Improving Experience of Care through people who use services

How patient and carer leaders can make a difference

August 2015

Contents

The appendices are contained in a separate document

Foreword

The NHS Five Year Forward View says that 'we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services'[1] (2014). The concept of patient leadership is emerging as one important new way of working collaboratively with patients and carers. 'One new concept – patients as leaders – is beginning to gain popularity'[2] (Kings Fund 2013). This project was about trying to understand how patients and carers as leaders can make a real difference in improving experience of care.

NHS England commissioned this work to produce learning for commissioners and providers from good practice that is already happening. We wanted to find out if patients and carers as leaders make a difference in the attention that experience of care gets alongside clinical effectiveness and safety. We also wanted to discover if patient leaders can support NHS organisations to act on patient and carer feedback to improve experience of care and to understand what NHS organisations need to do to make this approach work.

We have intentionally carried out this work on a collaborative basis. This meant that patient and carer leaders co-designed the project and co-produced the learning through a workshop, use of Twitter and a Patient Leaders Expert Advisory Group. We believe that the findings have much greater value and validity as a consequence.

What we have learned is that patient and carer leaders can raise the profile of improving experience of care and can have a real impact on action being taken in response to patient and carer feedback. Notable examples of working in this way have been identified, some with more marginalised and vulnerable patient groups including young people and users of mental health services (but very few with people from black and minority ethnic communities which should be a priority in future). The learning about the building blocks that need to be in place will be particularly helpful for NHS organisations.

We are committed to continuing to work together to promote this way of working, to sharing the learning from this work and to supporting organisations across the NHS to embed the conditions for success. As a next step NHS England has sponsored The King's Fund 'Leading collaboratively with patients and communities' programme[3] to support continued learning about the impact that patient and carers as leaders can have.

David McNally
NHS England

Steve Sharples MA
Patient leader

---

[1] http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf.

[2] http://www.kingsfund.org.uk/publications/patient-centred-leadership.

[3] http://www.kingsfund.org.uk/leadership/leading-collaboratively-patients-and-communities.

Acknowledgements

We would like to acknowledge the contributions to the project made by all the organisations that contributed case examples, in particular the patient, carer and system leaders from the four visited case examples. We also acknowledge the contribution of the members of the Patient Leaders Expert Advisory Group, and of Roz Davies who also co-delivered the project.

The project was co-delivered by Ernst & Young (EY) and Experience Led Care (ELC).

A note on the content of the report

The report includes a short Executive Summary. The main report has the following sections:

- **Introduction:** sets out the background to the work and introduces the key concepts.
- **Phase 1:** sets out the learning from a one hour Twitter conversation (Tweetchat) and a workshop with 70 participants.
- **Phase 2:** draws out the main messages from the 18 examples of good practice and the four detailed case studies.
- **Phase 3:** introduces building blocks for organisations to consider as they invest in health leadership.
- **Conclusions:** draws together the main points from the research.

The Appendices provide more detail on the programme itself and who was involved, along with the individual case study findings for those who want to read more.

Executive summary

1. Executive summary

NHS England commissioned this programme to explore how patient leaders can play a more prominent role in defining, assessing and improving patient experience. Patient leadership in the NHS is an emerging concept. Our work was intended to be an organic and qualitative co-production process. We worked with patients and system leaders to:

- Assess which elements of patient leadership were most important and should be explored further
- Look in detail at examples of good practice
- Develop recommendations for building blocks for organisations to consider as they invest in patient leadership

In Phase 1 we co-designed the scope of the research with the people who will be using the findings. This included an hour-long Twitter conversation (Tweetchat) and a workshop with 70 people. The main finding from Phase 1 was that the element of health system management that people felt was most important to improving care experience through patient leadership was 'feedback'. There is a clear link between patient leadership and feedback.

In Phase 2, the research and discovery phase, we looked at 17 organisations that had involved patient leaders in improving care using feedback across England. Our Patient Leaders Expert Advisory Group (PLEAG) selected a number for more detailed study, and our programme team visited four areas to undertake a more detailed case study review.

The three **key messages** from that came out from this work were:

1. **Invest in Patient Leaders.** The 17 organisations confirmed that patient leaders are a valuable asset and make a demonstrable impact on services and on the care experience. Patient leaders bring a credible voice, and can work with system leaders to create a compelling case for change. This gives the system 'permission to act'. Patient leaders influence health services' priorities, placing a greater emphasis on the experience of care. Patient leaders can help to design services on the ground, and when system leaders involve patient leaders and carers in this service design, they are able to focus more closely on what patients and carers want. More radically, commissioners may reduce the risk of future legal challenge about the decommissioning decisions they make in large scale procurements and transformation programmes, if they involve patient leaders armed with robust evidence of what matters to local patients and families. Patient leaders can have a role as 'champions' in their communities promoting broader social movement around health and wellbeing.

2. **Put robust feedback mechanisms in place so that organisations listen.** A consistent theme in the research has been the need for organisations to put effective feedback mechanisms in place. Many NHS organisations told us that they struggle to analyse qualitative feedback such as stories and are more comfortable with quantitative analysis and data such as survey results. Equally valuing qualitative feedback and quantitative evidence is a significant shift in thinking that the system is just starting to make. As one of the staff interviewed said 'Redefining Business Intelligence is central to this', bringing together different sources of information to develop a better overall understanding. This requires a shift in mind-set away from engagement compliance, to focus on the quality not the quantity of feedback. There should be a supporting shift in investment of resources, with a re-balancing and shift away from 'one-way' broadcast communication and more towards 'two-way' involvement of people and communities as equal partners in change and improvement.

   Organisations should be proactive in reaching out to patients, making a conscious effort to engage with harder to hear communities. They should use different means of communication to reach different groups. They should ask staff for feedback and learn from positive as well as negative feedback.

Organisations need to have clear processes to log and act on feedback, bringing together different sources of information. They should always close the loop, reporting what they did with the feedback.

3. **Develop the culture and systems to act on feedback.** Organisations who invest in feedback possess an 'improvement mind-set' and are committed to getting better. They understand that change is possible, and that things can be done differently. They put an infrastructure in place to enable patient leaders to contribute.

   Organisations should be aware that the process of developing and involving patient leaders requires a sustained commitment over time. It will be important to build momentum and generate goodwill through celebrating success.

There is no single model for patient leadership and organisations will have different approaches. However, our findings suggest that when NHS organisations want to involve patient leaders as partners or enhance existing activity, ensuring these conditions are in place and supporting these 10 building blocks, will increase their chances of success.

