. In 2012, the Trust appointed a full time patient experience officer with a background in youth work and the forum took off. Young people who attended fed back on issues around communication and relationships with clinical staff – both on the ward and at outpatient appointments. The group decided that they wanted to support doctors at all levels to communicate better and understand what it feels like to be a child or young person living with health issues, supported by hospital care.

The young people developed a pocket card of top tips for doctors so doctors could reflect on their own clinical practice. The young people were clear that the card should be a gift because they appreciated 'how hard it is to become a doctor'. They felt how doctors received this gift was very important. The young people asked to meet with and present the card to doctors themselves.

The Trust supported this and arranged a couple of group sessions that doctors could choose to attend. These went well, with good feedback from participants. But they were not well attended. After a lot of work by the patient experience officer to get people on board, the trust arranged for the session to become part of student doctors' Foundation Year 1 Education Curriculum – in other words, a mandatory session. This meant no clashes with other training and no distraction or disruptions, e.g., bleeps or call back to ward duties. The doctors came from all areas of the hospital, including two from paediatrics. Many said they were interested in specialising in paediatrics in the future.

As it was their third session, young people had grown in confidence and successfully ran a mandatory training session that:

- Tapped into the doctors' personal experience of being a patient as an icebreaker
- Shared feedback from young people about their current experience
- Presented the Top Tips card
- Shared the work of Victoria's Voice
- Built rapport and encouraged discussion, comments and questions

The young people also asked for feedback from the doctors to see what impact the session had. They asked, 'what have you discovered today?' and invited the doctors to pledge a change. Doctors' feedback included:

- I need to inform and talk to young patients, not just parents
- I have gained an understanding of a young person's perspective of doctors, hospital and being in ill health
- I have appreciated the need for honesty and to show respect for my young patients
- I need to allow opportunities for and promote young patients asking questions

Doctors also shared that they found the session 'enlightening' and 'thought provoking'.

Doctors pledged to: be honest; treat young patients as a person and with respect; encourage young people to speak – communicate at their level; engage young patients in management plans and all aspects of care – even if it takes more time; involve and inform every young patient – no matter how big or small, and to keep their top tips card with them.

The training is now part of the Trust's mandatory foundation student training programme. There are plans to roll out the workshop to other staff within the hospital through the 'Grand Round' in partnership with the Trust's Patient Panel. This monthly, informal education session is open to all staff. The Trust plans to enhance the training evaluation process and future plans are in place to include a follow up session to reflect on the pledges made by the students.

**Impact and changes the programme has created:**

- Young people involved in Victoria's Voice are feeding back that relationships with staff have improved
- Young people involved in delivering the training have gained confidence from running training sessions with doctors
- Doctors have reflected on how they need to change their clinical practice to respond to young people's feedback with pledges
- Participating doctors have fed back they remember the session
- Feedback from young people has directly influenced the training curriculum and there is now a mainstream, mandatory training session, led and delivered by young people.
- The programme highlights a commitment to involving patients and joins up other work such as young people's involvement in interviews for consultants

**Key learnings:**

- The consultant paediatrician, who also has the role of foundation Programme Director, championed this work and proposed the session, be included in the curriculum. This was key to the success of this work: 'without the consultants' early support and involvement it would have been much harder'
- You need to stand back and let young people lead. Do not put words into their mouth. Embrace letting go. Have faith. Great things will happen because they will be authentic and people respond to that
- Doing something new and innovative takes determination and a lot of effort to get people on board. Investing in a dedicated patient experience officer for the childrens' department ensured there was time for this
- Building on existing mandatory training increased impact. The idea of training around patient experience is a new concept. It may be the first time that doctors have experienced it – so the benefit may not be obvious until they have to do it!

**Replicable?**

*'Absolutely. I think that there is also space for this level of involvement in medical schools and for nurses too'*

## C12: Royal Berkshire NHS Foundation Trust and Berkshire Healthcare NHS Foundation Trust

**Brief description of programme:** This acute trust set up its 'Patient Partners' scheme several years ago. The Patient Partners are volunteers who either have experience as a patient or have a close family member who has. They are people who want to make a difference to care: 'We roll our sleeves up and get things done'. Here are three examples of changes that Patient Partners have led:

- Children's A&E: Patient Partners with children worked with the paediatrics team and shared their concerns about their children being in the same A&E as adults because it could be quite scary for both children and parents. In response, the Trust created a separate waiting room for children in the A&E department
- Carers handbook for dementia: driven by personal experience of caring for a parent with dementia, patient partners worked with carers, local mental health liaison team and the local university to develop a handbook, which provides details of local support services in one place. It is available on the internet and a patient leader has been active in promoting it to national dementia leaders to showcase the idea. It is now being produced as an E book
- Carers Passport: Two patient partners who sit on the Trust's Elderly Care Strategy Group and have experience of caring for a parent with dementia attended a regional dementia conference. At the conference, they saw a 'carers' passport', developed in another hospital that aimed to build more carer centred thinking and support within NHS organisations. This was before Carers UK 'Triangle of Care'. They approached their senior contacts at the Trust and suggested a carers' passport should be made available. The senior leaders listened and the patient partners made sure it happened. One of the patient partners also took the idea to another local trust where they had senior contacts and persuaded them to adopt it too. Posters advertising the passport are visible throughout the hospital

### Impact and changes the programme has created:

- Children's A&E: parents and children feel safe and have their own A&E space
- Carer's Handbook for dementia: carers welcomed the resource to signpost them to help
- Carer's Passport: 2 local trusts have adopted carer's passport at scale. The carer's passport is used widely. Patient partners perceive that the carer's passport is making a difference. Although no formal evaluation has been undertaken, these partners know lots of people who have used it and benefited. Staff reports requests for the passport. Family carers now routinely:
  - Get free parking (present ticket at reception for stamping)
  - Don't need to leave when there is a doctors' ward round and are involved in care planning
  - Can remain at meal times and eat with their loved one
  - Can remain at the bedside outside of visiting hours

We have built on our Patient Partners Scheme and in April last year we launched the successful 'Patient Leadership programme'. Patient Leaders take part in a six-day training programme to give our patient leaders a better understanding of the NHS and how we work.

*'Patient partners picked things up that were not coming through in NHS feedback'*

*'You get heard and can influence through relationships, networks and being passionate about patients. It helps if you can talk at the same level as the others round the table.'*

- Relationships, networks and ability to influence make a big difference to patient leaders' impact e.g. 'a background in the NHS is very helpful and demystifies the NHS'
- Patient leaders can share learning and spread ideas that they recognise could solve a local problem. They have the time to do it. It may be the ideas come from attending local or national conferences (bursaries for free entry are usually available). This saves NHS managers' time and speeds adoption and spread of good ideas – although it may take years to get through the hurdles of NHS approval processes – see next point

- Well-developed relationships with senior staff – e.g. Chief Executive, Chief Nurse, Governors, help patient leaders fast track change, promote innovation and make the case for its adoption, ‘They might have had to do it anyway. We got it to happen faster’
- Patient Leaders are in a unique position to act as connectors between local NHS organisations through their contacts
- A pragmatic approach to making the case for change, based on patient leader’s feedback can work where there is a determined, passionate champion and a receptive health professional
- Enthusiasm is infectious. Passion is key
- Any leadership training should involve both patients and professionals to build human connection and understanding. Training should be local – including induction training
- Local context is key. People are usually motivated to engage by what is happening locally
- National initiatives around supporting patient leaders are still in their infancy and haven’t yet established a policy
- Patient leaders must stop saying ‘they are not listening to us’. They need to knock on doors and ask to be included. It is so rewarding when the door is opened
- Both Patient leaders and Health professionals are on a steep learning curve and need to be not only tolerant of each other but supportive
- Social media can be a tremendous asset and connect patient leaders. However it can also fuel negative conversations from people who don’t have a clue what we are talking about!

