



Bring it on - 40 ways to support Patient Leadership



Our ambitions for the NHS in the Midlands and East

- Improve population health
through prevention, early
diagnosis and care
- Significantly improve quality
and safety of primary care
- Create a revolution in patient
and customer experience
- Work across sectors (public, private, voluntary &
third sector) to improve health and wellbeing
of the population
- Ensure radically strengthened partnership
between the NHS and local government



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Section 1

Introduction and background



Our ambitions for the NHS in the Midlands and East



- Improve patient care and experience
- Improve patient quality and safety in primary care
- Create a revolution in patient and customer experience
- Improve patient experience and safety in secondary care
- Ensure reliable, integrated governance between the NHS and local government



Introduction

Patient Leaders are patients, service users and carers, who work with others at strategic level to influence change in health and healthcare. Patient leadership is more than patient and public engagement and can make a unique contribution to improving services. This Guide - the first of its kind - explains what patient leadership means and the role and purpose of patient leaders. It aims to help NHS organisations foster patient leadership and Patient Leaders. In particular, it is designed so that senior managers, board members and staff in NHS and social care can develop and/or maintain an environment where:

- Patient Leaders are able to engage in effective dialogue with clinical and managerial leaders and others about the health care they provide
- Patient leadership can thrive
- Patient leaders are supported and developed
- People want to become patient leaders

It can also be used by Patient Leaders themselves.

This guide has been written by the [Centre for Patient Leadership](#) and [FPM](#). It has been developed as part of a wider initiative that promotes a transformation of the way in which the NHS relates to patients and the public. The aim of the 'creating a patient and customer services revolution' ambition is to stimulate a revolution in patient and customer experience across the NHS Midlands and East.

It aims to ensure that sustainable improvements in patient and customer experience are achieved through working closely with and through organisations across the NHS Midlands and East to support and generate a patient revolution. For more information: [NHS Midlands and East: Patient Revolution](#)

In a Nutshell: What is Patient Leadership? Who are Patient Leaders?

Patient Leaders...

- Are patients, service users and carers who work with, and for others to **influence** decision-making at a strategic level - this is shared decision-making at a collective and strategic level.
- Are **everywhere** - They can have a wide range of roles: formal and informal representatives, community enablers,

campaigners and activists, peer-to-peer support workers and entrepreneurs... and more.

- Have a **mind-set** focused on reflection, dialogue, collaboration and co-creating solutions. They build effective relationships built on trust, credibility and respect.
- See the big picture, act **strategically** whilst paying attention to results and outcomes.
- **Lead and manage** their own health and well-being and build on this experience to lead and influence others - they are more than 'lay' leaders (i.e. those who are 'non-professionals').
- **Lead themselves** effectively (e.g. have a clear sense of what motivates them, their strengths, weaknesses, beliefs, values, purpose and vision).
- **Lead by example** – showing in their behaviour the values and principles associated with the changes they seek to make.
- Require **learning and support**, focused on developing confidence and capability - particularly 'process' skills (e.g. around dialogue), rather than merely knowledge.

Patient Leadership

- Is **driven** by patients, users and carers
- Is about seeing people who live with health problems and use services as an **asset**, rather than 'the challenge' to be met.
- Creates a **dialogue of equals** between patient, clinical and managerial leaders
- Builds innovative co-produced **solutions** to current health and healthcare challenges

What's in the guide?

The guide provides descriptions of key concepts and ideas and things that can be done to foster patient leadership. It includes examples and case studies of Patient Leaders and quotes from clinical and managerial leaders that illustrate what can be done.

We know this is a new and emerging field. We have tried to include as many practical tools, such as self-assessment frameworks, checklists, top tips, useful background materials and places to go for more help.

The first section provides an overview of what we mean by patient leadership. Section 2 and 3 are aimed primarily at what senior managers and Boards can do at strategic level to foster patient leadership. However, section 4 is also relevant to other levels of the organisation - it's about the crucial task of working together. Sections 5 and 6 are about the nuts and bolts - what can be done operationally to take the work forward. In all, this Guide provides 40 steps or 'top tips' - 8 in each section - that you can take to developing patient leadership and Patient Leaders.

Dr Stephen Dunn, Director of Strategy, NHS Midlands and East

"I have always been passionate about the need to listen and engage with patients in order to drive improvements in the customer experience. I was, however, unsure how the idea of introducing "Patient Leaders" into the NHS would be received by clinicians.

But since, we introduced Patient Leaders into NHS organisations across the Midlands and East Anglia we have seen 160 Patient Leaders supported to develop into patient champions, working with clinical and managerial leaders, to dramatically improve the patient experience. They have fed the perspective of the patient and carer directly into work to improve the patient experience at a strategic, and not just an operational, level. If the NHS embraces working with patient leaders it will get a deeper perspective of patient needs."



Point 1:

Why we need Patient Leaders

There are numerous and unprecedented challenges to improving health and healthcare. Patients, users, carers and members of the public have a valuable role to play in tackling the problems facing health and social care at a national and local level. Have a look at:

[Health Service Journal: The Rise of the Patient Leader](#)

[Health Service Journal article: Why Patient Leaders are the New Kids on the](#)

However, people who live with health problems and use services are an *asset*, rather than 'the challenge' to be met.

In the wake of the [Francis report](#) (it is clear that we need to do far more to 'put patients first' in the healthcare system, and move away from what has been termed institutional paternalism in services. Initiatives, such as the [NHS constitution](#) can help.

But more needs to be done to support the empowerment of patients and to ensure that there is a dialogue of equals between patients and clinicians/professional staff at individual level. This needs to be mirrored at the top-tables, where strategic decisions are made. Patient Leaders need to work with, and influence clinical and managerial leaders in order for patients interests to be heard and acted upon.



Point 2:

Go beyond patient and public engagement

There has been a welcome rise in patient and public engagement (PPE) - how patients and the public can be involved in decisions about design and delivery of services: And there is a rich seam of work to draw upon for that work. See, for example: There are many guides and toolkits that focus on patient and public engagement (PPE)

- [The Engagement Cycle Introduction](#)
- [The Participation Compass](#)

PPE is often a consultative process, one in which the terms of engagement are dictated by clinicians and managers. Patient Leaders are often involved in PPE initiatives, helping to shape services. But the concept of patient leadership is broader. It is about people (patients, users, carers) influencing change - and being supported to do so - in a variety of ways, at every level of activity and across different settings - not just as part of formal PPE initiatives.

