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# Patient leadership: Taking patient experience to the next level?

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## Abstract

NHS England commissioned the project described in this article to explore how patients and carers can, acting as leaders, make a real difference in improving experience of care. The work was carried out on a collaborative basis, co-designing the scope of the research with patient leaders and commissioners. We gathered case examples across England that had involved patient leaders in using patient and carer feedback to improve experience of care. A Patient Leaders Expert Advisory Group selected four case examples that were visited to undertake a more detailed study and subsequently discussed and agreed the key learning points and conclusions. The Advisory Group chair provided a patient leader view on the project. The main learning points were that in order for patient leadership to have a significant impact on improving experience of care, health organisations should invest in patient leaders, put robust feedback mechanisms in place and develop the culture and systems to act on feedback. Our findings identified ten building blocks that provide a basis for success, including a set of key roles across systems. Our conclusion is that patient and carer leaders can raise the profile of improving experience of care and have a real impact on action being taken in response to patient and carer feedback.

## Keywords

Patient leaders, patient experience, patient and carer feedback, quality

## Note

## Introduction

The National Health Service (NHS) in England 'Five Year Forward View', published in October 2014, 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]. The concept of patient leadership is emerging as one important new way of working collaboratively with patients and carers (family or friends providing regular unpaid support). A recent report from The King's Fund identifies that: 'One new concept – patients as leaders – is beginning to gain popularity"[2].

While others have explored patient participation in quality improvement in general[3], the project described here set out to understand how patients and carers, acting in leadership roles alongside clinical and managerial leaders, can make a real difference specifically in improving experience of care[4].

NHS England commissioned this work to find out if patients and carers as leaders can 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 influence NHS organisations to act on patient and carer feedback to improve experience of care. We also set out to understand what NHS organisations need to do to make this approach work.

We intentionally carried out this work on a collaborative basis. This meant that patient and carer leaders co-designed the project, starting from the concept and specification and then shaping the phases of the project itself. They also co-produced the learning. This was done through meetings and workshops, use of Twitter and establishing a Patient Leaders Expert Advisory Group for the life of the project. We believe that the findings have much greater value and validity as a consequence of this collaborative approach.

## The English policy context

Since 2008 the NHS has had a view that quality in health services should be made up of three components – clinical effectiveness, safety and experience[5]. Although the National Institute for Health and Care Excellence (NICE) has published two patient experience Quality Standards[6], experience of care has arguably not been widely regarded in practice as being equal to clinical effectiveness and safety for health professionals, managers or commissioners. Jocelyn Cornwell recently explored in this journal why this is the case for health professionals[8].

An increased priority has been placed on experience of care in the NHS following the highlighting of unacceptable experiences in the Francis report into Mid Staffordshire NHS Foundation Trust[10] and the uncovering of abuse at Winterbourne View[11]. One reflection of this was that NHS England, at its inception in 2013, established a national Patient Experience team[9] as one of five NHS Outcomes Framework quality domain teams, together with patient experience staff in regional teams.

In a recent publication, the National Quality Board has updated the NHS Patient Experience Framework, seeking to develop a shared understanding among national NHS bodies of what is meant by the experience of care, why it is important and what good experience looks like[12]. A previous article in this journal describes the process utilised to develop a consensus and the key elements of a shared 'narrative' on experiences of care for that publication[13].

Central to NHS England's ambition is to place the patients and the public at the heart of all its work, including the development of national policy, new programmes of work and direct commissioning[14]. This is supported by a statutory duty to make arrangements to involve the public in the commissioning of NHS services and is strongly reinforced in the NHS Five Year Forward View[1].

Guidance on Transforming Participation in Health and Care has been published[15] and an NHS Citizen programme[16] commissioned to address how the board of NHS England can be held to account and can better take into account the views of patients, service users and the general public when making decisions about the NHS. 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. It is also working with partners to build up youth voice and leadership input through the NHS Youth Forum, regional youth voices programmes and an annual 'Takeover Day' programme.