*‘If you don’t care, you can’t do it. If you really care, you will find a voice. You can do anything. You might need a bit of help and buddying through the first few steps, but anyone with passion can change things – and they will be heard’*

## C13: University College London Hospitals NHS FT

### Brief description of programme:

Discussions began in 2013 as a result of one person's passion to improve others' experience of surgery for head and neck cancer. The Trust was concerned to hear the patient's voice, to build patients' trust in the service and to improve the image of the department. The project started in September 2014 and has quickly developed to gather and use patient feedback to improve care experience. The two key elements of this programme are:

- A 'buddy' peer support programme
- Patient experience feedback programme

The buddy peer support programme: aims to improve patients' experiences before and immediately after surgery through buddy style support for patients and their families from someone with first hand experience. The patient leader provides buddy support to people and families – and gathers feedback about the buddy support service. Medical, nursing and management teams are really positive. They recognise this as something that they cannot provide. At present, there is only one buddy but there is talk of more.

The patient experience feedback programme: grew on the back of buddy support because the patient leader was gathering feedback and patient stories and recognised that the Trust could improve the service. There is currently uncertainty about what the Trust will do with all the feedback and stories it now has. There is a PhD student available to work with the patient leader to help analyse, make sense of and produce meaningful insights that the Trust can respond to in a 'You said. We did' format. With no patient experience lead to drive this work and support the patient leader, they are in on-going discussions with the Trust management about how to make this happen. Macmillan is very supportive of the patient leader.

### Impact and changes the programme has created:

- Patients who use the service and the medical team have embraced the buddy programme with 'open arms'. Consultants view the buddy service as a valuable support tool and refer patients to it regularly
- Macmillan is following with interest and sees this as a really good example of patient involvement and leadership that could be rolled out in other areas
- Patients undergoing head and neck surgery are often disfigured. They have lots of confidence issues as well as some communication challenges after surgery. The patient experience manager introduced 'Changing Faces' training courses to coach the team – in particular administrative staff – on how to behave and act towards people on the journey. Staff now recognise and support patients through this transition. The team are spreading inter-departmental learning too – and raising awareness of peoples' confidence and communication issues after head and neck surgery with others because many patients attend other areas of the hospital
- Greater respect and understanding amongst the medical team of just how powerful and useful it is to have a buddy system in place
- New patient information leaflets, with a particular focus on 'what matters to patients' and 'how to prepare yourself for this journey'
- Improved waiting room experience, based on feedback: improved attitudes and treatment of patients as a result of Changing Faces training; reduced patient anxiety in the waiting room because they connect with a volunteer who can offer peer support during the clinic:

*'Patients love nothing better than seeing a fellow patient further down the line than themselves. It promotes hope and therefore empowerment from a patient's perspective'*

- The Trust is starting to look at what it can stop doing to start investing in the things that people say they value most, including psychological support

## Key learnings

*'Taking something from an idea to making it happen can feel like moving mountains'*

- Patient leaders need support from NHS trust management, e.g., patient experience leads to make progress and smooth the path of change. Unsupported, they struggle
- Getting buy in and support from medical teams is key
- There is a real need for more work led by patients to improve experience for patients. Patient led, coproduced improvement may build responsive services more quickly
- Learning about and recognising the frustrations of medical teams is enlightening for Patient Leaders. Staff experiences should also be used to make change and improvements
- This work is about supporting people to deal with surgery and understand what matters around recovery. It is not about cancer. There is already a lot of support out there for people living with cancer
- Patients need support from the beginning, i.e., diagnosis
- A buddy system provides a platform to build a continuous feedback conversation from diagnosis onwards
- Buddy support can reduce time pressure on consultants. Feedback from this work suggests that by putting in place peer to peer support in clinics, from diagnosis if possible, means people would require less time with consultants
- For patient leaders working unsupported, implementing change is difficult ...

## Replicable?

*'Definitely – nationwide I would think'*

## C14: Thames Valley area team (Now NHS England South Central)

### Brief description of programme:

In April 2013 this area team (then called Thames Valley) formed a 'Patient Experience Strategy Group' (Strategy Group) in collaboration with the Academic Health Science Network, Strategic Clinical Network and NHS England's Nursing Directorate. The vision is to support partner organisations to further develop person-centred care across care delivery, commissioning, research and innovation. The Strategy Group includes a range of partners: patient leaders, Clinical Commissioning Groups (CCGs), local authorities, the third sector, HealthWatch and provider organisations.

Part of the Strategy Group's work has been developing a patient leadership programme to support patients, carers and lay members to work with health professionals. The programme will embed patient involvement and leadership. It will develop collaborative approaches to improving healthcare at a strategic level. A pilot training programme ran from March-May 2014.

Participants gave feedback to shape the development of the training programme. An independent evaluation was carried out on the training pilot. The evaluation team provided recommendations that the Strategy Group has responded to. It is changing the training programme specification and is now looking to commission the next phase of its development.

Following the patient leaders training programme pilot, NHS England, South Central (then Thames Valley) developed an exciting and innovative model for including patient leaders in the NHS England CCG assurance process. This model was agreed following consultation with the two Patient Leader members of the Strategy Group and key NHS England colleagues. We developed a recruitment campaign, with a role description, application form, shortlisting process and interviews. The area team selected six people from thirty five applicants to take part in assurance work. A training programme was developed and the process of involvement of patient leaders in the assurance meeting was piloted with two CCGs and evaluated and has now been fully rolled out across all CCGs in the area. An in-depth evaluation of the full programme is currently being completed.

This area team has found the formal, independent evaluation of both programmes and the subsequent feedback to be a really good source of learning. The group continues to capture and embed independent feedback to shape these ongoing programmes.

### Impact and changes the programme has created:

*'I now have confidence. I have managed to persuade them (the committee)'*

- Patient leaders now feel confident and competent to contribute in a more meaningful way; something that is especially important when working at strategic level
- Positive changes in how people who have been through the programme communicate
- Involvement of patient leaders in the area team's CCG assurance process and in key roles in the Strategic Clinical Network and Clinical Senate Governance groups gives patient leaders meaningful ways of contributing
- Patient leaders are contributing to embedding patient leadership in medical training in Manchester
- A fair recruitment process and framework, co designed with patient leaders for the CCG assurance
- Six new patient leaders to spread CCG assurance work (out of 35 applicants)
- The local patient leaders now have input at national level and a positive national profile
- A sense that this work is starting to create a huge culture shift; a 'change that means staff and patient leaders work together as equal partners to improve healthcare'



**Key learnings:**

- Culture change is key. It is beginning to happen
- Involve people who have a real passion
- We have lots of committed people, raring to go
- There is still a lack of cultural diversity amongst our patient leaders, despite going out widely to recruit. Learning how to build diversity at a strategic level in the NHS is still a work in progress
- People need to be paid for their time; follow Patient and Public Voice guidelines
- Celebration events work really well and can have a positive, motivating impact and cascade effect
- We still have a long way to go

**Replicable?**

*'Yes ... and in fact I have pulled together a recruitment and training toolkit (for the CCG assurance work) that can be shared'*

# Appendix D

# Detailed case studies

# Appendix D Detailed case studies

## Identification of the case studies

The Patient Leaders Expert Advisory Group considered the 18 examples of NHS organisations currently making good progress on improving care experience by working with patient leaders using feedback.

The group scored the 18 summaries on a scale of one to five against six criteria:

1. **This organisation demonstrates robust collection, interpretation and use of feedback:** this criterion judges how close the case study comes to the definition of good feedback developed in Phase 1.
2. **This organisation demonstrates involvement of patient leaders in one or more areas of the feedback cycle:** this criterion judges how involved patient leaders are in the feedback work the organisation does. This may include, for example, how involved patient leaders are in making sense of the feedback in a genuine and meaningful way – or how involved patient leaders are in coproducing improvements in services in response to feedback.
3. **This organisation demonstrates change in response to feedback:** this criterion seeks evidence that things have changed as a result of the organisation listening to feedback.
4. **This organisation can show a positive impact on experience of care:** this criterion looks for specific evidence that people's experience of care has improved as a direct result of feedback work.
5. **This organisation has worked in partnership with other organisations:** this criterion looks at whether the organisation has worked with other NHS or voluntary organisations as well as patient leaders to create change. This is important because all too often change happens in one organisation, for example in a hospital, but other organisations don't change at the same time, e.g., the patient's GP is not involved or aware of the change.
6. **This work is relevant to the rest of the NHS and could be copied:** this criterion looks at how helpful the learning from this case study would be to others – and whether the organisation's work could easily spread and be copied.