In addition, PPE success (in terms of impact on decision-making and service improvement) is patchy.

There may be several reasons for this:

- Many initiatives gather a lot of data on patient experience but fail to utilise that data to inform decision-making and improve services.
- Organisational approaches to involvement can be restricted to mechanisms for 'feedback' (e.g. consultations, surveys, focus groups) that limit opportunities for patients to be more involved in subsequent decision-making
- Ongoing involvement opportunities are limited or traditionally built around institutional structures with one or two 'lay representatives' present
- Patients are seen as a 'problem' to be solved, rather than as solutions to problems.
- Professionals (clinical/managerial) fail to recognise patients as leaders who can co-produce solutions.
- Few services are organised, run by, or influenced by patients or users.
- Current approaches to building the capacity of patient representatives, activists and community leaders are ad-hoc and under-funded.
- Patients can feel isolated and disempowered. The learning and support that is on offer does not meet practical, emotional and psychological needs.
- Patient leaders lack the knowledge, skills and confidence to build dialogue, create trusting relationships, influence power, enhance accountability and improve services.

The following conceptual framework, adapted from [Arnstein's ladder of participation places Patient Leadership in the context of Patient and Public Engagement \(PPE\)](#).

Degree of influence and control Level of patient and public engagement	Providing Information	Feedback	Influence	Control
Individual level (having a say in decisions about my own care and treatment)	Information to patients about care and treatment options	Feedback from patients (e.g. PALs, complaints, NHS Choices, Patient Opinion)	Advocacy and increased self-determination	Self-care; self-management
Collective level (having a say in decisions about planning, design and delivery of services)	Information to citizens about services	Aggregated data (insight); Qualitative and quantitative data capture (e.g. surveys, focus groups)	Representation and involvement in decisions	Patient Leadership

<http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>



Point 3:

Bring Patient Leaders into the Frame

In order to transform services and place patients truly at the heart of healthcare, there are three necessary pillars for health care leadership – clinical, managerial and patient. Or you can see it as a 3-legged stool. There are many calls for high quality clinical or managerial leadership, particularly in the current socio-economic climate and amidst turbulent healthcare reforms. Leadership programmes for health professionals abound.

Clinical leaders are embedded throughout the whole system at national, regional and local level. They are engaged in leading organisations, organisational change, providing and commissioning of services. Managerial leaders are also embedded throughout the system at national, regional and local level. They are also engaged in leading organisations, leading organisational change and providing and commissioning of services.

Patient leaders - those patients, users and carers with the confidence and capability to work with others to influence change - are often not in evidence. Therefore the system loses the focus of the 'end user' and as such these systems in action do not benefit from the perspective and challenge of the service user at a strategic level.

It is no wonder therefore that the clinical and managerial paradigm prevails and patient experience and customer experience has not been given the focus it deserves. Recent changes in policy provide increased opportunities for the manifestation of clinical leadership (e.g. in clinical commissioning groups). Changes to patient and public engagement mechanisms (e.g. the transition of LINK to Healthwatch) mean that there is also an opportunity to foster patient leadership in emerging plans.

**Donal O'Donoghue, Consultant Kidney doctor,
Professor of Renal Medicine and National Clinical Director for Kidney Care**

"I spent ten years as a health professional trying to work out how to offer choice in our health care system, principally focused on the choice of whether kidney patients choose dialysis or choose not to dialyse. This is a hugely complex, and ultimately a life or death decision.

Working with Patient Leaders on this has been inspiring. With them and with health professional colleagues, we have been able to think through what choice and shared decision-making actually means - in theory and practice. Before working with them, I knew we needed to improve and had an impression of where we needed to go, but what was missing were the road maps we could all understand so as to move to the vision. I wasn't able to describe precisely what was needed, measure progress or describe adequately where we were going.

We now have those definitions around shared decision-making, a conceptual framework that means everybody is singing from the same hymn sheet, shared understanding of the vision, and a way of translating what we are doing across different audiences. It means I can go into groups of patients, clinicians or managers, confident that we are all pulling in the same direction. This has only been possible through working with inspiring Patient Leaders who have been able to hold their own in discussions with clinical and managerial leaders at strategic level.

The result of this collaboration has profoundly changed the way I work. But, more importantly we, patients and healthcare professionals, now have the right words, the tools and the measures to really offer healthcare choices. My hope is this will change the lives of others facing difficult decisions including those with advanced kidney disease."



Point 4:

See Patient Leaders as assets

Patients and carers are a vast untapped asset. They know what it's like to live with health problems and to experience health care first hand and they continually find creative solutions to challenges in their daily lives. In some ways, our view of patients should shift - many are, or could be, natural innovators and entrepreneurs. Ill-health for some is crisis and/or opportunity - the crucible within which many have to re-think their lives, reframe and build new identities.

Many patients and users have the passion and empathy to help others and come up with new ways to do things. When it comes to service quality, they experience both the good and bad of services and might provide innumerable ideas for how things could be better. But that will only happen if their views are valued and if they are supported to take part in decision-making.

The NHS often sees patients as problems - patients to be managed, people who raise expectations or create over-demand, potential complainants, bed blockers or frequent flyers. The language we use can be a powerful indicator of underlying assumptions.

When patients can lead and manage their own health and well-being and when they have developed the confidence and skills to lead and influence others, something special happens! Experience of innovative approaches to system improvement that build on people's lived experience of health and health care can transform services; [The NHS Institute for Innovation and Improvement: The ebd Approach \(Experienced Based Design\)](#).

New collaborative systems of healthcare are beginning to take shape and positive changes and solutions emerging to healthcare problems in the local community. Some examples and stories can be found on the [Altogether better](#) site.

Thousands of people already volunteer their time and energy for the benefit of their own communities, helping to improve health related services. They are the activists, representatives on committees, governors of hospitals, members of new commissioning groups (in England), community leaders, peer-to-peer support workers or just individuals wanting to make a difference to their community's health and wellbeing.