We would observe that many people working in the English health system, in particular commissioners, conflate engagement and participation with improving experience of care. The former is often assumed to be a proxy for patient experience, irrespective of whether the particular engagement activities have a specific focus on improving experience or the participants' contribution has a basis in lived experience. Whether described as collaboration, partnership or co-production (all contested terms), a principled approach to improving experience of care with, and not on behalf of, patients and carers underpins NHS England's patient experience work and the project described in this article.

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. 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[17].

### Patient and carer leadership

The concept of patient leadership implies a different, collaborative rather than professionals 'know best', relationship between individuals, communities and the NHS. It means moving towards what is frequently called 'coproduction' as a more reciprocal relationship between the individual and health professional (clinical and managerial) where there is equal power and respect and values, purpose and responsibility for outcome is shared. Alison Cameron, herself an acclaimed 'patient leader', has articulated how co-production goes beyond a simple rebadging of 'patient/service user involvement'. She concludes by saying that:

> "If we can take the risk of emerging from our boxes of "patient" or "professional" and venture into the territory where boundaries are blurred, and both "sides" are prepared to walk in the shoes of the other, then we have the potential to create something of radically new. This is not about professionals having to relinquish power in an already chaotic and uncertain climate, but about strengthening the power base so there is more of it to go around"[18].

Through this work we learnt that while some people are very comfortable using the term 'patient leadership', others feel that the term is language used by clinical and managerial system leaders and can represent an approach, which in itself creates barriers. Not surprisingly, in different places, people had adopted different titles e.g. champions, members or experts by experience.

The Centre for Patient Leadership has said that patient leaders are 'patients, service users and carers who work with, and for others to influence decision-making at a strategic level'[19]. National Voices in a paper called 'Patient

Leadership: The Start of A New Conversation' 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'*[20].

We did 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 to develop an understanding of the characteristics that make '*patient leadership*' effective in influencing decision-making at a strategic level to improve care experience. Figure 1 provides an overview of the breadth of settings and ways that patient leaders currently get involved in improving the experience of care across the health and care system.

NHS England commissioned this project to produce learning for NHS commissioners and providers from what already works in terms of patient leaders' impact on care experience. Previously the focus of NHS work with patient leaders has primarily been on advocating the concept of patient leadership and capacity building through training programmes. The learning from this work is intended to help NHS organisations that want to improve experience of care understand how they can go about that by building robust, effective, systematic partnerships with patient and carer leaders.

**The approach used for the project**
The project was delivered in three interlinked phases, each building on the preceding phase, and was developed and delivered using a collaborative and iterative approach.

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.

*Phase 1 – what we did*
We invited the active participation of people who are involved in patient leadership and improving experience of NHS care to shape the programme. They included managers and system leaders from NHS providers, clinical commissioning groups and commissioning support organisations, people and family carers who participate as patient leaders in NHS organisations, advocacy groups, the voluntary sector and NHS England.

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 face-to-face workshop with 70 people. The *Tweetchat* and workshop explored the ways in which patient leaders can impact on experience of care and what could enable greater impact in future.

Themes were identified from the *Tweetchat*, tweets and workshop to shape areas for subsequent phases of the project. Obtaining, understanding and acting on patient and carer feedback to improve the experience of care emerged as the area where participants felt patient leaders could make the biggest difference.