The members of the Patient Leader Expert Advisory Group scored the two page summaries against those criteria. This selection also took account of the following guiding principles:

- **A spread of good practice** – examples across different types of NHS organisations so that each area of the NHS can find something to learn from the case studies
- **A spread of geography** so that people can see examples of good work happening across the country rather than assuming it is only relevant and meaningful to a particular geography, e.g., rural and urban settings; north and south
- **A range of different approaches** to involving patients leaders in feedback work so that people and organisations can see diverse approaches and can adopt the elements that they feel are most relevant to them and their area
- **A spread of patient leaders** – to include young leaders, older people, the public and patient participation groups for example

Applying the criteria and the guiding principles, the PLEAG selected the following areas to be developed as detailed case studies:

- Birmingham CCGs (Birmingham Cross City CCG, Birmingham South and Central CCG, Sandwell and West Birmingham CCG)
- Ipswich Hospital NHS Trust
- Midlands and Lancashire Commissioning Support Unit
- Shropshire CCG
- Thames Valley Area Team

The Thames Valley Area Team subsequently withdrew from this third phase.

The four detailed case-studies are set out in this Appendix. The case-studies consist of the background of the organisation, a description of the programme and the impact it had, key learnings from the site and illustrations of the identified building blocks for organisations considering similar investment in patient leadership.

The key contacts for the four organisations are set out in the table below.

Reference	Organisation	Contact
D1	Birmingham South Central CCG on behalf of three CCGs	Karmah Boothe (Commissioning Manager, Maternity) <a href="mailto:karmah.boothe@nhs.net">karmah.boothe@nhs.net</a>
D2	Ipswich Hospital NHS Trust	Sarah Higson (Patient Experience lead) <a href="mailto:sarah.higson@ipswichhospital.nhs.uk">sarah.higson@ipswichhospital.nhs.uk</a>
D3	Midlands and Lancashire CSU	Lesley Goodburn (Head Insight and Involvement) <a href="mailto:Lesley.Goodburn@staffordshireccs.nhs.uk">Lesley.Goodburn@staffordshireccs.nhs.uk</a>
D4	Shropshire CCG	Karen Higgins (Young Health Champions Project Manager) <a href="mailto:karen.higgins@shropshireccg.nhs.uk">karen.higgins@shropshireccg.nhs.uk</a>

# Appendix D.1

# Birmingham CCGs

## D.1: Birmingham CCGs

### Background

Between them, Birmingham South and Central CCG, Birmingham Cross City CCG and Sandwell and West Birmingham CCG commission health services for more than 1.5m people.

In assessing the needs of its young population:

- Birmingham is a young city, with 28.8% of the population under the age of twenty
- It is also an extremely ethnically diverse city with 62.9% of school children from a black or minority ethnic group
- The level of child poverty in Birmingham is worse than the national average with 33.5% of children aged less than 16 years living in poverty based on accepted indicators

### Brief overview of the programme

Working with young experts by experience, the three CCGs have commissioned an integrated children's and adolescent (people aged 0-25) mental health service (CAMHS) at a cost of c£22mn a year. Over the previous five years, the CCGs and the main providers had worked incrementally to improve performance. However, CCGs had heard from young people and families that there were gaps in service provision as the existing service was commissioned to support young people up to 16 and adult mental health care kicked in from 18 years. Young people were also saying access to care and support was still limited. The CCGs took the decision to re-tender the service. Birmingham South and Central CCG led the tender and worked with patient leaders – called Experts by Experience – to develop a new service specification. The Experts by Experience received training to ensure that they were able to assess the bids. They also hosted a mid-tender review. Within the quality domain of the assessment, which accounted for 90% of the vote, they awarded 20% of the marks. This meant they had the power to help choose the provider.

### Detailed programme overview:

In direct response to feedback from a 'Young Person's Question Time' where young people quizzed the CCG Board, the CCG produced a case for change for CAMHS and transition to adult services. Consultation began in January 2014. During consultation, the CCG held workshops with providers, clinicians and children and young people. The workshop for young people included lots of interactive zones and questions in every zone. Participants collected stamps as they answered the questions and had a go at new crafts, sports and dance activities as they went. There was also a zone for free text comments and a video booth to record a message to the CCG. The CCG also ran a paper and online survey through all GP practices, youth facilities and schools and the usual engagement channels across the city and council. The CCG made sense of what everyone had fed back and published a 'You said. We did' report and its analysis of feedback. It also updated its draft service specification in response to the feedback. This became part of the tender of £124mn over five years.

The CCG split involvement opportunities in the tendering process into 'volunteering assignments'. It estimated these would take 10 x 4 hours to complete. It asked volunteer experts by experience to apply for the assignments. 14 young people, parents and guardians came forward. 10 volunteered. Each played to their strengths and chose tasks that interested them. The group designed and ran a 'mid tender event' for bidders in August 2014. They used role-play; the creative spoken word and personal stories. Providers described it as an eye opener. It had a big impact. This was evident because what young people said clearly shaped the service proposals submitted. All 10 experts received six weeks' training and evaluated the bids. There were four evaluation panels. The experts by experience chaired their own panel. Of the quality marks, their scores counted as 20% of the total score. The others were: CCG (60%), clinical experts (10%). The remaining 10% was technical and included cost. The young people also worked as equals with senior commissioning managers and clinical leads to agree the final decision to award. They knew the successful candidate at the same time as everyone else in the CCG procurement team.

The CCG is continuing the journey. Now the contract is awarded, the experts by experience have the chance to choose further volunteering assignments in: communications, quality improvement, performance management and evaluation. The plan is for them to run a stand-alone Board, with the appointed service provider directly accountable to children, young people and their families. The CCGs are also looking to involve them in mystery shopping and at accrediting volunteering and the skills they have gained.

**Impact and changes:**

- Direct impact on design of service specification, which will change care experience in the long run. The new one was very different from original and included:
  - More peer support
  - More support for parents past their child's 18 birthday
  - The provider capturing feedback and responding to both parents and children
  - Inpatient beds included in service specification
  - A bigger focus on improving transition to adult care AND handover between services at all stages
  - Locally based services
  - Face to face services with online an added bonus – not substituted as an equal alternative
- Transformation in the way the CCGs commission services. The CCGs will commission other services in the same way
- Young people with new valuable skills and experience
- Young people with direct influence over the choice of provider: 20% vote within the quality score and through their input and feedback into the design of the service specification

**Core learning from this site**

The Birmingham CCGs reached out proactively to families, children and young people living with mental health issues. This is a group whose voice is traditionally harder to hear.

- The experts had power and authority because the CCGs gave them a 20% stake in the commissioning decision. The CCGs have stuck to this principle. Moving forward, the experts will have decision making power over 10% of future discretionary spend:

*'If you are going to take patient representation seriously it's got to be embedded in the way you do things, particularly with commissioning. But because we have a fixed interest in it, that made it a valid thing to do. This all centres around the commissioning bit of being the stakeholder, saying that patients representation will have a formal x amount % of the decision making stake. It won't work any other way really.'*

**Patient leader**

*'The experts by experience will be involved in evaluating the service and their feedback will count for 10% of the money received by providers.'*

**System leader**

- Involving patient leaders in this way is an integral part of robust risk management around any possible legal challenge.