People often move through different types and levels of volunteering and involvement and need to be supported through these pathways of participation,' see Involve, [Involve, Pathways through Participation](#).

NHS organisations could help support this reservoir of talent, experience and passion and it could be the basis of a support network. If these individuals can also be provided with learning and development to facilitate their growth and success, then collaborative working between patient leaders, clinical leaders and managerial leaders might become the norm.



Section 2: About Patient Leaders and Leadership



Our ambitions for the NHS in the Midlands and East



- Improve operational performance and efficiency
- Improve patient quality and customer experience
- Create a revolution in patient and customer experience
- Ensure healthy, integrated partnerships between the NHS and local government



Point 5: Identifying who are Patient Leaders...

Patient Leaders are those patients, users and carers who have the confidence and capability to influence change. Their main purpose is to improve health and well-being in the community and/or improve health and social care services. They do this by working with others to influence decision-making.

Patient Leaders may be patients, service users, clients, citizens or carers. Crucially, they can draw upon their own experiences of ill-health (as user or carer) and/or using services in order to develop their Patient Leadership skills (see below). Patient Leaders are everywhere. [See this selection of short videos where patients, service users and carers outline their own views on patient leaders and patient leadership](#)

Patient Leadership is not about the 'great leader' at the top of the organisation. It is about leadership that is distributed at every level. Supporting Patient Leaders is about creating an environment in which patients at every level can take a lead in a constructive and creative dialogue with clinicians and managers to improve health care.

The principles of distributed leadership are discussed in a brief paper from Cranfield University; [Take me to your Leader: Distributed Leadership and Strategic Leadership](#) and in more depth by Alma Harris from Warwick University; [Distributed Leadership](#).

We can think of two broad categories of Patient Leaders (not mutually exclusive):

- **System-influencers** - seeking to influence health and social care design and delivery - may range across a spectrum - They may be 'insiders' with formal or statutory accountabilities to the organisation they work with (e.g. FT Governors, Lay Members of CCGs). Others work on the boundaries and are 'outsiders-inside' (e.g. informal patient representatives on projects or groups, patient group members, Health Watch volunteers). Others may seek to influence from a more external location, as campaigners or activists.
- **Community-enablers** - seeking to promote health and well-being in the community - may have a wide range of roles, such as community leaders or organisers, lay community development workers, community researchers, health champions, health ambassadors, people working in public health initiatives. Patient Leaders may also take a completely different route towards influencing change - becoming patient entrepreneurs, leading their own initiatives in health, developing projects and innovative solutions to unmet need. They may also be providing peer to peer support to individuals in the community or to patients, for example as advocates, mentors and coaches. Note that these peer to peer Patient Leaders work primarily with individuals and not (necessarily) at strategic level.

Dr Ruth May, Director of Nursing, Midlands and East

“As a nurse, I know how important it is to develop the right partnership between patients and healthcare professionals in order to provide the right support for that individual and their carers.

The benefits of Patient Leaders embedded in our organisations and working in equal partnership with clinicians and managers are equally important. Organisations that value, listen and learn from the patient voice will ensure continuous improvement in the quality of patient care and patient experience.”



Point 6:

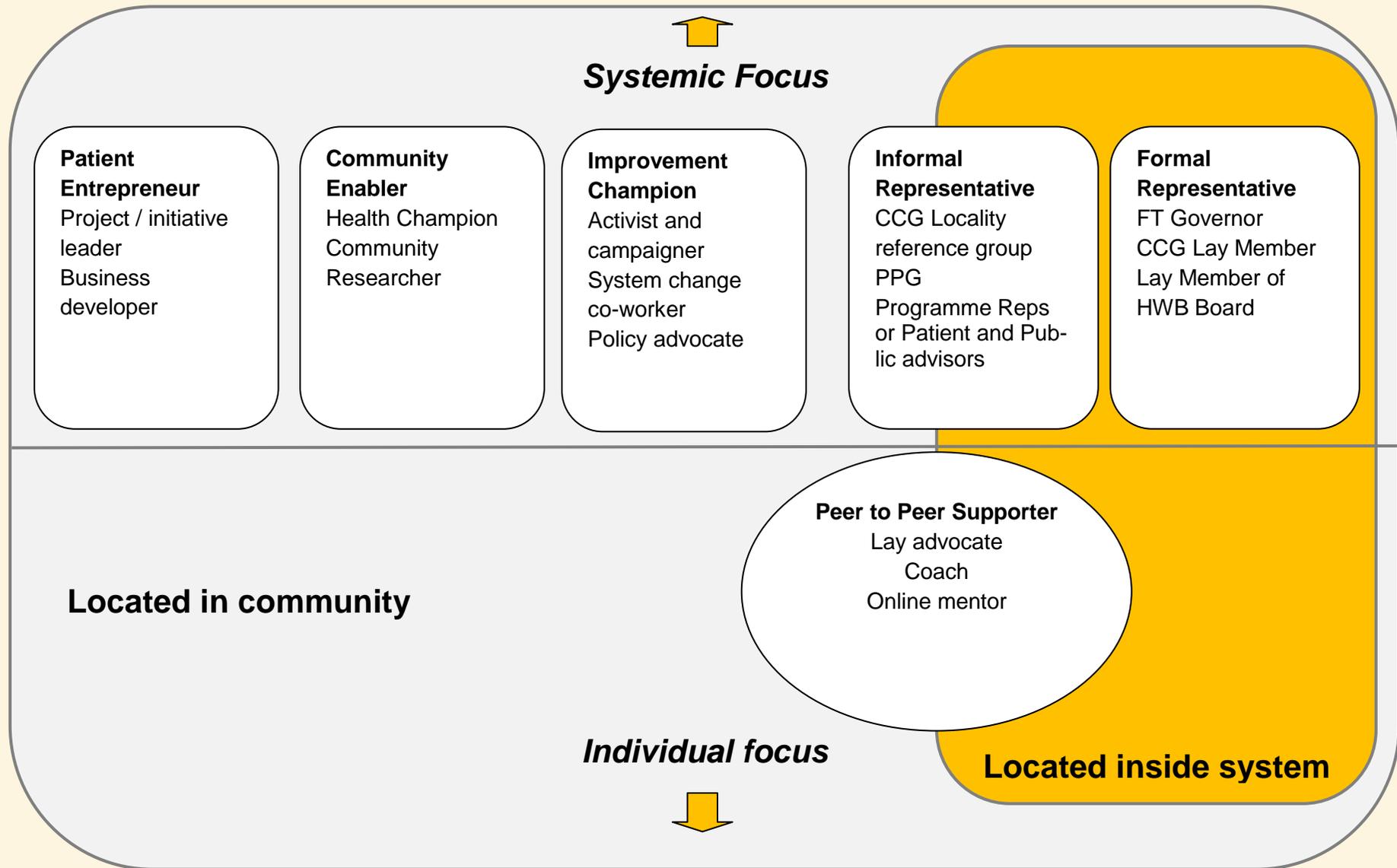
Identify where you find Patient Leaders in action?