*Phase 2 – what we did*
Participants in Phase 1 had highlighted over 50 NHS

**Figure 1. Ways that patient leaders can influence patient experience**
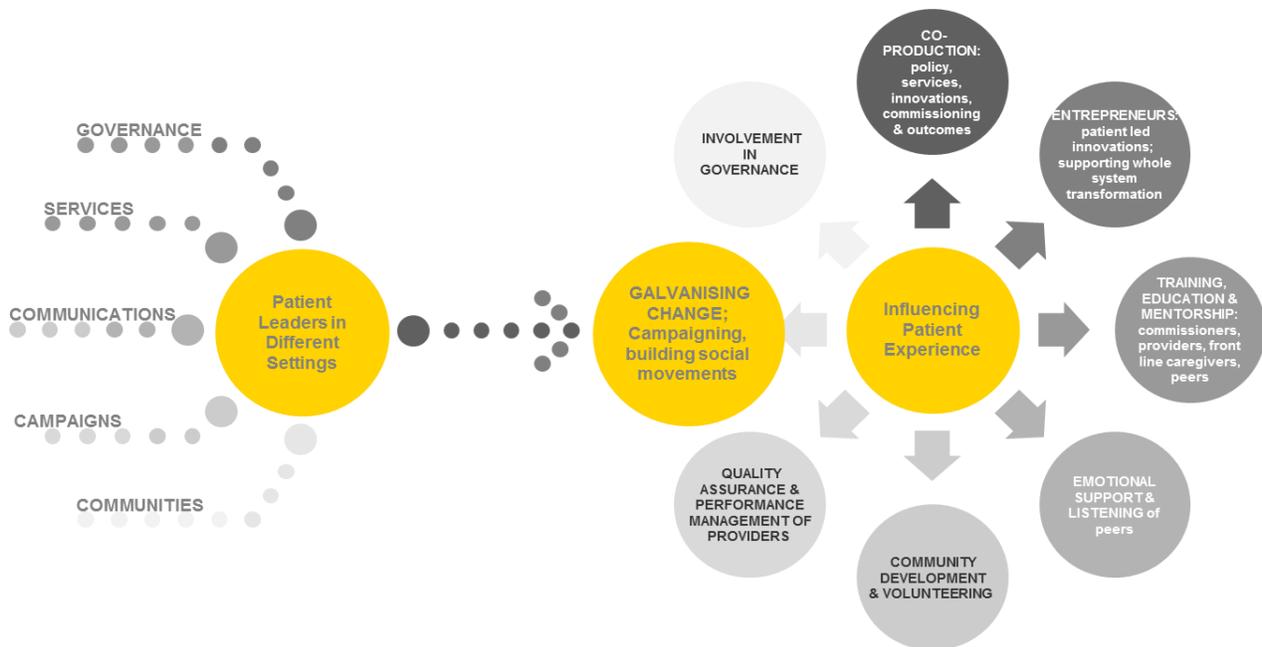
organisations that were involving patient leaders or working to improve care experience with people and families. Seventeen organisations could demonstrate that they had made progress on using feedback and patient leaders to improve care experience and were willing to participate in this research.

We carried out a semi-structured telephone interview with the key system or patient leader/s within these 17 organisations clarifying the details of their project, the impact and changes it had created, their key learnings and their insights about the replicability of their work elsewhere. This resulted in 18 mini case study reports (as one organisation submitted two examples).

In the next step, members of the Patient Leaders Expert Advisory Group selected five organisations for detailed, site-based case study, applying a set of criteria relating to impact, wider relevance and the principles in listed in Figure 2.

Four of the selected organisations agreed to participate in a site-based, detailed case study visit that had two elements:

- Semi structured interviews with patient leaders (n=10) and system leaders (n=12). In one site, instead of interviews, nine young health champions (young people working with commissioners to design services and coproduce healthy lifestyle initiatives within their communities) participated in group discussions. Patient leaders were asked about what had helped them, the lessons they had learned, and the recommendations they would make to others aiming to work in this way. Interview transcriptions and group discussion notes were reviewed and approved by the interviewees/participants.

- A workshop that applied the principles of appreciative inquiry and created the space for local patient and system leaders to reflect on their learning, and what had helped them to succeed and overcome the challenges they had faced together. The notes from the workshops were transcribed and approved by the local site visit key contact.