The 10 **building blocks** for developing patient leadership are:

Invest in Patient Leaders

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

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

3. Ensure systems invest in tailored, task-specific training and development of patient leaders

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

5. 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

6. 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
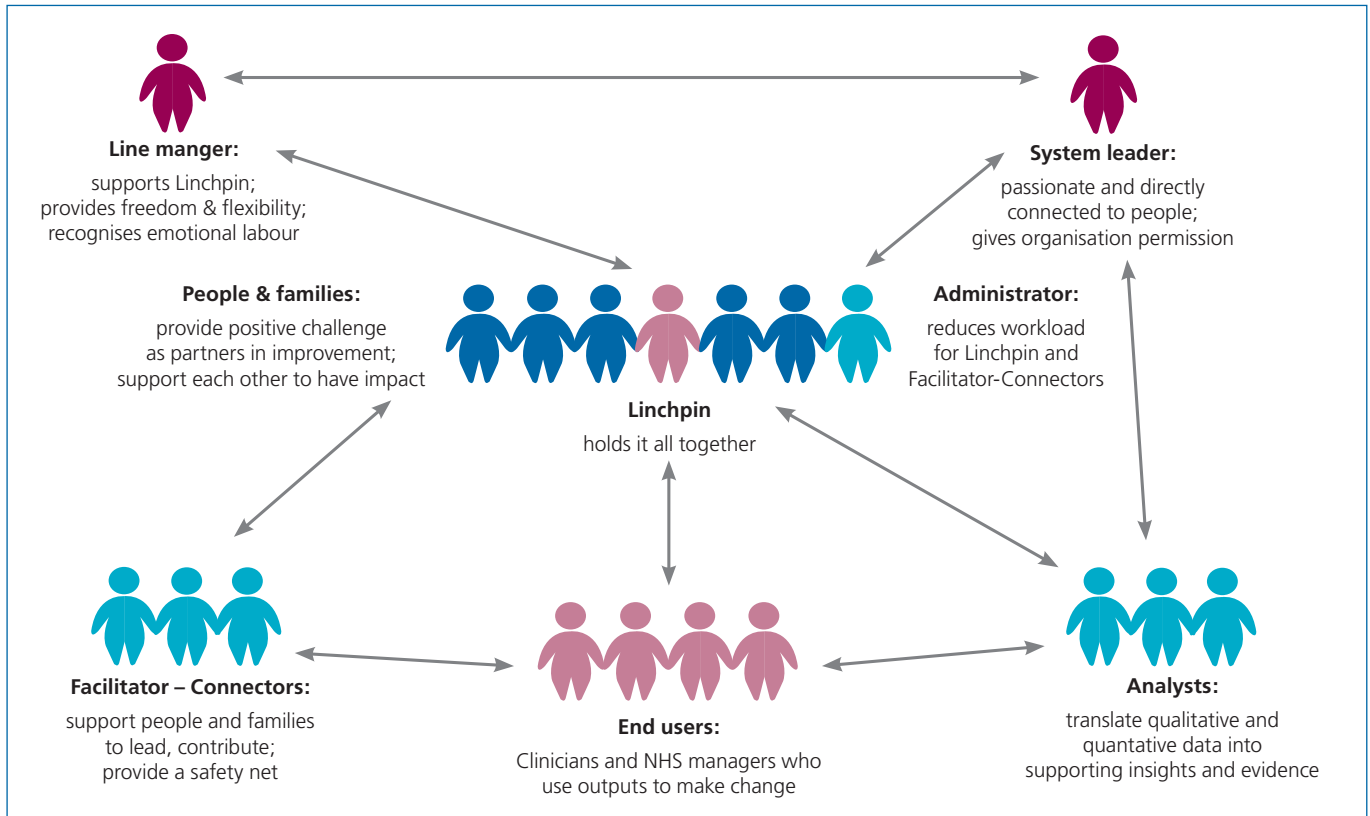
Put robust feedback mechanisms in place so that organisations listen

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

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

Develop the culture and systems to act on feedback

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

10. Put in place the supporting roles for transforming care outlined in the '8 Role Model'. This is contained in the following illustration.

Figure 1: The 8 Role Model

Line manger:
supports Linchpin;
provides freedom & flexibility;
recognises emotional labour

System leader:
passionate and directly
connected to people;
gives organisation permission

People & families:
provide positive challenge
as partners in improvement;
support each other to have impact

Administrator:
reduces workload
for Linchpin and
Facilitator-Connectors

Linchpin
holds it all together

Facilitator – Connectors:
support people and families
to lead, contribute;
provide a safety net

End users:
Clinicians and NHS managers who
use outputs to make change

Analysts:
translate qualitative and
quantative data into
supporting insights and evidence

Individuals may carry out more than one of these functions. The roles can be filled within one organisation or increasingly may be pooled across the health economy.

In conclusion, this work recognises 'patient leadership' as a core and essential component of a 21st century health and care system. This system itself is co-creating the best services it can within resource constraints and the complex, dynamic social and political world within which it sits.

Our analysis has identified a number of health organisations which have invested in feedback and are working with patient leaders to improve services. They are passionate about working with patients and their families and share an ambition to involve them as partners. Key learnings from these organisations inform the building blocks for success in working with patients and carers as leaders to improve the care experience.

Main report

2. Introduction

2.1 NHS England's commitment to listening and to working with patients and the public

Central to NHS England's ambition is to place the patients and the public at the heart of everything we do, including in the development of national policy, new programmes of work and direct commissioning. We encourage patient and public participation in the NHS, treat people respectfully and put the interests of patients first. We believe that involving people in decision making allows us to develop the insight to help us improve outcomes, meeting the needs of all communities and reducing inequality.

Our approach to placing patients and the public at the heart is supported by our statutory duty to make arrangements to involve the public in our commissioning of NHS services.

NHS England's business plan for 2013/14 – 2015/16, called Putting Patients First,[4] explains how our commitment to transparency and increasing patients' voice are fundamental to improving patient care and delivering better services.

The Five Year Forward View,[5] published in October 2014, was developed by NHS England and other arm's length bodies and sets out a commitment to 'engage communities and citizens in new ways, involving them directly in decisions about the future of health and care services.'

The guidance Transforming Participation in Health and Care,[6] 2013, describes NHS England's vision for public participation: 'NHS England will ensure that public, patient and carer voices are at the centre of our healthcare services, from planning to delivery. Every level of our commissioning system will be informed by insightful methods of listening to those who use and care about our services.'

NHS Citizen is a programme commissioned by the board of NHS England. It is designed to address how the board of NHS England can better take into account the views of patients, service users and the general public when making decisions about the NHS and can be held to account by the public which it serves. Through an open design process the NHS Citizen project team has developed a model for NHS Citizen which comprises:

- Deliberative and decision-making processes and events, such as the Gather process (which will give people opportunities to 'gather' around particular issues) and Assembly meetings (which will consider the most important issues in an open and deliberative forma, providing an opportunity for robustly evidenced citizen-generated proposals to be discussed with the NHS England Board).
- A set of values and behaviours which are intended to create a culture of participation within NHS Citizen.
- A set of tools and approaches designed to find and connect pre-existing patient participation as well as to identify gaps and hidden voices.

In addition to NHS Citizen, NHS England is developing an online space (working title *Participation Academy*) to support the learning and sharing of good practice in relation to patient participation. This learning and development hub will be aimed at both citizens and staff, and will be piloted by April 2016. Support for public participation also includes 'Bite size guides' with guidance on a variety of participation subjects ranging from citizen voice in governance, to making public participation accessible, as well as a number of other topics. Complementing these resources is the development of a 'People Bank' aimed at matching members of the public that register to engagement opportunities within NHS England.

[4] http://www.england.nhs.uk/pp-1314-1516/

[5] http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

[6] http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

We want to ensure that the views of patients, carers and the public are heard and are able to influence NHS England's own decision-making. This means embedding people's voices as part of our governance structures, such as by having lay members as part of our committees, and through effective, and ongoing engagement activities.