The following Patient Leadership framework may help to think through where an organisation may 'find' Patient Leaders. This framework outlines some different types of Patient Leadership roles. They are not mutually exclusive:

You can use the framework to think through:

- **Where are Patient Leaders?** What Patient Leaders can you already identify who are already undertaking these various roles? Where are they? What are they doing? Where can you find more of them? What organisations or people can help you identify where Patient Leaders are playing a role?
- What **opportunities** exist already for Patient Leaders in your patch - what might you do to create or develop these roles?
- What **support** do these different Patient Leaders need? How do you know? What support are you able to provide (logistics, incentives, admin)? How can you create more support in order to build capacity?
- What **learning opportunities** are there for Patient Leaders to build their confidence and capability? What learning can you - or others in the locality - provide?
- **Impact and outcomes** - what impact are these Patient Leaders having? On quality of decision-making (transparency and accountability), on services (responsiveness) and in terms of building relationships and trust (between communities and the organisation; between individual patients and professionals); How can you measure success?

The Patient Leadership Framework



But, many people don't fit these sorts of categories or may fulfil many different roles. Ultimately, it is not about how NHS organisations see them, but how they see themselves and what sort of opportunities can be created together. [Click here](#) for full version of the framework and for further information and resources about each of the above roles of a Patient Leader.

You can use this framework as a **self-assessment tool** within your own organisation or locality to see how well you are doing at identifying or promoting local opportunities for different sorts of Patient Leaders.

This is a development tool, not a benchmarking exercise. It is intended as a foundation for the development of ways that you can help foster Patient Leadership and work together with others (including Patient Leaders themselves) to bring in, and bring on, Patient Leaders. It should provide strong clues as to what can help to take things forward.

Not all Patient Leaders are 'representatives' as can be seen from the framework. It is important to recognise the myriad of activity that goes on beyond the institutional walls, and that may not be directly related to the provision of services.

Self assessment tool: How well connected are you to Patient Leaders?

Explore how well connected your organisation is to the range of different Patient Leaders using the chart below and then make your plans to improve in partnership with Patient Leaders:

Rate your organisation's connection with each type of Patient Leader:

0 = No links at all

1 = You are aware of these leaders but rely on informal contact from them.

2 = You initiate contacts with these leaders but it tends to be ad hoc.

3 = You initiate regular, systematic contact with these Patient Leaders.

4 = You have a regular, effective, continuing dialogue with these Patient Leaders about improvement in health care

Location of Patient Leader		How connected are we?					
Patient entrepreneurs	List your examples e.g. <ul style="list-style-type: none"> • Project leader • Business developer 	0	1	2	3	4	5
		0	1	2	3	4	5
Community Enablers	List your examples e.g. <ul style="list-style-type: none"> • Health Champion • Community researcher 	0	1	2	3	4	5
		0	1	2	3	4	5
Activists and campaigners	List your examples e.g.	0	1	2	3	4	5
		0	1	2	3	4	5
Informal representatives	List your examples e.g. <ul style="list-style-type: none"> • CCG locality reference group member • Patient Participation Group member • Programme representative • Patient advisor • Public advisor 	0	1	2	3	4	5
		0	1	2	3	4	5
		0	1	2	3	4	5
		0	1	2	3	4	5
		0	1	2	3	4	5
Formal representatives	List your examples e.g. <ul style="list-style-type: none"> • FT Governor • CCG Lay member • Lay member of Health and Wellbeing Board 	0	1	2	3	4	5
		0	1	2	3	4	5
		0	1	2	3	4	5
Peer to peer supporters	List you examples e.g. <ul style="list-style-type: none"> • Lay advocate • Coach • Online mentor 	0	1	2	3	4	5
		0	1	2	3	4	5
		0	1	2	3	4	5



Point 7:

Think about the stages of development of Patient Leaders

People will be at different stages of their 'patient leader' journey - it is important not only to focus on existing Patient Leaders in established roles - the formal or 'embedded' Patient Leaders (e.g. Clinical Commissioning Lay Members, FT Governors, representatives on committees, etc), but to think about emerging and potential Patient Leaders (see section on identification and recruitment). This is particularly true if the health service is seeking innovative ideas and solutions, or needs to hear from people from different parts of society and walks of life - the so-called 'seldom heard'.

Some people may come from community, voluntary or patient groups or organisations. Others may be individuals who have been 'brought in' because of their particular experiences or perspectives (see also sections below).

They may also be heading in 'different directions' with regard to their role. Not all Patient Leaders are 'pegs' to be slotted into institutional holes, brought in merely to serve the current need for representatives in a given structure.

The whole point of Patient Leadership is to cultivate an environment whereby patients, users and carers are able to work with professionals and create their own opportunities to improve health in the community or healthcare systems. And they may have their own ideas for doing so, but face barriers that organisations can help remove. For some of the barriers and challenges that Patient Leaders face, see [Health Service Journal, Why Patient Leaders are the new kids on the block](#).



Point 8:

Consider what Patient Leadership is

Patient leadership is the range of attributes or qualities that a Patient Leader brings to bear in their role and requires in order to be an effective change agent.

Patient Leaders display all the attributes of effective leaders in any walk of life. Michael Fullan (2004) summarised these in a useful diagram on Page 4 of his paper, [Principals as Leaders in a Culture of Change](#).

The NHS has developed a [leadership framework](#). It is worth reflecting on this framework and how well it resonates with the approach to Patient Leadership that we describe in this guide.