*Phase 3 –what we did*
A thematic analysis of the 18 mini case studies and the 22 semi-structured interviews from the four detailed case studies was undertaken and any additional themes from the workshop transcripts were added. This produced a set of overarching key messages and building blocks for developing patient leadership for impact on experience of care.

A summary of the findings was shared with an advisory group of patient and system leader policy experts from The King's Fund, Point of Care Foundation and NHS England's Patient Experience, and Patient and Public Voice teams. Their judgment, experience, and challenging exploration of the emerging themes both shaped and helped to confirm findings.

The findings were then shared with the Patient Leaders Expert Advisory Group members who discussed them and reflected on how the NHS might respond to and use these insights.

## Results

We found that there is no single approach to building impactful patient leadership, with NHS organisations adopting a range of approaches. However, our learning from NHS organisations able to demonstrate that collaboration with patient leaders had made a significant difference to experience of care, led us to identify ten building blocks, under the three overarching key messages, that can create the conditions for success. They are:

**First key message: Invest in patient leaders**
1. *Make patient leaders an integral part of formal and informal decision-making*

**Figure 2: The principles used to select the organisations for further detailed study**

Principles:

1. A spread of good practice - examples across different types of NHS organisations

2. A spread of geography - examples of good work happening across the country and across different population demographics

3. A range of different approaches to involving patients leaders in feedback work

4. A spread of patient leaders - to include young leaders, older people, the public and Patient Participation Groups for example

Organisations chose different ways through which patient leaders exercised authority to make decisions. For example, patient leaders involved with a Clinical Commissioning Group procurement of children's and adolescent mental health service awarded 20% of the marks within the quality domain of the assessment of bids.

*'This all centres around the commissioning bit of being the stakeholder, saying that patient representation will have a formal amount 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. The most effective patient leaders were able to develop strong, direct relationships with the system leaders 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… with [the] 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 importance of involving patient leaders in designing services was recognised by organisations. 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 …- everything falling into place.'*

Some participants expressed regret that they had not involved patients earlier.

*'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 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*
Organisations 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 had two main benefits. Firstly, it equipped patient leaders for specific activities they were engaged in e.g. in procurement. 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 patient feedback data, that is robust, evidence-based and easy to understand and use*
Patient leaders were listened to and gained influence when they were able to bring quantitative and qualitative patient and carer feedback data and analysis into their conversations about improving care experience. When this happened, patient leaders found they were taken seriously and had more evidence to support the case for change.

*'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*
Organisations 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.'*

It was recognised that patient leaders mostly came from a relatively narrow social 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, particularly with black and ethnic minority communities.

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.

### Second key message: 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*

The power of qualitative feedback as a tool for improving services was recognised, but many 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 were able to make the connections with similar feedback that had previously been made and to identify areas for improvement.
*'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.'*
Patient leaders shared that getting feedback made them feel valued and engendered trust. When this did not happen, they felt ignored.