*'We've had a very strong set of messages we are able to use whenever anyone challenges us on what we're doing. We are able to say, 'well this is what the people who use your service are telling us' ... The fact is that actually we are in need – not just in Birmingham – of trying to change the way of mental health in children and young people. With everything else going on – and a general election later in the year – all that stuff could derail the process so that you end up not being able to make significant service change. So it is a big thing. Push it through; sort it out and get on with the mobilisation.'*

**System leader**

*'The fact we have managed risks fully and have good support from the experts means that the chances of legal challenge are much smaller. Really it's the wrong way around. We need to recognise it can reduce cost in long run to involve experts by experience – including potentially supporting robust risk management around challenge– and spend the money we would otherwise keep aside just in case.'*

**System leader**

- It takes significant time and resource to work with patient leaders and respond to their feedback. This needs investment and senior leaders' support:

*'Invest the resources and time into building experts by experience. Realise that they (experts) are not an unlimited resource. Appreciate that a rolling process is needed and that the recruitment process needs to be tweaked, according to the skills that you need from the volunteers in order to achieve the objectives of that particular volunteer assignment.'*

**System leader**

*'I think the penny dropped (with the CCG team) when we had done the mid-tender interviews in August because we had some of our senior management team at that event who were really taken aback by it and came back and spoke very positively about it – and I think that is when the realisation came that if you want engagement, you have to invest time. I think the CCG had bought into that.'*

**System leader**

The end result is that the service specification for children's and mental health services is significantly improved, which will result in improved quality of care and outcomes in the future.

### **Building blocks**

This section makes the link between the Birmingham CCGs and the overall building blocks

#### **Make patient leaders an integral part of formal and informal decision-making processes**

*'... certainly one of the things we did with the bidders was to have the experts by experience come along and give a mid-tender presentation, which was very powerful.'*

**System leader**

#### **Get patient leaders involved in the experience of care, shaping, co-designing and leading proposals from the earliest stage**

*'I would have liked to have had the experts by experience involved right from the beginning – right from when we started thinking about changing services. Too much was done from an officer perspective. It is one of the key learnings that we have learnt for the next phase – making sure we take the experts by experience on the whole journey with us.'*

**System leader**

*'For example, we would say we recognise 'you need to support parents' – but what does that mean to parents? Parents were saying that they only needed toolkits – not consultation sessions with psychologists – which potentially we might think they need and would cost about £60 per hour. Whereas a tool kit may cost you £1,000 to develop, but how many times will it be used? Over and over again.'*

**System leader**

#### **Ensure systems invest in tailored, task-focused training and development of patient leaders**

*'The process at the end where we had to mark and moderate the tenders – we had training for that section. We did example questions. We had people come in to do that. It was an afternoon session. There was quite a lot about confidentiality; exercises to get us to think about things.'*

**Patient leader**

#### **Devote time, resource and effort to building strong and meaningful relationships of respect and trust with patient leaders**

*'One of the things we needed to do was build relationships with the experts by experience. So one thing we did at the beginning of every session was to check out with them how they were; if they'd had a good week; if we could help them at all. We spent at least an hour and a half, asking people these kinds of questions. It was very valuable as it built up trust. One of the key bits of learning for me was that people have a lot of fears when it comes to being experts by experience – that whatever they say will actually have an impact and be used.'*

**System leader**



**Listen to patients whose voices are traditionally not heard, using a range of media and working closely with organisations that have existing links with these communities**

*'I am an open person so will talk about it to people I know, but I wouldn't mention to people I don't know or don't need to know. I am lucky. I have lots of understanding people in my life. To get young people involved and engaged, I think the best way is through social media, Facebook, Twitter; TV adverts, radio adverts.'*

**Patient leader**

**Place equal emphasis on making sense of and responding to the qualitative feedback from stories as on the quantitative evidence from numbers**

*'The challenge (from the provider) will be, 'As our provider, all our service users from what you've gathered and all the information, are saying they're not happy. So you're going to take 10% of our money? Give us hard facts. If we get that back from a provider, this is where the danger is. And we could fall back into the old system. They're that side of the table and we're this side of the table- and we're arguing about these type of things. We shouldn't be arguing. We should say your clients are telling us that you're not delivering what they want, why? What are you going to do about it? How are we going to make this work?'*

**System leader**

**Foster an 'improvement mind-set' through the organisation so that everyone believes change is possible and things can be done differently**

*'Our accountable officer ... (is) very much into 'everyone is a leader'. If you've got a good idea, she's quite happy for you to run with it and because of that, it gave us an open field in relation to experts by experience. At the same time, she wanted experts by experience to be actively involved.'*

**System leader**

# Appendix D.2

## Ipswich Hospital

### NHS Trust

## D.2: Ipswich Hospital NHS Trust

### Background and Context

The Ipswich Hospital NHS Trust is a National Health Service Trust, providing hospital-based healthcare to more than 443,000 people who live in and around Ipswich and East Suffolk. It is a single-site, medium-size acute hospital, providing hospital services to the residents of Ipswich and East Suffolk and some specialties, such as spinal surgery, radiotherapy and percutaneous coronary intervention (PCI) to a wider population, as well as outreach services in a number of clinical specialties.

The hospital has 552 beds (as at 31 March 2014) in general acute, maternity, paediatric and neo-natal services and had an annual turnover of £249mn in 2013/14. It employs just over 3,700 whole-time equivalent NHS staff.

### Brief description of programme:

The Trust has maintained a focus on patient involvement over ten years. The Trust has set its ambition as moving away from a 'talking shop mentality' towards collaboration and partnership. The Trust wants to improve its services through analysing what people say as well as looking at statistics. It gathers feedback in a number of ways: surveys, including Friends and Family Test; comments, compliments and complaints; PALS; feedback from Patient Opinion and NHS Choices; Twitter and the Network's 14 user groups. It also maintains an external focus through community listening and engagement.

### Detailed programme overview:

The main route for patient leader involvement is the Trust's 'User Involvement Network' (The Network) of 14 user groups. Each user group has a lay chair who works closely with a Trust lead (senior member of staff). On The Network, there is also representation and involvement from external organisations, specifically Healthwatch and carers' organisations. The Network can also request Clinical Commissioning Group (CCG) attendance and involvement. The key roles of The Network are:

- Bringing people (patient and carer leaders, staff and other organisations) together
- Providing a forum for User Group chairs to share experiences and issues
- Identifying trust-wide themes and escalating these
- Providing a platform for broader engagement; acting as a 'one stop shop' for Trust plans and strategies to be discussed and debated

This involvement structure enables partnership working at different levels within the organisation and out into the community.

In 2014/15, the Network received its own budget.

Patient experience is a strong focus at the Trust Board level. Every public board meeting starts with a patient or carer story. Next, The Network Chair gives a brief overview of The Network's current work and issues.

The Trust is currently working with The King's Fund to develop and test the concept 'Shared Leadership.' This 'understanding approach' is about creating closer partnership working towards a clear vision. The Trust sees itself on a journey and recognises it is only at the beginning and has greater strides to take, which it is now beginning to explore with The King's Fund.

### Impact and changes the programme has created

The Trust sees The Network members' involvement in the Trust is as much – if not more – about changing culture as it is about service improvement. This shift in culture recognises the value of involving, listening and responding to the patient and carer voice. The presence of The Network members on a range of committees; their involvement in the Trust's transformation programme and in the development of the Trust's values and behaviours is moving away from a traditional leadership model and towards more collaborative, shared leadership.