NHS England has recently launched its new Patient and Public Voice expenses policy, giving an easier and more consistent approach to ensuring that patients are not out of pocket when working with us. The policy makes provision for an Expert Patient Advisor role that recognises patient involvement at an enhanced or leadership level of input.

NHS England is working with partners to build up youth voice and leadership input in our work through programmes like the NHS Youth Forum, the four regional youth voices programmes and the annual Takeover Day programme.

2.2 Improving experience of care

Since 2008 the NHS has had a view of quality in health services as being made up of three components – clinical effectiveness, safety and experience, although for much of that time experience has not been regarded in practice as being equal to clinical effectiveness and safety.
An increased priority has been placed on experience of care in the NHS following publication of the Francis and Winterbourne View reports.

At its inception in 2013, NHS England established a national Patient Experience Team as one of five NHS Outcomes Framework quality domain teams. NHS England's work on improving patient experience is in large part undertaken as an integral aspect of clinical improvement work. Examples include the following service areas: cancer; urgent and emergency care; children and young people; maternity; older people; people with a learning disability. There are also substantial programmes of work on improving support for carers and acting on and learning from complaints. An Insight Strategy is being developed by NHS England's Insight Team to provide commissioners with practical approaches in how to gain and act on insight from patients.

The importance of improving experience of care is seen in a systematic review of evidence on the links between patient experience and clinical safety and effectiveness published in the British Medical Journal[7] which concluded that 'patient experience is consistently positively associated with patient safety and clinical effectiveness'. A King's Fund report has also found evidence of a positive association between staff experience and patient and carers experience of care.[8] The National Institute for Health and Clinical Excellence (NICE) has published two quality Standards relating to patient experience: Quality Standard 15 addresses patient experience in NHS services and Quality Standard 14 service user experience in adult mental health.

National Voices, as part of its work on prioritising person-centred care, has published a summary of evidence[9] from systematic reviews on the top things that managers and clinicians can do to enhance patient experience.

1. Improve consultations

- Use patient-centred consultation styles
- Provide communication skills training for professionals
- Have longer consultations
- Encourage people to be involved in decisions about their care
- Provide patient information, education and regular communication

[7] http://bmjopen.bmj.com/content/3/1/e001570.full

[8] http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/improving-nhs-care-by-engaging-staff-and-devolving-decision-making-jul14.pdf

[9] http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/enhancing_experience.pdf

2. Use feedback

- Act on direct feedback from patients via surveys, focus groups and complaints
- Use patient-reported outcome measures (PROMs) to target improvements
- Publicly report performance indicators

3. Redesign services with patients at the centre.

- Redesign services to support patients and carers, for example using patient portals
- Improve continuity of care

How NHS provider organisations are collecting and making use of patient experience feedback is looked at in a recent report from Membership Engagement Services/In Health Associates.[10] The report looks at, what patient experience data is being collected, how it is being used for improvements and how patients are being involved. It recognises that 'patients are becoming more involved in patient experience work, from gathering data to providing insights and working with staff on data-led improvement work'.

In a recent publication,[11] the National Quality Board has updated the NHS Patient Experience Framework, seeking to develop a shared understanding amongst national NHS bodies of what is meant by the term 'experience of care', why it is important and what good experience looks like. It says that experience of care can be assessed both in terms of:

- **What** the person experiences when they receive treatment, whether they knew who to contact if they had a problem, whether the nurse explained the procedure to them, and whether the doctor asked them what name they would like to be called by.
- **How** that made them feel – for example, whether they felt treated with dignity and respect, and whether they felt that the doctor told them about their diagnosis in a sensitive way.

In considering 'What is a good experience of care?' the document says that when measuring the patient experience, all users of health services should be able to say the following:

- 'I am involved as an active partner in my care – this means playing an active role, when I'd like to, in making decisions about my care, treatment and support, and being supported to look after myself day-to-day'.
- 'I am treated as an individual – my needs, values and preferences are respected'.
- 'I am able to access services when I need them, and my care is coordinated so I know where to go next and where to turn if I have a problem'.
- 'The people providing my care recognise that I am the expert on me – this means that my knowledge, skills and expertise as a result of living with my condition, as well as the effect that this has had on my life and on the lives of those who are important to me, are respected'.
- 'I am asked how I would like to be communicated with so that communication is tailored to me and is delivered with care and compassion, and that I have the opportunity and time to ask questions and have a conversation about my care, treatment and support'.
- 'I have access to the information I need, which is presented in a way that is right for me, to make sure I understand what is happening and can play a role in making decisions if I'd like to'.
- 'I have access to the support I need and is right for me, including emotional and practical support, and I am able to involve my loved ones in decisions about me'.
- 'The environment in which I receive my care is clean and comfortable and makes me feel dignified'.

---

[10] http://www.membra.co.uk/case-studies/making-sense-and-making-use-patient-experience-data
[11] http://www.england.nhs.uk/wp-content/uploads/2015/01/improving-experiences-of-care.pdf

2.3 Patient leadership

The concept of patient leadership is emerging as one important new way of working collaboratively with patients and carers. 'One new concept – patients as leaders – is beginning to gain popularity'[12](Kings Fund 2013).

Patient leadership implies a different relationship between individuals, communities and the NHS. As a literature review[13] highlighted, the traditional relationship between the patient and the doctor is one of deference, where being ill is a passive state and the doctor heals. There has been a shift towards the citizens having explicit rights, for example in the NHS Constitution. Co-production implies a reciprocal relationship between the individual and the state where there is equal power and respect and values, purpose and responsibility for outcome is shared. Alison Cameron, herself an acclaimed 'patient leader' in her article for 'The Edge'[14] explains how co-production goes beyond a simple rebadging of 'patient/service user involvement'. She goes on to quote the New Economics Foundations definition:

'Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change'.[15]

Through this work we learnt that some people feel that the use of the term 'patient leadership' is language used by clinical and managerial system leaders and can represent an approach which in itself creates barriers. In the places we visited, people had adopted many different 'titles', e.g., champions, members or experts by experience. There has been much discussion about patient leadership, looking at the roles patients working as leaders can play and the qualities which they bring to organisations. Many experts in the field have sought to define the term, or to offer alternatives.

The Centre for Patient Leadership, together with Policy to Performance, have said[16] that patient leaders are 'patients, service users and carers who work with, and for others to influence decision-making at a strategic level' and that clinical, managerial and patient leadership are all needed to transform services and place patients truly at the heart of healthcare.

National Voices in the paper 'Patient Leadership: The Start of A New Conversation'[17] say: 'The new concept of Patient Leadership … describes an aspiration – that a portion of these active patients may come to be recognised as service leaders, equal in esteem and influence to managerial and clinical leaders'.

Doughty and Gilbert[18] develop further this link between patient leaders' personal experiences and their approach to leadership:

'Once people have the confidence and self belief that they can lead and influence their own lives, we find them more willing to see how they can use those skills to work with others.

'People need time to reflect on what they have been through and about the knowledge, skills and behaviours developed during dark times. Then, in the relative tranquillity of a learning process, they can choose behaviours to better support their vision of leadership.