### Third key message: 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*

Organisations were predominantly driven by doing the right thing rather than by policy. They demonstrated system wide commitment to learning and improvement. Organisational leaders led by example and fostered a culture of connecting with patients as well as listening and responding. 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 patients and families drove service improvement. The stories of patient leaders were shared and helped win the hearts as well as the minds of clinicians and managers.
Successful NHS organisations especially valued the fresh perspective patient leaders offered and small changes often had a big impact on 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'*
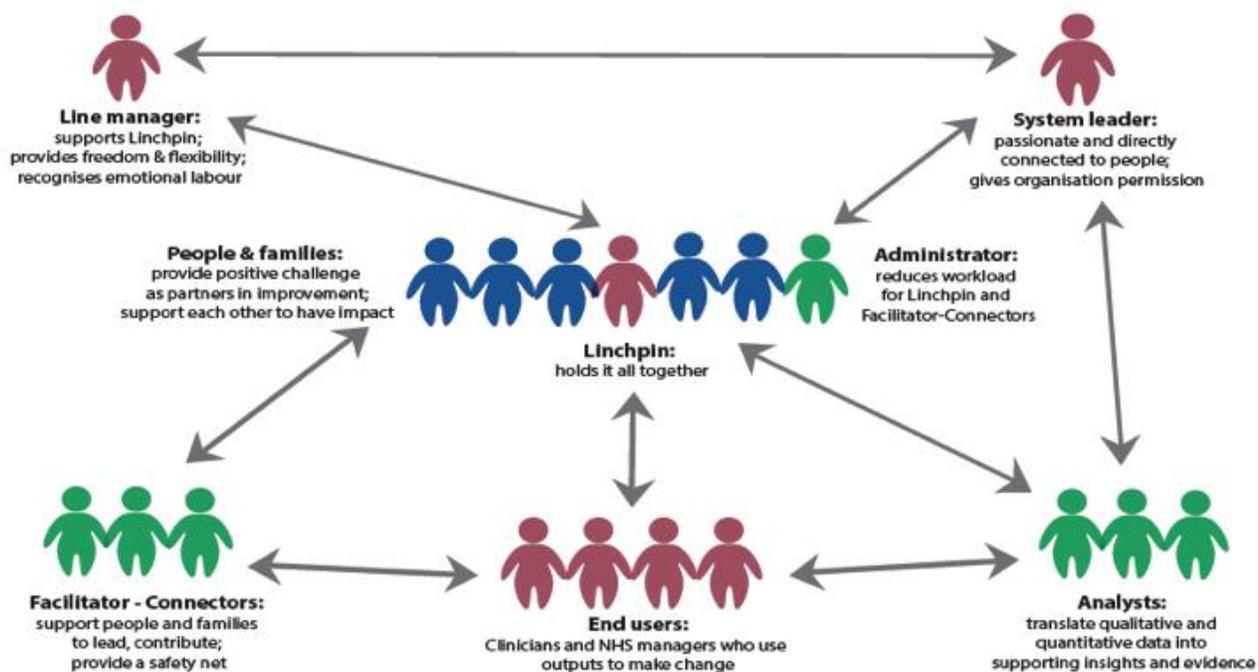
10. *Put in place the supporting roles for transforming care outlined in the '8 Role Model'*

Data analysis from the 18 mini case studies, validated further through the visits to the case study sites, suggests that there are 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 (Figure 3). It should be noted that individuals might carry out more than one role. We have called it the 'The 8 Role Model'.

Where organisations in this study described barriers to progress, they usually described an absence of one of these roles and few organisations had recognised or resourced all of 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, external partners, including commissioning support organisations, the voluntary sector or other third parties, undertook the roles. This work suggests that these eight roles are needed whatever the scale of the context, though individuals can fill more than one role. 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.

**Figure 3: The 8 Role Model for improving care experience**



| Role | Description |
|---|---|
| **People and Families** | Patient leaders emerge from this group. They draw on their own experiences, resources and ideas to make an active contribution to the care experience and the health and well-being of others |
| **System leader champion** | Senior clinician or NHS manager. The system leader champion works with the organisation's senior management team to set a vision that includes working with patients as leaders. The system leader stays connected to patient leaders, championing their involvement and recognising their contributions |
| **The Linchpin** | Welcomes patient leaders into the organisation and supports them to have an impact. The Linchpin is well connected within their organisation and the wider community and is able to connect patient leaders, managers and networks. The Linchpin usually a middle grade NHS manager |
| **Linchpin's 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** | Provides administrative support to the Linchpin. The administrator arranges events, maintains stakeholder leaders, chases tasks and acts as a contact point for patient leaders |
| **Facilitator-connectors** | Helps patient leaders to access patient groups through their links to the community. Facilitator-Connectors may be external to the organisation |
| **End Users** | Clinicians and NHS Managers. End users are the group that will enact the changes identified by patient leaders, with the Linchpin playing a vital link role between these two groups |
| **Analysts** | Turn complex feedback data into evidence-based, actionable insights that can be used to improve care experience |

### A patient leader perspective on the project and findings (Steve Sharples, Chair, Patient Leaders Expert Advisory Group)

For years in the NHS there was a culture of patients not being heard and the clinician being all-powerful. This project was another nail in the coffin of this past culture. For me it was total involvement with NHS England staff and the project team on an equal footing.