Whoever they are, whatever they do and wherever they are found, there are key attributes that are necessary to becoming an effective Patient Leader. Of course, Patient Leaders will need some degree of knowledge about the particular organisational or community context and their own particular role. But it is the attributes, behaviours and confidence that make all the difference. These include:

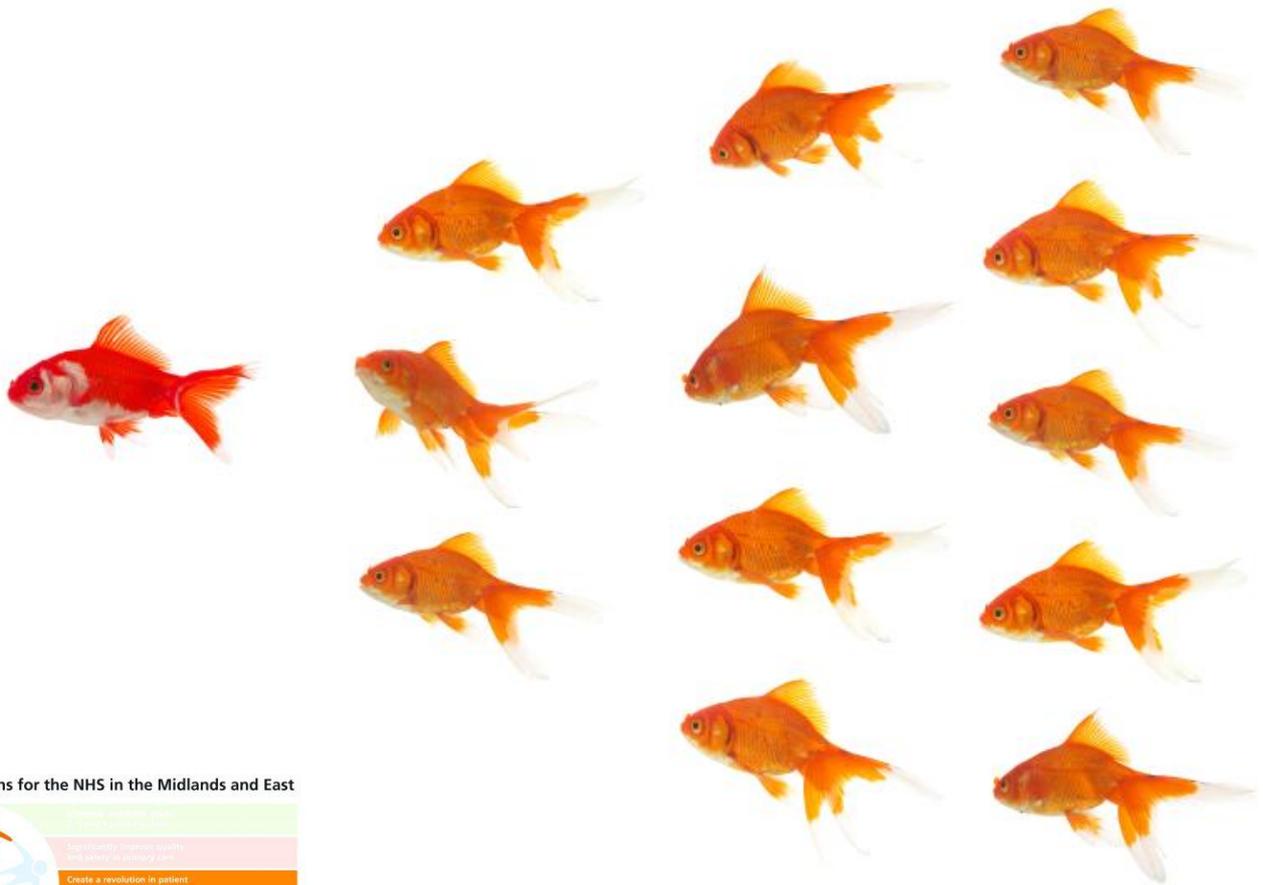
- Leading themselves effectively (e.g. having a clear sense of what motivates them, their strengths, weaknesses, beliefs, values, purpose and vision).
- Leading by example – showing in their behaviour the values and principles associated with the changes they seek to make.
- Building effective relationships built on trust, credibility and respect.
- Ability to successfully challenge, and to manage conflict and disagreement.
- Communicating effectively, particularly using the skills of dialogue (advocacy and inquiry) and coaching.
- Seeing the big picture, act strategically whilst paying attention to results and outcomes.
- Becoming a lifelong learner.
- Building and maintaining a network of peer support.

For some examples of how these attributes are manifested in Patient Leaders, see: [Health Service Journal: When patients become leaders](#)

For more information on approaches to learning and support, please see section 6 of this Guide.



Section 3: Leading the transformation to Patient Leadership



Our ambitions for the NHS in the Midlands and East



- Improve patient care, experience and safety
- Significantly improve quality and safety in primary care
- Create a revolution in patient and customer experience
- Build a new, joined-up, primary care system to improve patient experience, health and wellbeing
- Form mutually strengthened partnerships between the NHS and local government





Point 9:

Capture People's Hearts and minds

Senior leaders in NHS and social care organisations need to create and maintain an organisational culture that puts patients first. This is a vital part of the job of managers, leaders and staff at all levels. For more on the role of leaders in building and sustaining an organisation's culture see this paper from the [Northern Leadership Academy: How does leadership make difference to organisational culture and effectiveness?](#)

Get people excited by the notion of Patient Leadership is about capturing hearts and minds.

You might want to **get Patient Leaders as involved as possible with your organisation.** This might include Patient Leaders on the Board, presenting some of the examples in this guide, or find local inspiring examples of your own. It may extend to Patient Leaders running meetings or being increasingly involved in decision-making. Perhaps bring in Patient Leaders to tell their stories to staff.

More broadly, you might want to develop a more widespread strategy for Patient Leadership - you can use this guide to identify, recruit and support Patient Leaders across the local health community and develop more widespread opportunities for their development.

This will depend on making the vision clear and enabling people to come on board. Build a shared understanding of the purpose and benefits of Patient Leadership - for example how Patient Leaders can help solve current challenges and bring benefits to patients, staff and leaders in terms of having a dialogue of equals.