---

[12] http://www.kingsfund.org.uk/publications/patient-centred-leadership

[13] http://www.nhscitizen.org.uk/design/wp-content/uploads/Citizenship-in-the-NHS-Literature-Review.pdf

[14] http://theedge.nhsiq.nhs.uk/classic/classics-co-production-radical-roots-radical-results-by-alison-cameron

[15] New Economics Foundation, 2009

[16] http://engagementcycle.org/wp-content/uploads/2013/03/Bring-it-on-40-ways-to-support-Patient-Leadership-FINAL-V-APRIL-2013.pdf

[17] http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/patient_leadership_briefing_note_0.pdf
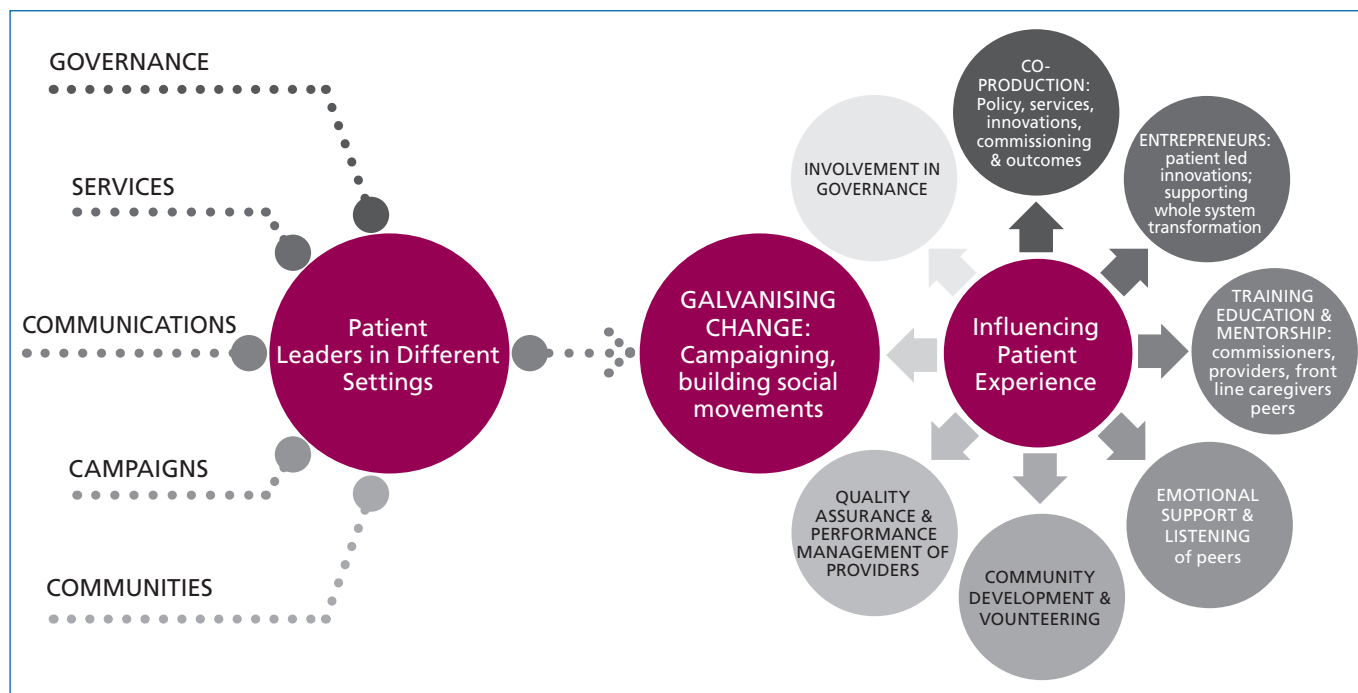
[18] 'When patients become leaders', Health Service Journal, 13 September 2012.

'When patient leaders learn to build collaborative relationships based on shared values and inspired by a shared vision, there is a move away from command and control; away from a situation where authority is derived from status, to one where it comes from understanding gained through experience. They move from dependence to independence and interdependence.'

We have not as such set out to define the term 'patient leadership' as part of this work. We have instead opted to build on previous debates and definitions by developing an understanding of the characteristics of 'patient leaders' and of patient leadership. In the context of this work, 'patient leaders' are people who invest their time and resources to influence decision-making at a strategic level that improves care experience. They 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. When we refer to 'patient leaders', we include leaders who are patients, patients' family members and patients' carers.

We have developed the model below to provide an overview of the breadth of settings and ways that patient leaders can currently get involved in improving the experience of care across the health and care system.

Figure 2: Different settings where patient leaders make an impact

2.3.1 The work of this project

The work described in this report was commissioned by NHS England to produce learning for commissioners and providers about what works already in terms of patient leaders' impact on care experience.

From the beginning, the project team carried out this work on a collaborative basis, with patient and carer leaders co-designing the project and co-producing the learning through a workshop, use of Twitter and a Patient Leaders Expert Advisory Group.

The aim was to find out if patients and carers as leaders make a difference in the attention that experience of care gets (alongside clinical effectiveness and safety), if patient leaders can support NHS organisations to act on patient and carer feedback to improve experience of care and to identify the critical success factors for NHS organisations to make this approach work.

In order to address this aim, the project was delivered in three interlinked phases, each building on the preceding phase:

- **In Phase 1 (November 2014)** we asked patient leaders and system leaders to design the scope of the programme. This focused largely on understanding how patient leaders can have the greatest impact on improving the experience of care. The identification and analysis of the key messages in this phase shaped the scope for phase 2.

- **In Phase 2 (December 2014 – March 2015)** we undertook more detailed analysis of NHS organisations that have been working with patient leaders. Following the results of Phase 1, the focus of this phase was specifically about patient leadership and feedback. The phase included 14 mini case studies and four more in-depth case study visits in exemplar areas that are successfully working with patient leaders and using feedback systems to improve experience of care.

- **In Phase 3 (March 2015)** we developed our main conclusions from the work, which are grouped under the key messages identified in Phases 1 and 2.

The learning from this work will inform how NHS organisations wanting to improve experience of care can build more robust, effective, systematic partnerships with patient and carer leaders.

3. Phase 1: Co-design of the scope of the programme

3.1 What we did

In Phase 1, we invited the active participation of people who are involved and interested in patient leadership and improving experience of NHS care. They included: NHS managers and system leaders from providers, clinical commissioning groups, commissioning support organisations; people and family carers who participate as patient leaders in NHS organisations; advocacy groups; the voluntary sector and NHS England itself. We worked with them to understand how patient leaders can best help to improve patients' experience of care.

During November 2014, we used social media in the form of a scheduled one hour Twitter discussion (Tweetchat). 350 people took part in the scheduled Tweetchat and a further 600 people posted comments on Twitter before and after.

We also held a workshop in Birmingham with 70 people. The programme team and NHS England Programme Board members invited participants from their networks. Most of the participants were active patient leaders, with the remainder being representatives from NHS organisations already working with patient leaders.