From the beginning with the review of the tenders, I felt that I was treated as an equal and not as a token patient. Later when the workshop was discussed, I suggested that patient leaders should be included. This was agreed and some forty plus patient leaders like me were welcomed with open arms. All of us, not only made a huge contribution to the day, but also, pointed the way forward for the next phase of the project. We took part in selecting and examining the 18 projects that were put forward.

The project team went their merry way and talked to all of the projects. The patient leaders, including myself, received the reports of the work undertaken with the projects and were asked to select five for further examination by a voting process. To me this was patient involvement as it should be.

At the first Patient Leaders Advisory Group meeting the results were very close which led to some lively discussion among the patient leaders, all without intervention by the project team or NHS England. The result was five projects chosen by the Patient Leaders, which, in many ways, reflected our various perspectives.

At a final Advisory Group meeting the project team presented us with their findings, asking us to consider them and give our thoughts and impressions. One or two Advisory Group members did this robustly and their views were heard and responded to.

My thoughts overall are that patients at last had been give the opportunity to take part in a high level project with equal voice and we were not only listened to, our comments were also acted upon too.

The big point is that all the case examples of patient leadership demonstrate that patients/carers are being listened to and worked with. This also shows that a great deal of effort is being undertaken to provide better pathways for patients, addressing issues such as those relating to young people or ways of collecting information from many sources which in turn is used to make informed decisions.

Patient and carer leadership is becoming increasingly recognised by august bodies such as National Voices, The King's Fund and NHS England as key to making patient voices heard and this is a major step forward.

The 18 case examples show a wide range of approaches in the way administrators, clinicians, patients and their carers are working collaboratively to build patient leader projects. Outcomes will benefit not only current patients but will also improve services for those waiting for treatment. Patient leaders and NHS organisations can learn a lot from these examples for their own use.

I think that in future, if possible, developing a consensus on the definition of a patient leader would be useful and I would like to see some future research into the sustainability of this way of working.

The findings show that when patients and carers as leaders and paid NHS staff collaborate, a lot of good can be achieved with commitment on all sides.

### Conclusion

We started this work with a hypothesis: that enabling patient and carers to act in leadership roles in partnership with clinical and managerial leaders, would make a difference both in the attention that experience of care gets (alongside clinical effectiveness and safety) and in influencing NHS organisations to act on patient and carer feedback to improve experience of care.

The examples that were submitted from NHS providers (across different service settings) and commissioners were greater in both number and range than we had anticipated. Examples encouragingly included 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 needs to be a priority in future). The number and range of examples enabled us to identify the building blocks that organisations need to have in place, which included a set of key roles across systems, and also suggests that working in this way is becoming increasingly common in the NHS in England.

We have learned from patient, carer, and local system leaders that patients and carers acting as leaders can raise the profile of improving experience of care within and across NHS organisations. They can also have a real impact on action being taken in response to patient and carer feedback. Our hypothesis seems then to have been borne out by what we discovered in this work.

We are committed to continuing to work together to promote this way of working, to sharing the learning from this work and to support organisations across the NHS to embed the conditions for success. As a next step NHS England has sponsored a 'Leading collaboratively with

patients and communities' programme being run by The King's Fund[21] to support continued learning about the impact that patient and carers can have as leaders. Health systems have learned a great deal about what it takes to improve patient experience. We believe that enabling patient and carer leaders to be at the centre of how improving experience of care is led and managed, in particular in understanding and acting on patient and carer feedback, can take patient experience to the next level.

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