This process is also about making clear what Patient Leadership is not about – it is not tokenism, nor is it about consultation with patients. It is not about angry patients being given the chance to have a go at managers and clinicians. It is about creating a culture where it is seen as normal and unremarkable for patients to be involved as equals in a dialogue about improving health care.

Dr. Paul Watson, Director of Operations & Performance, Midlands & East, NHS Commissioning Board

“I became convinced of the merits of fostering Patient Leadership through our regional work improving patient care in partnership with clinicians, managers and most importantly, patients and carers. The presence of Patient Leaders has been invaluable in focussing discussion on the key purpose of the NHS – that of providing good quality patient care. The natural scepticism of some was soon dispersed when they also saw the value.”



Point 10: Lead by example

Clinical and managerial leaders need to model the principles of leadership. Build senior commitment for the work through senior leaders who understand the purposes of Patient Leadership and how it fits with everyday business. Senior leaders need to model styles of leadership congruent with Patient Leadership values. This means moving away from 'command and control' approaches and embracing ways of working that stress 'working with' patients, carers and citizens.

Edgar Schein (1992) identified several ways in which leaders can embed culture:

- By what they are seen to value and praise; what they measure and control
- How they react to critical incidents
- Where they allocate resources
- How they support and coach their staff
- How they are seen to promote staff or reward performance

Test your own culture – how well do you and your other leaders perform in on each of these points in respect of Patient Leadership?

Find local inspiring examples of professionals who believe in the work and who 'walk the talk' on leadership - particularly models of leadership that align with Patient Leadership. These are likely to reflect transformational and distributed approaches to leadership. For more on these approaches follow these links:

Transformational Leadership:

- [Transformational leadership - general](#)

Distributed leadership:

- [Take me to your Leader: Distributed Leadership and Strategic Leadership](#); Cranfield University
- [Distributed Leadership](#); Alma Harris from Warwick University

This helps fuel the development of a culture and systems that foster Patient Leadership.

Board members, senior leaders, staff and all health professionals may need opportunities for learning and support to be able to work effectively with patients and the public and with Patient Leaders. There are many resources available that can help.



Point 11:

Develop a shared understanding

A lot of people mean different things when they talk about Patient Leadership. Present Patient Leadership at Board level and with different stakeholders. Hold conversations that flush out different assumptions about the concept and work towards a shared understanding so that people are talking about the same thing. The definitions, frameworks and models in this Guide can help towards a shared understanding of what Patient Leadership means, its different purposes and benefits. When it comes to developing Patient Leadership, there are two particular areas to think about:

- Cultivating the soil - Fostering a culture of Patient Leadership
- Sowing the seeds - Bringing on people as Patient Leaders

The rest of Section Three focuses on the former. Section Four focuses on the latter.



Point 12:

Get strategic

Get clear on the business, health and social benefits of Patient Leadership. This is an emerging field and evidence from other related fields may help. See for example:

- [NHS - Engagement for commissioning success](#)
- [Picker Institute Europe: Invest in Engagement](#)

This will also help cement relationships with other stakeholders. Use the concepts of Patient Leadership outlined in section one as the basis for developing a Patient Leadership strategy.

Operational plans linked to organisational development plans and outcomes frameworks can specify who needs to do what to make it really work.

This might include chapters that mirror sections of this guide, but be adapted to local circumstances.

Sir Neil Mckay, Chief Executive, NHS Midlands & East

“I have been impressed by the quality of Patient Leaders I have seen contributing towards regional initiatives. They bring a freshness to our work on patient experience and engagement. When we take the time to support people and work together to provide the right opportunities, Patient Leaders are well able to help identify solutions.

The benefits have been tangible - changes in the way we make decisions and changes to what we as professionals thought we should be doing. I am confident that this is leading to real changes on the ground. In some ways building Patient Leadership seems to be the 'missing link' in engagement work. Now we need to make it part of what we all do every day.”



Point 13:

Get clear on Patient Leadership and governance

Think through where Patient Leaders fit at corporate and strategic level - on Boards of CCGs, for example. For commissioners, there is a need to get clear on the role of board lay members. Just as the board has a collective duty for Patient and Public Engagement, so should plans to foster Patient Leadership not be left to one person. The CCG lay member is one type of Patient Leaders or representative.

All representatives are 'outsiders-inside' - coming from the community with a patient/user perspective ('outside') to try to influence the system ('inside'). It requires them to be:

- A community channel – externally facing, credible, in touch with local communities and bringing in wider perspectives;
- A critical friend – internally facing, flying the patient flag, offering strategic advice from a non-institutional perspective see: [NHS smart-guides on 'working with lay members'](#)

See also 'The Effective Lay Representative' under 'articles at [InHealth Associates](#)



Point 14:

Hard-Wire Patient Leadership into the organisation

Identify the key systems and processes that will ensure it runs through the culture. These will include monitoring and performance management systems; resource allocation for the work; staff support; developing opportunities for Patient Leaders and Patient Leadership and developing policies that support Patient Leaders (for example, a reimbursement policy, see Point 38).

Make sure that other strategies and plans make clear their link with Patient Leadership. Organisational development, leadership support, QIPP (The Quality, Innovation, Productivity and Prevention programme) and communication plans should be developed in tandem with Patient Leadership.

Patient and public engagement (PPE) plans should be developed with Patient Leaders and make clear how Patient Leaders will be supported and trained.



Point 15: Monitoring and Performance Management

Set up systems to know how you are doing - How effective are you being able to develop Patient Leadership, how effective are you at supporting them (process) and how effective they are in influencing change (impact).

Keep abreast of the ways in which Patient Leaders are being supported and developed; and the impact of the work. This might include overseeing the extent and nature of opportunities for Patient Leaders to be involved in strategic decision-making; or the opportunities for learning and development.

The Board collectively is responsible for ensuring a culture that fosters Patient Leadership across the organisations, and there should be regular agenda items (just as there should be with PPE) that focus on progress. Build Patient Leadership into business decisions.

Plans and business cases for change and service improvement require assurance that Patient Leaders are playing a key role in decision-making before signing off. But Patient Leadership is more than just a focus on how PLs are 'involved' in designing and delivery of services.



Point 16: Be clear on who does what

Roles and responsibilities for Patient Leadership at strategic and operational level need to be clear.