Our discussions focused on seven questions:

1. In what ways can patient leadership impact on experience of care?

2. Of those, which are the most important ways that patient leaders impact on care experience?

3. Describe your ambition for patient leaders' changing NHS care experience

4. Describe a positive possible future in 2017 where patient leaders have a positive impact on NHS care experience

5. Where are we now in relation to that vision for 2017?

6. What are the bold steps that will accelerate progress so that patient leaders have a greater impact on care experience by 2017?

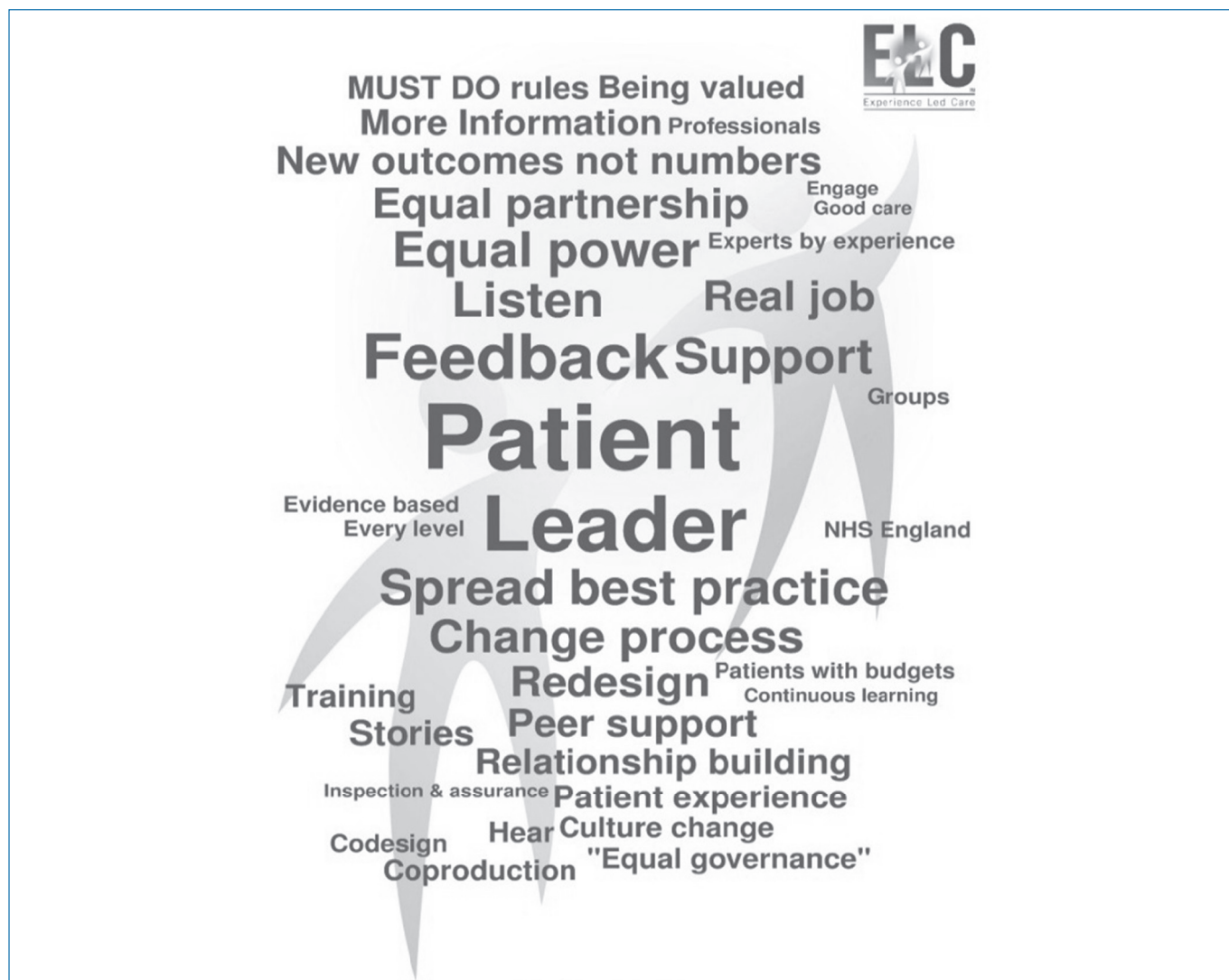7. What will you personally do next to take this work forward?

The participants in the sessions shared their views about what was helping and getting in the way of patient leaders making a positive difference. The participants also described how the future could look if effective patient leaders were in place.

We analysed people's feedback and responses to these questions. This informed the scoping of Phase 2.

3.2 What people said

We used the 4,000 Tweets and the table-top notes that people made in their groups at the workshop to produce the following 'word cloud'. The size of each word in the graphic represents how often that word was mentioned by people. The word cloud summarises the ideas that people said were important about how patient leadership impacts on the experience of care.

Figure 3: 'Word cloud' used to summarise main findings from Phase 1

In general, participants believed that patient leaders added value to the experience of care. The participants placed a priority on collecting and using meaningful feedback and the importance of listening and then acting to change processes. They said that organisations should support a culture of equal partnership and relationship building to develop patient leaders and to respond to patient feedback.

These findings set the direction for Phase 2 where more authoritative findings were developed through case study analysis.

Appendix B contains more detail on what the patient leaders said and wrote and on their proposals of what good feedback looks like.

Responding directly to the emphasis placed by participants on the importance of feedback, NHS England's Programme Board agreed that feedback would be the main focus for the remainder of the programme and the programme team would look at how NHS organisations, working with patient leaders, are using feedback systems to improve care experience.

4. Phase 2: Research and discovery

Feedback emerged as the most important issue in Phase 1, Phase 2 offered the opportunity to explore current practice in greater depth through a number of case study reviews.

4.1 What we did

In Phase 2 of this programme we considered examples of NHS organisations in England that are working with patient leaders and carrying out good practice to improve patient experience of NHS care. Participants in Phase 1 had 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.

On further investigation, we found that 27 of these organisations were using feedback and feedback systems to improve care experience in partnership with patient leaders. Seventeen of these 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. We have included summaries of the 14 examples that were not subsequently selected to become an in-depth case study site in Appendix C.

At the end of Phase 1, a Patient Leaders Expert Advisory Group (PLEAG) was set up to guide the rest of the programme. Members of the Patient Leaders Expert Advisory Group selected five of the 18 examples for further in-depth case study review, based on a number of shortlisting criteria about the project:

1. Demonstrates robust collection, interpretation and use of feedback

2. Demonstrates the involvement of patient leaders in one or more areas of the feedback cycle

3. Demonstrates change in response to feedback

4. Evidence of positive impact on the experience of care

5. Evidence of partnership working with other organisations

6. Evidence that this work is relevant to the rest of the NHS and could be readily shared

Of those selected by the Patient Leaders Expert Advisory Group, four were happy for the team to visit to carry out a more in-depth case study review. These were:

- Shropshire Clinical Commissioning Group
- Midlands and Lancashire Commissioning Support Unit
- Birmingham Clinical Commissioning Groups
- Ipswich Hospital NHS Trust

In each site, we conducted one to one semi-structured interviews with both patient and system leaders and supported a group reflection and review session with patient and system leaders together.