Patient leaders are responsible for the following service improvements:

- Volunteer floor walkers who give directions and accompany patients and carers to find their way across the site
- Changes to X-Ray. In response to problems with access identified by the Rheumatology User Group and escalated to The Network, open access X-Ray now runs from 8am and across the lunchtime period to smooth out peaks in demand
- Thinner bread in sandwiches served to inpatients; patients offered a bedtime snack at night
- 'Over-the-bed' covers for deceased patients
- Wall and handrails fixed on the slope leading to the Day Unit
- Introduction of email communication to patients
- The Network has shaped the development of the Trust's values through a series of 'In Your Shoes' workshops
- The Network has identified 6 things the Trust could ask of patients and carers
- Additional car parking spaces for cancer outpatients
- Free Wifi throughout the Trust in response to feedback from 12 year old patient leaders

**Key learnings from this site:**

- Patient leaders can contribute and take on key leadership roles within the organisation including:

- **Leadership of PLACE (Patient Led Assessments of the Care Environment) audits**

*'I have been heavily involved with the 'PLACE' audit and started scoring them – how they divulged how they scored, then I was able to set up templates which enabled them to actually produce results for the hospital which they haven't done before – able to analyse a result- in accordance with the one that came down nationally, so I was able to give the Trust details of how it worked.'*

**Patient leader**

*'He does the spreadsheets, which saves me so much time.'*

**System leader**

- **Inspecting services**

*'Both the Chair and myself have also been involved in hospital inspections. One of them was quite pleasing that I was involved in last year. We went along to neurophysiology and it was a dreadful place to be and we said so and because we said so, the hospital have done something about it.'*

**Patient leader**

- **Mock CQC Assessments**

*'We have patient involvement in our CQC internal assurance framework. A few years ago, we decided that rather than wait until the CQC came in and start rummaging around the place, it would be a lot better to have some friendly people coming to do that. So we started on the internal assurance. So using all the CQC standards, we devised audit forms and do self- assessments on our own individual areas and do an internal peer assessment on individual areas .... For the patient assessors, we put on a training session to talk through the background; what it is, what is involved; the paperwork, what we expect of them, etc. ... On the day we assign them to a team with health professionals and a lead inspector.'*

**System leader**

- **Seeking feedback:**

*'We started doing health checks, and found out that a lot of people with learning difficulties didn't have annual health checks; we went to all the day centres where the people went and sent out questionnaires. I think when people are in other places people talk for them, and don't give them the chance to find out if they need one or not – weren't being listened to – so we did some of that 'listening' with our group and compiled a report and it went up to the top people.'*

**Patient leader**

- **Recruitment:**

*'It shows how much the Chief Executive thinks of us. We three have all been trained to be lay chairs for the consultant recruitment panels. We had a couple of training sessions from a lady in HR. We were trained in how to recruit and I think that will be on-going. We always ask a 'patient based' question and that has really caught some consultants out.'*

**Patient leader**

- **When patient leaders have a budget to support their work, it builds trust:**

*'Trust is a BIG thing. We were given our own budget last year for the first time – £10,000 to cover things like: the Kings Fund training; doing our own boards; the logo. It paid for our lunches. I think it shows how the Chief Executive views IHUG (The Network). That is quite a big commitment; to give that trust to The Ipswich Hospital User Group.'*

**Patient leader**

### **Building blocks**

This section makes the link between this site and the overall building blocks.

#### **Make patient leaders an integral part of formal and informal decision-making**

*'Me and the vice chairs have informal meetings. There aren't any minutes; just informal meetings with the Chief Executive as and when we want.'*

**Patient leader**

*'We are often seen as a solution to things. If there is a problem anywhere, they ask the patients 'what do you think?'*

**Patient leader**

#### **Get patient leaders involved in the experience of care, shaping, co-designing and leading proposals from the earliest stage**

*'Before you go to an appointment, it gets flagged up that you have learning disabilities so that when you arrive, they already know. You don't have to say anything. This has now been introduced. We use a purple dot on the chart above beds. We have a chart with patients names on; what they like to be called, food requirements ... We had a lengthy battle because staff told patients they didn't want them to be labelled – and patients said 'we want them to be labelled!'*

**Patient leader**

#### **Ensure systems invest in tailored, task-specific training and development of patient leaders**

*'Some sort of training package a training certificate that covers a few of the elements that are required – because not everyone can do it. We would then know who could do what and where it would be best to use them and play to people's strengths rather than guessing.'*

**System leader**

#### **Devote time, resources and effort to building strong and meaningful relationships of respect and trust with patient leaders**

*'Fear creates a negative experience for everybody. The people in The Expert (Learning Disability) Group feel that they own the hospital more now. In the beginning, they were really nervous, and I used to have to collect them to come up to our room. But now, you know, when they're here, they come here themselves. They'll come upstairs themselves and make coffee. They love going around the wards and it is a positive thing for them. It is the opposite of fear. It is feeling at home.'*

**System leader**

**Ensure that patient leaders can easily access what matters to local people as feedback that is robust, evidence-based and easy to understand and use**

*'Even now – as to getting the numbers – as to what actually has improved – at meetings I ask and I am told they haven't had time to get them ready yet. It is frustrating.'*

**Patient leader**

*'So for me to do my role, I really need a constant stream of information about the latest experiences – and I haven't got that'*

**Patient leader**

**Listen to patients whose voices are traditionally not heard, using a range of media and working closely with organisations that have existing links with these communities**

*'At the end of the day, it tends to be motivated people who join groups. So you do by the very nature of having to get up and join a group tend to get the more positive minded and motivated people. We try very hard to try and represent everyone. That is one of the things IHUG is all about; trying to represent all ages, all backgrounds and all different problems.'*

**Patient leader**

*'What can happen with formal structures, especially the patient users, (is) they become institutionalised. They go native or they have their particular hobby horse that they want to champion – and that can sometimes seem to be overriding the rest of people's views ... It is always good to have a fresh pair of eyes.'*

**System leader**

**Place equal emphasis on making sense of and responding to the qualitative feedback from stories as on the quantitative evidence from numbers**

*'It is one of our ambitions over the coming year to try and find a very systematic approach to pulling everything together. We are now on NHS Choices, Patient Opinion, comment and compliment cards, twitter, probably Facebook – all rich because they are narrative rather than 'tick box' – but, what on earth do we do with it all?'*

**System leader**

**Systematically log feedback AND report back (close the loop) on what has changed as a result of feedback**

*'Three different ways: formal reports (updates) that go through to IHUG on a quarterly basis: in the main outpatients, we have a display cabinet of 'you said, we did' and a bi-monthly newsletter with snapshots and brief information that goes out more widely to clinics, on the website, etc.'*

**System leader**

**Foster an 'improvement mind-set' through the organisation so that everyone believes change is possible and things can be done differently**

*'The Chief Executive understands personally what it is like. He has been a volunteer in the past and has welcomed us with open arms. He genuinely wants our help and wants to make this hospital the very best it can be, and you can't do that if you don't involve the people who the hospital is open for and the patients.'*

**Patient leader**

*'It brings fresh eyes to the organisation ... If you are disabled, are the facilities you need easily seen and accessible? We get feedback and have an action plan. Last year taps were identified in the outpatient-shared toilets if you've got arthritis or mobility problems. They're normal taps not levered one. That is now on a programme of works to get those changed.'*

**System leader**

**Put in place the supporting roles for transforming care outlined in the '8 Role Model'**

*'She ... helps us to make sense of all the jargon. ... It is people like her that make things like this happen, with all the support they give. There HAS to be a 'She' for projects like this to succeed.'*

**Patient leader**

*'I won a patient experience award last year, and wasn't able to go to the awards so we had a little award thing here and they were wonderful. I told them that the award was really about them; not about me winning the award. And they really owned the day. My colleagues who attended really celebrated with them, and it was just brilliant!'*

***System leader***

### **Conclusion**

Ipswich Hospital NHS Trust has made a significant effort over time to involve patients in shaping the way the hospital is run. This is making a real difference to the quality of services and the way patients experience care. It is an evolving process, with the Trust looking to make better use of qualitative feedback, moving to a model of shared leadership and involving a wider number of patients.

# Appendix D.3: Midlands and Lancashire Commissioning Support Unit



## D.3: Midlands and Lancashire Commissioning Support Unit

### Introduction

Midlands and Lancashire CSU supports 24 CCGs. It provides the following services: bespoke integrated language and communication; business intelligence and information; clinical quality; communications and engagement; contract management; corporate affairs; equality and diversity; financial management; healthcare procurement; human resources; individual funding requests; individual patient activity and continuing healthcare services; information management and technology; medicines management and optimisation; non-clinical procurement; organisational development; payroll; programme management services; referral management services; regional capacity management; strategy and transformation and service re-design.