These include specifying who has responsibility for promoting the vision of, and strategy for, Patient Leadership and the operational activities associated with success. These roles should be specified in operational plans.

It may be that a nominated director, or assistant director, could work with the patient and public engagement lead - and also with a Patient Leader - to lead the day to day work.

But remember, Patient Leadership is a collective responsibility and needs to be embedded across the organisation. Don't just leave it to one person.



Section 4: Working with Others



Our ambitions for the NHS in the Midlands and East



- Improve patient care and experience
- Improve patient quality and safety of primary care
- Create a revolution in patient and customer experience
- Ensure medical professionals have the resources and support they need to deliver the best care
- Ensure effective partnerships between the NHS and local government





Point 17:

Build trusting relationships

No amount of formal structures can substitute for building trusting relationships. It is crucial that senior leaders (managerial, clinical and patient) develop dialogue with each other, and with local patient and community organisations.

Formal meetings can be inaccessible for Patient Leaders. Often Patient Leaders are the only ones without a formal job title or 'Dr' in their title.

They can feel intimidated by the formal way in which meetings are run, or by papers that are lengthy, sent round too late or by jargon and acronyms. So, creating a culture that is more accessible is important.

You can make meetings work differently. For example, establish ground rules, so that people can only talk for a limited time, provide a glossary - or better still, use more user-friendly language.

See, for example [Westminster Learning Disability Partnership Board Away Day Notes](#)

There may be different ways to hold conversations at strategic level, and ways that individual professionals can build their capacity to listen better, ask questions and be mindful of assumptions - in a way that enables others to be better heard and in order to mirror the very qualities expected of Patient Leaders themselves.

Bring in examples of patient stories that bring strategic conversations to life see [patient voices](#), or bring in Patient Leaders themselves who can help focus discussion on improvement and what can be done.

Ask 'so what' questions, for example: 'so, what does this discussion mean for patients and the public? 'So, what are we doing to engage with Patient Leaders?' etc.

Simon Wood, Director of System Redesign & Performance, Bedfordshire & Luton PCT Cluster and Programme Director, Healthier Together

"I have become convinced of the importance of facilitating Patient Leadership through working on many change management programmes. Recently, working on the Healthier Together programme, we established a Patient and Public Advisory Group and appointed an independent person to chair it.

This individual sat on all the key governance groups for the programme, including the Programme Board, thereby ensuring that the voice of the patient was absolutely central to the work of the programme"



Point 18: Working in partnership

Patient Leaders will emerge best when this work is developed in partnership across a local community and with local partners, such as statutory organisations, the voluntary sector, local businesses and local community directly.

Take every opportunity to build links with local people and groups - be ready to 'walk the talk' and be able to explain clearly what you are doing. For example, one NHS Commissioning Board Director has become a trustee of a voluntary organisation that does community development work. The private sector regularly encourages its staff to become volunteers.

Organisations could align their efforts to foster Patient Leadership initiatives and to support individual Patient Leaders. Local partners could develop their own 'people bank' of Patient Leaders - this is more than a passive citizen's panel, but a pool of talent, supporting people into different roles, such as health champions, a hub for innovative solutions, or peer-reviewers for local services).

Having Patient Leaders 'in the room' for discussions on service improvement will trigger efforts to promote continuity of care, integration and alignment of services. In fact, working with Patient Leaders, who often emphasise continuity of care, can be the 'glue' that promotes partnership working. In particular, the community and voluntary sector have a huge role to play in developing Patient Leadership.



Point 19: Involve staff

Staff may have experiences of being a patient or caring for someone who has a health condition. In the past, this sort of experience has not been harnessed in order to build connection between professionals providing care and those receiving it. While institutionally, staff can't be pure Patient Leaders - the primacy of their formal role, and corporate roles, responsibilities and accountabilities prevent that - they have a vital role in fostering Patient Leadership at middle management, clinical level and during everyday interactions with patients and carers.

You might want to test out ways by which staff can be supported to consciously reflect on their learning via being a patient or carer; see:

- [Both Sides Now Project](#)
- <http://www.nhslocal.nhs.uk/> which has a number of web-based tools for staff interested in personalised care planning, the principles of which are aligned to fostering Patient Leadership
- http://www.institute.nhs.uk/quality_and_value/experienced_based_design/case_studies.html provides illustrative examples of staff stories



Point 20:

Provide learning and support to staff

Many of the critical skills needed to be an effective patient leader are about being [emotionally intelligent](#), listening, and being mindful of one's own assumptions, asking questions. These are qualities that need to be cultivated in the workforce as well of course. Numerous training opportunities and useful resources are available for staff and managers. Often, professional communication training is a pre-requisite at a clinical level.

More needs to be done at strategic decision-making level to ensure that Boards and senior leaders are practicing the art of listening and dialogue. Why not bring in Patient Leaders who can lead or co-facilitate a Board level seminar on the subject, or help discuss an important issue that concerns patients and the public? A shared learning session on Patient Leadership - Patient Leaders and professional leaders coming together and learning together is the best way to model and learn the art of fostering Patient Leadership.



Point 21:

Work with the voluntary sector

Many Patient Leaders will have emerged originally in the community, and/or through the local voluntary. And partnerships with the community and voluntary sector are crucial as Patient Leaders are supported to take up opportunities and to be more effective. Though you should not entirely rely on the voluntary sector to reach all parts of the local community and walks of life (the 'seldom heard'), they can help you identify and recruit the right people. National condition-specific organisations often have local branches and networks that can help you find people with a particular perspective. [National Voices has a list of its members](#) - many of which have local networks.

[NAVCA](#) - an organisation that supports local voluntary and community action - has a list of all Councils for Voluntary Services on their website which is a good route to find local relevant organisations.

[Regional Voices](#) has produced a guide for the voluntary sector working with Health and Wellbeing Boards that has useful general information too about partnership working.

But the voluntary sector needs to be valued too. They need capacity building and support in order to fulfil this function, so you still have to invest to get the right help.

The voluntary sector can help jointly to shape cultures and systems for Patient Leadership. They can also advise you on how it might be done. They can also help deliver services that involve Patient Leaders in co-production.