Interviewers applied a standardised interview framework across all four sites and asked the leaders about:

- Their involvement in the work
- What had helped them to make progress
- The lessons they had learnt
- Their recommendations to others within the NHS regarding the best way to support patient leaders to have impact with a particular focus on using feedback to achieve impact

Appendix D sets out further detail on how the four case study review sites were selected from those 17 organisations. Appendix D also contains full details of the four case study review sites.

4.2 What they said

We analysed the experiences of the four organisations that participated in the case study reviews, together with the information provided by the other 14 organisations. The findings are presented below.

These findings help us to explore the role of both patient leaders and feedback systems in improving care experience and how having feedback to hand helps patient leaders to influence and achieve impact.

4.2.1 Invest in patient leaders

The organisations confirmed that patient leaders are a valuable asset and make a demonstrable impact on services and on the care experience. The organisations said:

- **Patient leaders bring a credible voice, and can work with system leaders to create a compelling case for change.** This gives the system 'permission to act.'

  '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.'

- **Patient leaders change health services' priorities, placing a greater emphasis** on the experience of care.

  '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 the 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 leaders can help to design services on the ground.** By proposing small, practical changes, patient leaders impact positively on the experience of care.

  'I could see results happening/changes being made, small changes like more highchairs in reception, using low check in desk so people in wheelchairs can see the receptionists, general things, and over a period of time it helped a lot.'

  'One of the big things that has come from the diabetes user group was to campaign to get the diabetes foot clinic physically moved; another thing was to get electronic doors when you go into the diabetes centre.'

  'In a hospital trust, a teenage diabetic patient designed a 'teenage' room. 'Now there are settees – long ones; bean bags, walls with pictures. I had some ideas for the pictures – everything falling into place.'

- **Patient leaders can help in service design,** focusing services more closely on what patients and carers want.

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

- **Patient leaders reduce the risk of future legal challenge,** when commissioners involve them and have access to robust feedback in commissioning.

'The fact we have managed risks fully and have good support from the experts means that the chances of legal challenge are much smaller. … We need to recognise it can reduce cost in the long run to involve experts by experience.'

- **Patient leaders can have a role as 'champions' in their communities** and lead a broader social movement towards health and wellbeing.

'We've also got something else in this particular process, which is about building almost a social movement in Birmingham about emotional wellbeing for children and young people.'

'We helped create an alternative Race for Life for families and kids. The young health champions organised it. We agreed what we wanted to do and raised £2,500 on the day.'

4.2.2 Put the feedback mechanisms in place so that organisations listen:

A consistent theme was the need for organisations to have effective feedback mechanisms in place. The organisations said:

- **Improve NHS organisations' and patient leaders' ability to make sense of and apply qualitative feedback.** Many NHS organisations told us that they struggle to analyse qualitative feedback and are more comfortable with quantitative analysis and data such as survey results. Some organisations said that they do not use free text feedback and other qualitative data because they cannot analyse it. This limits the impact that feedback has on care experience. It is one thing to listen to patient stories: it is another to work out what actions need to be taken in response.

'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?'

- **Place equal value on qualitative feedback and quantitative evidence such as surveys.** This is a significant shift in thinking the system is starting to make. Patient feedback is currently decoupled from more mainstream business intelligence – which is often predominantly focused on 'number crunching'. As one of the staff interviewed said 'Redefining Business Intelligence is central to this'

'It is business intelligence, but people don't see it as that. It's 'pink and fluffy' in their eyes …. This work needs to be reframed as business intelligence; patient voice driving transformation.'

- **Bring together different sources of information.** Participants told us that the best feedback systems use a range of ways to gather feedback, e.g., through patient surveys; volunteers speaking to service users; online feedback platforms; analysing complaints and compliments, etc. In the organisations we visited, gathering feedback directly from patients was one of the ways in which they mobilise patient leaders. Participants felt that patients would be more likely to share the truth with other patients and that gathering feedback was an important role that patient leaders could play. Specific feedback methods should be used to reach the harder to reach groups.

'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.'

- **Shift the mind-set away from engagement compliance**, to focus on the quality not the quantity of feedback. People told us that the NHS tends to be impressed by and to reward NHS organisations that talk to large numbers of people – even though they said that talking in depth to a small group of people provided better quality feedback, which is more useful in supporting local improvement.

'There are legal requirements, but sometimes we engage for the sake of engaging – not truly hearing what people have said. … I have learnt a lot. It used to be all about large events – what did we get out of it? Not a lot. It's about quality, not quantity.'

- **Shift the investment of resources**, with a re-balancing and shift away from 'one-way' broadcast communication and more towards 'two-way' involvement of people and communities as equal partners in change and improvement.

  'We spend a lot on communications and engagement – posters and things. They have a very limited impact. This is not an effective way of doing things.'

  'You need less reputation management. I believe if you do meaningful involvement and involve the right people, your reputation starts to look after itself, and you don't need some of those things.'

- **Be proactive in reaching out to patients.** The best feedback systems make a conscious effort to engage proactively and routinely with harder to hear communities. NHS organisations may work closely with patient leaders from particular groups or through voluntary sector organisations that have existing relationships. One very powerful example was at Blackpool Teaching Hospitals when young people were invited to share their views on what it feels like to be a child or young person living with health issues. The young people developed a pocket card of top tips for doctors so doctors could reflect on their own clinical practice.

- **Use different means of communication for different groups.** Patient leaders can be effective in reaching out to vulnerable groups.

  '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.'

  Young people are likely to be reached through use of social and digital media, with one patient leader commenting

  **'To get young people involved and engaged, I think the best way is through social media, Facebook, Twitter; TV adverts, radio adverts.'*

- **Ask staff for feedback.** Organisations told us that gathering and responding to feedback from NHS staff (both clinical and managerial) is very important. Some of those who manage feedback systems make a big effort to give feedback themselves. This provides the opportunity to do informal quality assurance and reassures them about how well the system is working.

  'When we involve people in improvement, it happens faster and is more likely to sustain. It often enables staff to make changes they have wanted to make for years.'

- **Learn from positive as well as negative feedback.** People told us that staff respond best to appreciative feedback and that how patient leaders share feedback is really important. They said that feedback systems need to be equally good at collecting compliments and information about good and improving quality as they are at collecting complaints and evidence of poor quality. People said that sometimes feedback systems make it harder to record positive stories. They also said that staff find quantitative feedback from national surveys like the Friends and Family Test can be demotivating, especially when the feedback provides no suggestions about how to improve things.

  'And we need to flip that as well – and get those who have had a good experience. Then we can start to make real changes having both sides.'

- **Develop the processes to log and then act on feedback**. Having a robust system in place to log feedback reassures patient leaders that peoples' voices are being heard, listened and responded to. This in turn builds trust and confidence in services. It also enables the patient voice to contribute to making difficult decisions.

  'I see people and data gathering as both part of the work. 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.'

- **NHS organisations should always 'close the loop',** reporting what they did with the feedback. Most NHS organisations agreed that this is important, but many recognise that they do not do it consistently well. Closing the feedback loop is critical to maintaining trust and building a positive relationship with patient leaders. It must be an 'Always Event'. A positive example of this is at King's College Hospital, where the Trust shares feedback with the 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 NHS assurance processes could prompt organisations to close the loop, e.g., by asking them to maintain a '*You said. We did'* log in the same way they are mandated to maintain risk logs within programme management paperwork. This would nudge organisations to use feedback and involve front line staff, people and families.