### Brief description of programme:

The CSU has developed a sophisticated electronic Insight database to collate and make sense of patient experience feedback, including: feedback from focus groups, consultations, surveys, social media, Patient Opinion, NHS Choices, media, MP letters, PALS and complaints. The database has developed organically in response to CCGs' requirements since 2009. The database is central to 14 CCGs' responses to recommendations in Francis, Keogh and Berwick Reports.

The database categorises feedback under five domains of patient experience: safe, high quality care; better information more choice; building closer relationships; a clean comfortable place to be, and access and waiting. These categories match national surveys. This means that the CSU can benchmark local data against national surveys. The database links feedback to named service providers and so builds a real time picture of each provider's performance and creates real time feedback reports at: organisation, department, service, specialty, ward and even person level. Insight is available as a patient experience dashboard.

CCGs, contract managers and quality staff within the CSU; colleagues at the NHS England area team, GP practices, providers and voluntary sector groups can all access the dashboard. Providers can record their actions and responses to feedback on the system too.

The CSU is also working to expand application of the database more widely, including with:

- Local Health and Well Being Boards to share intelligence and feedback
- 1 CCG and all its 54 GP practices to include clinician feedback and incident reporting in primary care. Nine additional CCGs have signed up for this option too. The future implementation will see 600 GP practices, using the system to collate GPs' insights and concerns
- 1 CCG and their out of hours providers
- 1 CCG and public health team, local authority to scope how to include local care homes
- Dentists, pharmacies and opticians and one area team
- Local Healthwatch to explore how to integrate their feedback into system

7,000 members of the community have registered interest in feeding back, and receive a monthly e-mail bulletin, inviting them to contribute feedback, including attending focus groups, workshops and events. GP practice patient participation groups (PPGs) tap into the membership scheme and recruit new members to it as well.

The database membership and PPGs are connected through locality groups and are also all linked into a Patient Congress at CCG level that includes Healthwatch and representatives from the community and voluntary sector. There is an overarching Patient Congress across the patch that works in partnership with 14 CCGs to provide support, advice, challenge and scrutiny of commissioning. The Patient Congress is chaired by a CCG PPI lay member and reports directly to CCG governing bodies.

The CSU has put significant resource into continuing to support this engagement model.

There are 76 people in the CSU communications and engagement team, with 13 dedicated to engagement, involvement and insight. The remaining 63 are predominantly dedicated to broadcast communication. About 16 of the communications staff have embedded roles within CCGs and support engagement as well as communications.

#### Impact and changes the programme has created:

- 21,715 pieces of feedback are available on personalised real time dashboards. At the time of writing, 14 CCGs, over 400 GP practices, 5 NHS providers, 4 patient support groups and the NHS England area team can access and use this feedback. Organisations are making good use of the database:
  - Six CCGs are actively using insight and feedback to shape and manage county wide contracts and CQUINs and to improve quality and patient experience work programmes at scale
  - Individual CCGs are using feedback to manage performance, quality and drive provider service improvement
  - There is a step-change in responsiveness and the alert system around areas of concern
  - Insight is shaping CCG and CSU communication and engagement strategies and helping target patient and public involvement work
- Robust insight and involvement together is changing culture and enabling patients to test and challenge responsiveness:
  - Patients providing feedback know it will be recorded. This builds trust
  - The Patient Congress can easily track and challenge how well organisations are responding to patient voice. This enables scrutiny
  - Organisations are becoming more willing to share data in an open and transparent way. This improves quality of data
  - Involvement, patient leadership and responding to feedback are gradually becoming part of everyday activity
- Insight has supported changes that impact on care experience:
  - Design of a new system to inform GP practices when a patient dies in hospital
  - Use of locum radiographers to clear identified backlogs in imaging; review of coding in radiology and changes to radiology pathway
  - Improved, standardised discharge summary reports and communication
  - Improvements to: the paediatric discharge pathway and referral system for children's mental health service; confidentiality and training on information governance; plain film reporting; the scripts used in NHS 111 calls
  - Contract reviews of NHS 111, radiography service and ambulance service (in particular processes for dealing with suspected fractures)
  - Full clinical review of district nursing services

#### Key learning from this site

- **Having robust feedback to support the case for change gives patient leaders more power, influence and credibility:**

*'Someone from the CCG picked up on an issue – a small thing. Someone said a group they go to used to have craft activities, but no longer does. The issue was picked up and sent to me through the Insights system. I was able to go to the group and tell them that people wanted craft activities and can it please be re-instated. It is a good way of 'prompting' things to get done – closing the loop. Having 'tangible' evidence helps.'*

*Patient leader*

- **Having a robust feedback database enables organisations to bring different combinations of data together and generate valuable insight:**

*'In the beginning (the combination of the feedback database and the patient involvement hierarchy) was something that worked well in North Staffordshire. Stoke was interested in it. Then we started to think about feedback data in a holistic way. We started to explore other ways of bringing in other data around clinical effectiveness and quality into the system.'*

**System leader**

- **Building skills in both engagement and data analysis enables a fully effective feedback model:**

*'Being part of a great team; having two arms to the team. We have great people with data expertise and people who build involvement structures; talk to people. They do engagement really well. It's a real sharing of expertise. We are very lucky. We are a great team and come together so well. It is really powerful. We pull together.'*

**System leader**

- **Integrating and rebranding feedback as business intelligence would increase its impact:**

*'It is business intelligence, but people don't see it as that. It is 'pink and fluffy' in their eyes; just something that's done. Money doesn't come our way. It is the same old, same old. This is a big issue. This work needs to be reframed as business intelligence with patient voice driving transformation. We need to get the message out and develop a better understanding of services we have. That needs local intelligence.'*

**System leader**

- **Pooling feedback resources across areas can drive efficiencies and make the use of scarce skills:**

*'Absolutely! It should be a shared function across health economies. CCGs don't think in terms of anything but health. Fundamentally it is a resource issue and skills issue.'*

**System leader**

### **Building blocks**

This section makes the link between this site and the overall building blocks

#### **Make patient leaders an integral part of formal and informal decision-making**

*'There is real value in having patients in the room. One GP said to me, 'when you are in the room, I know I need to up my game'. Sometimes clinicians focus heavily on safety and quality and forget the value of experience. I remind them of the value of the patient experience alongside safety and quality.'*

**Patient leader**

#### **Get patient leaders involved in the experience of care, shaping, co-designing and leading proposals from the earliest stage**

*'I stayed motivated because I could see results happening and changes being made; small changes like more high-back chairs in reception; using a lower check in desk so people in wheelchairs can see the receptionist; general things. And over a period of time, it helped a lot.'*

**Patient leader**

*'Try not to be all things to all people. Stay focused. Separate things. We do things in an order we can do them in. We let volunteers decide the order. For example, 20-25 people attend our PPG. For them, self-testing blood pressure was a key issue. So we bought a machine (and it is in the surgery) and lots of people use it and the surgery records their blood pressure in their notes.'*

**Patient leader**

**Ensure systems invest in tailored, task-focused training and development of patient leaders**

*'We had excellent training on the feedback system. The people who trained us couldn't do enough for us.'*

**Patient leader**

**Devote time, resources and effort to building strong and meaningful relationships of respect and trust with patient leaders**

*'It's an emotional currency. You need to build trust and relationships between people so they can have meaningful dialogue. Invest in people to give patients a voice. The Feedback loop is very important.'*

**System leader**

*'Patient leaders need to feel valued and understand what and why they are involved. They need time for reflection; and support. In the long term they can become mentors and support others.'*

**Patient leader**

**Ensure that patient leaders can easily access what matters to local people as feedback that is robust, evidence-based and easy to understand and use**