4.2.3 Develop the culture and systems to act on feedback

Organisations which invest in feedback possess an 'improvement mind-set' and are committed to getting better. They support the development of patient leaders and invest significantly in feedback mechanisms. The organisations said:

- **Have system leaders that provide strong support to patient leaders.** In many of the organisations we worked with, the clear commitment of the organisation's leaders was identified as a critical factor.

  '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.'

- **Have staff whose role is to support the development of patient leaders.**

  '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.'

  'The programme's coordinating function is key. It is better for young health champions to have a separate person supporting them; building trust and confidence. They make sure I have the right group of people.'

- **Be aware that the process of developing and involving patient leaders** requires a sustained commitment over time. It is important to build momentum and generate goodwill through celebrating success.

'I think the penny dropped (with 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.'

5. Phase 3: Next steps

5.1 What we did

We held a meeting of the Patient Leaders Expert Advisory Group in March 2015. It reviewed the research findings and discussed ideas which could give further impetus to helping patients and carers become leaders. The specific suggestions made at this meeting are included in Appendix E.

Leading from the discussion, and having analysed the evidence further, we have been able to develop some building blocks for organisations to consider when developing their patient leadership capability.

5.2 Building blocks for developing patient leadership

There is no single model for developing patient leadership. However, the key findings from the organisations studied suggest that putting the following 10 building blocks in place will increase the chances of patient leaders improving the experience of care.

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

    The organisations in this study chose different ways through which patient leaders exercised authority to make decisions.

    For example, in a CCG procurement programme, patient leaders were given a 20% stake in the decision-making process.

    'This all centres around the commissioning bit of being the stakeholder, saying that patient representation will have a formal percentage of the decision making stake. It won't work any other way really.'

    In one hospital trust, patient leaders were given a £10,000 budget to support their work through training and for boards to publicise their work, etc.

    Equally however, the most effective patient leaders were able to develop strong, direct relationships with system leaders whom they needed to influence and work with to change the care experience.

    'We are the go to place if the Trust Board wants the patient view on things or to run things past us … Me and vice chairs have informal meetings, there aren't any minutes, just informal meetings with CEO as and when we want.'

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

    The organisations in this study recognised the importance of involving patient leaders in designing services. They acknowledged that the patient's perspective on their own care experience is invaluable and contains unique insights.

    '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. …. 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.'

    Some participants expressed regret that they had not involved patients from the outset.

'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.'

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

    The organisations in this study recognised that patient leaders needed to be supported through training and development in order for them to make the best possible contribution.

    '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.'

    The training provided had two main benefits. Firstly, it equipped patient leaders for the specific activity they were expected to perform, e.g., in procurement. This was not generic 'leadership' training. The second benefit was that it enabled patient leaders to build relationships with system leaders and with each other.

    In some organisations, patient leaders had designed training for other patient leaders.

    'We 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. We reduced it from two days to one day.'

4. **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.'

5. **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**

    The organisations in this study found that patient leaders were listened to and gained influence when they brought good quality, evidence-based feedback into their conversations about improving care experience. Many patient leaders were proactive in generating feedback about health services.

    'We are stronger (with the data). If an issue is raised I can say, 'tell me the issue and I can log it onto the system and it goes straight to the CCG'. If there are a lot of issues they will be listed and the CCG will see them. I feel it's made us more 'meaningful' as an organisation – feel we are very well respected.'

6. **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**

    The organisations in this study supported the development of patient leaders from all sections of the community.

    '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. So we allied ourselves with the Youth Authority Forum – a partnership with voluntary services, looking at working dynamically in that way.'

    The organisations recognised that their patient leaders come from a relatively narrow group within the community rather than from diverse groups.

    'What can happen with formal structures, especially the patient users, (is) they become institutionalised – go native or they have their particular hobby horse 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.'

    Moving forward, patient leaders and NHS organisations will need to work together to develop more diverse patient leadership.

The study also found that there are very few 'lone hero' patient leaders. In these case studies, patient leaders who were part of a team achieved more.

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

The organisations in this study recognised that qualitative feedback is a really powerful tool for improving services, but frequently struggled with how to analyse it.

'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.'

'It is one of our ambitions over the coming year to try and find a very systematic approach to pulling everything together.'

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

By logging qualitative feedback, organisations in this study were able to make the connections with similar feedback that had previously been made.

'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.'

It is essential for organisations to record what they have done or plan to do as a result of the feedback received and to communicate it.

''Three different ways: formal reports (updates) that go through to IHUG (Ipswich Hospital Users Group) 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.'

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

The organisations in this study were driven to improve the services they provide and patients' experience of them. Organisational leaders supported this culture of listening and acting on what is heard. These leaders were usually comfortable working outside formal, hierarchical boundaries.

'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. … She wanted experts by experience to be actively involved.'

The unique insights of the patients are used to drive improvements to services, often on a relatively small scale but which meant a great deal to the people affected.

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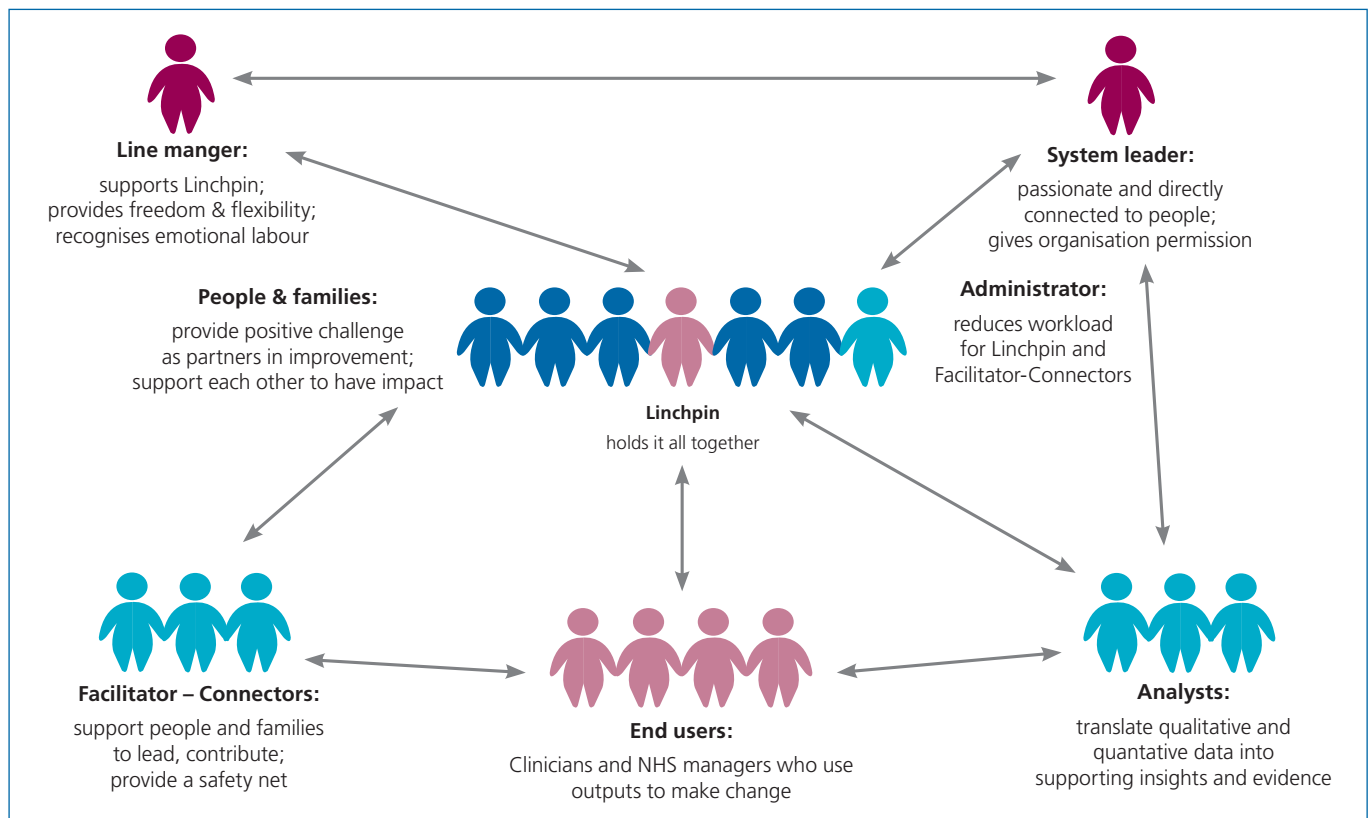
10. **Put in place the supporting roles for transforming care outlined in the '8 Role Model'**