*'I input my own issues onto it (the feedback database), and I can choose if I leave them open or close them. I have a 'to do' list on the database, and it is a good reminder of things that need doing. Also, I can log on to a particular issue about a certain service people have made comments about, and take the information to meetings. I can then update it after the meeting and close if it has been resolved, or (keep it) open if it hasn't.'*

**Patient leader**

**Listen to patients whose voices are traditionally not heard, using a range of media and working closely with organisations that have existing links with these communities**

*'We have been on a journey with the youth as we recognise that young people generally speaking just don't want to come to meetings. They work differently. So we 'allied' ourselves with the Youth Forum – a partnership with voluntary services, looking at working dynamically in that way.'*

**Patient leader**

**Place equal emphasis on making sense of and responding to the qualitative feedback from stories as on the quantitative evidence from numbers**

*'If anyone comes to me for a piece of work, I say 'I'm going to check what other people are telling me'. There might be 30 contacts about that service so I can be a better worker and understand the complexities and issues before I start – or the bits people are telling us are good so they don't get lost along the way.'*

**System leader**

**Systematically log feedback AND report back (close the loop) on what has changed as a result of feedback**

*'I can be at an event and hear what is being said and capture feedback. I may be at an event and someone has told me something isn't working well for them and I will take it back to the office and enter it onto the system and see what other data there is around that topic. It can lead to a full commissioning review of a service, e.g., podiatry waiting times.'*

**System leader**

**Conclusion**

Midlands and Lancashire CSU have developed an insight tool to support the effective use of qualitative feedback in improving health services. They combine data analysis with the ability to support organisations reach out to patients. This demonstrates that it is possible to pool feedback and patient leader resource across health organisations.

# Appendix D.4: Shropshire CCG

## D.4: Shropshire CCG

### Background

Shropshire CCG is one of the largest geographical CCGs nationally. It serves 302,000 patients across 44 GP practices and is currently placed second nationally for rural sparsity. Its mission is 'to have the courage to develop a health system that empowers the delivery of excellent outcomes founded on individual relationships, which nurture compassion, respect and dignity'.

### Brief description of programme:

The CCG has an older population profile and until this work began, young peoples' voices were often absent. Recognising that it was a deficit in the way it works, the CCG has made a sustained effort to engage with young people and involve them in commissioning. Their contribution has challenged existing thinking and held both managers and older people to account for taking a longer term view. The CCG worked with the charity Altogether Better and bid successfully for lottery funding to support young health champions. The CCG has also enabled young people to design services and supported young people to be champions of healthier lifestyles within their communities.

### Detailed programme overview:

This CCG has an older population profile. The Accountable Officer wanted the CCG to start listening to young people as their health and happiness agenda was receiving less focus and priority in CCG discussions and forward planning.

She invited young people to speak at a CCG 'Call to Action' meeting in 2012. The young speakers reminded the adults in the room that if they did not make difficult decisions now, there would be no NHS left for them when they were 60. Their challenge changed the conversation and the event.

The CAO was already in discussions with Altogether Better – a charity that supports communities to develop adult community health champions. They had met through a NHS England 'Citizen Hack' event. They worked together to develop a programme to develop young health champions and bid successfully to The Big Lottery. They secured two year funding in 2013.

In response to feedback from and in partnership with the young leaders involved in the programme, Altogether Better adapted its existing two-day training programme. The curriculum stayed essentially the same. The teaching methods changed, with more emphasis on fun, games, art and creative work. 190 children and young people aged 11-25 have completed the training plus 3 ten year olds and, including 12 young people with learning disabilities.

After training around 'health and happiness' where young people define what health and happiness meant for them personally as well as for their community, the children and young people chose a project to work on. This was either something the CCG suggests – a 'chocolate box' of opportunities to contribute. Most chose one of these. Or young people came up with their own ideas. Whilst fewer did this, this option led to some really exciting innovations. Examples include:

- Creating an educational film about diabetes for school staff to use as a training tool
- Building a dementia friendly school. This could have massive impact in the small rural town where this young leader lives
- Creating a sports programme for children with learning disabilities alongside able bodied children, which supports and builds integration and connection
- Education about Japan's approach to dementia care, delivered as a Japanese tea ceremony, which people have engaged with much more than with leaflets and traditional campaigns
- Dance classes run by a young person, supervised by an adult, for children who could never afford classes and often come from families where obesity is common
- Conversion of an empty high street shop in a larger town; filling it with health advice that young people felt was useful and providing a safe space where the young people in town on a Saturday with nothing to do can come and get advice and support from someone of their own age who has been there

- Transforming a dull room in hospital into a chill out area for young people

Young people have led and managed these programmes. An independent evaluation will assess impact of the programme, including its impact on participants' self-esteem. The CCG is now looking for funding for another three years and is committed to giving young people time and space.

#### Impact and changes the programme has created:

- Young peoples' perspectives and challenge has changed the CCGs' mind set. It now 'thinks forward' and recognises its responsibility to build a legacy for future generations. This guards against 'a knee jerk reaction' to the NHS's current challenges
- The CCG has changed its language and approach to communication to accommodate and welcome young people. Everyone likes the new approach better. Terminology is simpler and more engaging for everyone
- Before, young people were rarely seen at CCG workshops or meetings. They had no voice in CCG decision-making processes. Now they are visible, involved and influential
- Young people are improving care experience and coproducing public health initiatives, community support and services, such as a drop-in health shop in town and filming a video for schools about diabetes

#### Key learning from this site:

- Young leaders bring a fresh perspective to strategic health service review and commissioning:  
*'Young people bring a totally different dimension to how we work. They contextualise what is actually real to people. There is no baggage with a young person's voice; 'it is how it is'. Their perspective is a really useful starting point. They make no assumptions. When I am struggling with some work, I ask some young people working with us to help me find out what the 'actual issue is' and it's usually not as big as it might seem to us!'*

**System leader**

- Being involved boosts the confidence, self-esteem and ultimately the health of the young people:  
*'My sister is 13 and has dyslexia and dyspraxia. She usually can't remember what happens in a day at school but has become a young champion and comes home, telling us all about what has happened.'*

**Patient leader**

*'It was scary to help with it and speak; but quite an achievement, being able to speak on behalf of young people. 3-4 years ago I wouldn't have been able to do that. I suffer from anxiety. I spoke to a whole room of people. I was scared, but I did it. And it gave me confidence. It was a discussion of the biggest problems in the NHS.'*

**Patient leader**

- Young patient leaders can be powerful peer supporters and campaigners for public health in the broader community:

*'We made a video for schools about diabetes for young people. It's on You Tube... We all put ideas into it. Young people who live with diabetes played a big role. I acted on it. ... Newly diagnosed diabetics feel alone. I hope that if people watch this they will feel less alone. Doctors use complicated words and give you books when you are diagnosed but really you want to hear from someone your own age.'*

**Patient leader**

#### Building blocks

This section makes the link between this site and the overall building blocks:

#### Make patient leaders an integral part of formal and informal decision-making

*'We shared our good and bad experiences; what worked and what didn't and there were table discussions. Most people were a lot older. When we did sit at the tables and input on tables, everyone wanted to know what we thought.'*

**Patient leader**



**Get patient leaders involved in the experience of care, shaping, co-designing and leading proposals from the earliest stage**

*'We set up a teenage room in hospital because I go to hospital a lot and know what it is like. Teenagers mix with babies. Hospital is not a good space for teenagers to be in. I helped to design – I had a picture in my mind and it is nearly there. Before it didn't look much. Now there are settees – long ones; bean bags, walls with pictures; names on the pictures I had some ideas for the pictures – everything falling into place.'*

**Patient leader**

**Ensure systems invest in tailored, task-focused training and development of patient leaders**

*'I was involved in setting up the initiative and designing training. We went to Leeds and went through adult health champions' and assessed the training course. We came back and went through it and re-developed the whole course to suit young people.'*

**Patient leader**

**Devote time, resources and effort to building strong and meaningful relationships of respect and trust with patient leaders**

*'You can't expect to throw young people together in a room and expect them to just get on with it. We need time to bond; informal networking before moving into the training and activities.'*

**Patient leader**

**Listen to patients whose voices are traditionally not heard, using a range of media and working closely with organisations that have existing links with these communities**

*'We are actually being listened to- welcomed in the CCG. They are saying 'They have our support.''*

**Patient leader**

**Put in place the supporting roles for transforming care outlined in the '8 Role Model'**

*'Having people who listen, care and whom you can trust (like her and the youth workers). It wouldn't happen without her.'*

**Patient leader**

*'When there is a problem in my life, I can turn to her. She knows me and is supportive without being overwhelming.'*

**Patient leader**

**Conclusion**

Shropshire CCG has made a sustained effort to ensure that the young person's voice is heard in health commissioning. They have supported young people to be health champions in the community. This is a potentially exciting way to promote broader health and wellbeing, with today's lifestyle choices determining so much of future health demands.