Data analysis from the 18 case studies, validated further through the visits to the case study sites, suggests that there eight critical support roles that need to be filled within NHS organisations so that patient leaders can realise their full contribution to improving care experience using feedback. Most of these roles interact with patient leaders, some more than others.

These eight support roles are described in the infographic below. It should be noted that individuals may carry out more than one role.

We have called it the 'The 8 Role Model'.

Figure 4: The 8 Role Model

- **People and Families:** Patient leaders emerge from this group. They are people who draw on their own life, health and care experiences, resources and ideas to make an active contribution to improving the experience of care and the health and well-being of others.

- **System leader champion:** This is a senior clinician or NHS manager who is passionate about listening to and responding to patients. The system leader champion works with the organisation's senior management team to set a vision that includes working with patients as leaders. They stay connected to patient leaders, meeting and listening to them so they feel involved, important and recognised.

- **The Linchpin:** The Linchpin welcomes patient leaders into the organisation and supports them to have an impact. The Linchpin is usually a middle grade NHS manager. Linchpins are highly skilled communicators, well-connected within their organisation and wider community and are able to connect patient leaders, managers and networks.

- **The Linchpin's line manager:** The line manager supports the Linchpin, and gives the Linchpin permission and freedom to do what needs to be done so that patient leaders can contribute.

- **Administrator:** The administrator provides administrative support to the Linchpin. The administrator arranges events, maintains stakeholder leaders, chases tasks and acts as a contact point for patient leaders. When this support is not place, the Linchpin will often take on the administrative tasks and this significantly reduces his/her broader effectiveness.

- **Facilitator-connectors:** The Facilitator-Connector helps patient leaders to access patient groups through their links to the community. Facilitator-Connectors may come from a community development background and be external to the organisation.
- **End Users:** The end users are clinicians and NHS Managers. Patient leaders need the end users' support because it is this group that will enact the changes identified by the patient leaders as necessary to improving patient care. Linchpins are the vital link between patient leaders and NHS managers.
- **Analysts:** Analysts turn complex feedback data into evidence-based, actionable insights that system leaders, Linchpins, NHS managers and patient leaders can all use to improve care experience.

Organisations in this study found that the Linchpin and Facilitator-Connectors reaped huge benefit when strong administrative support was in place. They also found that most end user clinicians and managers were broadly supportive of the patient leaders' involvement. The end user clinicians and managers preferred a more collaborative approach that involved a wide range of patient leaders with relevant experience rather than a small number who were involved in a more formal capacity. In one of the case-study sites, a dedicated analyst team was in place. Patient leaders at this site told us that having access to feedback had made them more influential and able to achieve change.

Where organisations in this study described barriers to progress, they usually described an absence of one of those roles. Few of these organisations had recognised or resourced all these roles fully. One of the case study sites visited had most of the roles in place, with some roles funded by a Big Lottery grant. Most of these roles were done as part of a wider job remit. In some cases, the roles were undertaken by external partners, including commissioning support organisations, the voluntary sector or other third parties. For some organisations, there was a 'make or buy?' decision about how to fill the role.

This model can be used as a diagnostic tool by organisations that want to work closely with patient leaders and use feedback to improve care experience. This work suggests that these eight roles are needed whatever the scale of the context. If any of these roles are missing, patient leaders will have less impact.

Scaling the model up to a local health and care economy could prove more effective than individual organisations supporting systems in a fragmented way. This approach would potentially work well and could be piloted in some of the Vanguard sites prototyping the new integrated care models outlined in the NHS Five Year Forward View.[19]

---

[19] http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf.

6. Conclusion

Patient leadership is an emerging concept and has no single definition.

This work recognises patient leadership as a core and essential component of a 21st century health and care system which is co-creating the best services it can within resource constraints and a complex, dynamic social and political world.

Our work was intended to add value to the existing debate and to present some practical advice to local and national leaders (system and patients) about how patient leaders, armed with robust comprehensive feedback, can improve care experience. The research was designed to be co-produced with patient leaders. As a result, the scope was refined and developed through the research process in response to what participants said was most important to them.

We learnt that patient leaders are a valuable asset and make a demonstrable impact on services and on the care experience. They create a new partnership dynamic with system leaders and help improve relationships with local communities and promote health as a social movement.

Patient leaders have greatest impact and add most value when they have strong relationships with clinicians and managers. They also make more of a difference when they are part of strong teams with other patients and when they can make the case for change, using robust feedback from people and families to inform their conversations.

Our analysis has identified a number of health organisations which have invested in feedback and are working with patient leaders to improve services. These organisations possess an 'improvement mind-set.' They understand that change is possible, and that things can be done differently. They are passionate about working with patients and their families and share an ambition to involve them as partners.

These organisations support the development of patient leaders through investing in their training. They also invest time and management resource to help the organisation connect and build relationships with patient leaders, thus creating the right conditions for patient leaders to get involved. They ensure that staff are in place to provide the organisational context to support patient leaders to realise their full contribution.

Although there are many similarities in the way successful organisations have fostered patient leadership, there is no 'one size fits all' approach. Each organisation must develop patient leadership in a way that reflects its circumstances. Nevertheless, to support NHS organisations, patient leaders and their partners, we have developed 10 building blocks for organisations to consider as they invest in patient leadership.

These building blocks are articulated as conditions which can unleash the full potential of patient leaders to work in partnership with system leaders to improve the experience of care and therefore transform lives.

There is no doubt that investment in patient leadership requires a sustained commitment over time. As they gain experience, organisations may seek to develop patient leadership across the whole health economy, working closely with partner organisations and sharing infrastructure costs.

Please note:
Appendices can be found in a separate document.