# Appendix E

# Suggestions

# for National

# Organisations

# Appendix E Suggestions for National Organisations

During the Phase 2 research, participants were asked about their messages for the NHS. Feedback from local sites was that national policy can sometimes have unintended and negative consequences on learning from feedback effectively. These points have now been captured and will be considered by NHS England.

- **Short programme timescales** make it difficult for NHS organisations to work in partnership with patients and families and to build in their feedback. With this in mind, it is important that NHS organisations are proactively and routinely seeking and acting on feedback. Ideally, NHS organisations should already be aware of what matters to patients and what they think about services. Participants asked that those designing national programmes be mindful of the time needed to do meaningful involvement and build that time in to planning guidance.
- **Counting the number of engagement events rather than valuing what people say:** people said that often the measure of success for consultations was speaking to large numbers of people rather than showing evidence of having analysed and responded to what they said. They wanted more focus on rewarding responsiveness.
- **Prioritising quantitative over qualitative data:** participants expressed the view that NHS survey results count more than free text comments. This is reinforcing the beliefs and behaviours of NHS organisations that quantitative data is more valuable than qualitative data. They wanted a more balanced approach to how organisations were held to account in relation to feedback and more freedom to design their own improvement goals and demonstrate they had worked with people to gain feedback and respond to it.

Participants also shared that national organisations could play a supporting role in:

- **Allocating equal priority to local and national targets in responding to feedback:** participants felt that in an ideal world, they would be free to set their own targets around feedback that were meaningful in the local context rather than aimed at ranking their performance against the 'numbers' in national surveys. One participant suggested that they would like to work with their patient leaders to decide what improvements they should be measured on: a 'patient-centred outcome measure' of responsiveness.
- **Mandating that local patient leaders have greater say in procurement:** in two of the case studies, patient leaders held voting power within formal procurement processes and also controlled a percentage of the provider's performance related pay. These proved to be powerful drivers for patient leader involvement and impact. In the site where we explored this model in depth, having patient leaders involved in this way helped to shift the power dynamic in the system towards what matters to patients and family carers. Patient leaders who have experienced this model said they would like this to be a 'must do' mandated by the NHS. This could happen through an approval process at NHS Gateway, which is a sign off point in approval of major changes.
- **National support to create an easy to access 'Talent Bank':** patient leaders told us that they often felt that their talents and skills were overlooked. System leaders said they would like to know what talents and skills their patient leaders have. They suggested that National organisations could support the development of patient leaders by creating a talent bank that system leaders could search to find out who could help in their area, e.g., through the planned Participation Academy.

The Patient Leaders Expert Advisory Group met in March 2015. It reviewed the overall research findings and discussed ideas which could give further impetus to helping patient and carers become leaders. Many of these suggestions are relevant for national as well as local organisations.

**Invest in patient leaders**

1. Prioritise development of a Talent Bank for patient leaders through Participation Academy, i.e., mapping the wealth of skills and experience that patient leaders can bring to this work.
2. Put in place a requirement for NHS commissioners to allocate patients a formal stake in commissioning decisions (especially major procurements), e.g., 20% vote.
3. Create an organisation for patient leaders to grow the number of people involved, supported by NHS England.
4. Have a national 'memorable event' which signals a watershed around patient leaders and feedback systems, with patients in charge and presenting the findings of this work.
5. Have a patient leader to work alongside Simon Stevens for a year.
6. Support good ideas; enable patient leaders to test innovations, e.g., small monetary awards.

**Put the feedback mechanisms in place so that organisations respond**

7. Redefine business intelligence to include feedback and qualitative data about care experience, e.g., in commissioning support lots.
8. Create incentives for local organisations to drive right behaviours around meaningful feedback collection and analysis.
9. Get NHS organisations to review current spending on broadcast communication vs. current spending on two-way listening and engaging with communities. Nudge them to rebalance this expenditure, e.g., set a 'guide ratio' for spend on broadcast : engagement activities.
10. Build a narrative for different players in the system so they can see how they will benefit from the involvement of patient leaders in feedback, i.e., to answer their question, 'So what? Why should I do this?'
11. Look at ways to mainstream and systemise use of qualitative data in feedback.
12. Offer lots of different ways to engage people in providing feedback; spread use of volunteering assignments and know-how around designing them.

**Spread best practice on how organisations act on the feedback they receive**

13. Have a workshop with key national organisations to 'land' the results of the work and explore with these partners what action they can take to support spread – word of mouth; implementation of the key learnings around the '8 role model'.
14. Make space for more local targets to respond to feedback, e.g., could be a set of local organisation wide 'patient centred outcome measure' of responsiveness, coproduced with patient leaders.
15. Set up a 'Best Practice' exchange session with the 17 case study organisations involved in this work.
16. Describe 'The 8 role Model' in great detail; create a simple, practical story around how NHS organisations can deliver it.
17. Create a way of delivering the '8 role model', which sits outside NHS organisational structures so it is protected from system change; explore co-funding across NHS organisations and Local Authority infrastructure as a sustainable way forward. Learn from places where this may be starting to happen.
18. Explore impact of the current guidance for patient and public involvement on the behaviour of the majority of areas (as opposed to the early adopters in the case sites).
19. Create a network of 'Linchpins'. Support patient leaders who may be acting as Linchpins currently to find support from system Linchpins.

20. Support case studies where 'the 8 role Model' is applied across the 'whole system' of health and social and voluntary sector communities. Adapt and learn locally; share the learning nationally. The Forward View Vanguard sites could represent an opportunity for testing this approach.
  21. Create support for senior leaders to drive this change, e.g., National Leadership Academy.
- NHS England will explore these suggestions further with the Patient Leaders Expert Advisory Group.

# Appendix F

# Glossary

# Appendix F Glossary

**Patient leadership:** We have not sought to define the term 'patient leadership' formally as part of this work, given so much work in this arena has been done already by other organisations as referenced in the Introduction. In the context of this work, 'patients leaders' are people with valuable health and care related expertise, with strong empathy created by their own experiences, each with their own unique set of attributes. They are people who draw on their own life experience, resources and ideas to make an active contribution to improving the experience of care and the health and well-being of others. They display the characteristics of 'active citizenship' as defined by the British Council (a citizen who commits his or herself to an action that benefits society). When we refer to 'patient leaders', we include leaders who are patients, patients' family members and patients' carers.

**Feedback:** the insight-rich information that comes from people, families and staff sharing their stories and experiences of care with the health and social care system.

**Patient and public engagement and involvement:** activities that result in people providing feedback and how patients and the public are involved in decisions about design and delivery of services.

**Feedback system:** the process by which organisations systematically generate, collect, make sense of and translate feedback into management insights that support NHS managers to take action and implement change.

**System leader:** a person who is employed by the health and social care system and who works in a management role (includes clinicians and NHS managers).

***Leadership is about what people do to make change that improves care and wellbeing experience. In this context, system leaders and patient leaders both have the potential to turn feedback into action that improves care experience. The work of patient and system leaders is hence a key driver for changing experience of care.***

# Appendix G

# References

# Appendix G References

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