By building solid partnerships, Patient Leadership can flourish and Patient Leaders will emerge. Regional Voices also have other [resources on development in health and social care](#) that may provide useful tips on how to work with the voluntary sector:

For examples of local work, following investment in community empowerment networks, see:

- [LLCM University of Lincoln – Community and Voluntary sector](#)
- [Sefton Community Empowerment Network - What is the Community Empowerment Network \(CEN\)?](#)

You could also work with the voluntary sector to commission patient leadership programmes for members of local voluntary organisations. For a range of learning programmes possible, see: [The Centre for Patient Leadership Website](#).



Point 22:

Align Patient Leadership and work on putting patients first

Service improvement work is often a good place to test out Patient Leadership. Many improvement methodologies now stress co-production - how services can be planned, designed and delivered with patients, users and the public, see, for example:

[NHS Institute for Innovation and Improvement – Transforming Patient Experience: the Essential Guide](#)

Adding Patient Leadership to the mix is about being more explicit about

- Developing the confidence and capability of patients, users and carers involved in this sort of work so that they can be influential in their role
- Ensuring that those involved have ongoing opportunities to develop their roles as Patient Leaders
- Broadening the pool of talent and making sure that people from all walks of life and parts of society can contribute
- Developing the cultures and systems to embed Patient Leadership. Similarly, Patient Leadership work can complement initiatives around patient and public engagement (PPE) more generally. See for example, [Governance International; Co-production in Health and Social Care in Scotland](#)

There are also many initiatives on personalisation and shared decision-making that can be built upon. These will have involved potential and emerging Patient Leaders in the work, some of whom may be eager to continue to make a difference at a more strategic level. For more information and resources, see:

- [NHS Midlands and East: Delivering sustainable care: A personal approach](#)
- [Towards Excellence: Self Care](#)
- <http://www.rightcare.nhs.uk/index.php/shared-decision-making>



Point 23: Build Patient leadership info formal engagement mechanisms

Build opportunities for Patient Leadership into formal engagement mechanisms, such as Health and Wellbeing Boards (HWB), Overview and Scrutiny and Healthwatch. For example, it makes sense to augment the role of the Healthwatch Member of the HWB with other Patient Leaders on the HWB or on sub-committees.

Or supplement the work of the HWB with parallel Patient Leadership initiatives (eg project groups made up of Patient Leaders or focusing on Patient Leadership). You could augment job roles and competencies with the sorts of attributes of Patient Leadership described in this guide.

Have a broader strategy of engagement that does not merely focus on 'representatives' on committees, but seeks to pro-actively engage people in community-focused projects and other more innovative activities. Work with the local Healthwatch to tap into emerging talent. See, for example: [Healthwatch Communities Involved](#)



Point 24: Work with business partners

Organisations can look beyond their own usual partners. They can work with business and the private sector to foster Patient Leadership - there may be ways to encourage awards for Patient Leaders via the private sector, or to involve local educational establishments to foster Patient Leaders.

For an example of this in the professional development field, see [East of England, Aspiring senior leaders development programme.](#)

The social enterprise sector and not-for-profit entrepreneurial sector is also a place to go for ideas and collaborative plans.



Section 5: Preparing the Ground



Our ambitions for the NHS in the Midlands and East



- Improve patient safety and quality of care
- Significantly improve health and social care outcomes
- Create a revolution in patient and customer experience
- Work closer together to improve patient and community health
- Ensure clarity, strengthen partnerships between the east and local government





Point 25:

Map it out

There needs to be central mapping and co-ordination of Patient Leadership activities (see [Patient Leadership Framework](#)). This includes activities in which Patient Leaders are involved, as well as the training and support mechanisms for Patient Leaders. Use the framework in section one to think through what's going on and where you might find existing or potential Patient Leaders:

- Review where Patient Leaders are already to be found in your organisation and in the community. You may be surprised at how much is going on.
- Start by thinking about representatives on various Boards, committees or formal structures, whether your own organisation, within Partnership fora, or in the local health economy.
- Think about one off, or ongoing projects and initiatives where people have been involved. This might include people on service improvement projects, local voluntary sector leaders, members of local patient groups, etc.
- Consider the impact of existing Patient Leaders and whether they have had the right development and are appropriately rewarded.



Point 26:

Rebadge and reframe

Think of Patient Leaders as people bringing ideas and solutions to the table. Instead of asking people 'what the problems are', discuss solutions and what might be possible. Patient Leaders are more than 'representatives'. Patient Leadership is more than patient and public involvement. People can contribute more than 'data' about experiences, or raise issues of 'quality and need'.

This is not just about finding people to slot into institutional opportunities. Are there people who could:

- Provide support to other patients?
- Be part of a project to redesign services?
- Be entrepreneurs in waiting? Having a good idea, but needing someone to help them develop or fund it? For inspirational ways of supporting social entrepreneurs, see <http://www.the-sse.org/>
- Ambassadors for Change?
- Community health champions?
- Community Researcher?

This is about new ways of working together to change, finding new solutions to unmet need, tapping into a reservoir of talent that can help to develop trusting relationships. Ultimately, this is about changing an institutional mindset towards thinking about people and communities as assets.



Point 27:

Transform lay representatives into Patient Leaders

Many representatives find the roles they are slotted into frustrating and, even a waste of their talents. You could either make their job easier - making sure their role is clear, providing support and learning so that they can do their job more effectively and making sure meetings are run in ways that enable dialogue.

Alternatively, you could re-think the role of representatives - think of them as patient and public advisors, able to challenge with critical questions and support them to be able to have the confidence to ask the 'so, what' questions. Release them from having to know everything about what people think out in the community - work together instead to find out jointly people's concerns.

Consider changing the way committees run - make them innovation hubs, seeking to work on solutions to difficult issues. Think about how people's talents and skills could be better harnessed - but do this in discussion with Patient Leaders themselves.



Point 28:

Tap into potential talent

Think beyond 'representatives' and see if there are potential leaders waiting for the chance to help and work together. Focus on, for example:

- Activists and campaigners - how could they be harnessed as potential collaborators on joint solutions? Many campaigners feel marginalised and ignored. This often leads to fractious debates where nobody listens to each other. Ask them in to help you out. This doesn't mean promising the earth, but it does mean having the courage to negotiate what can and can't be done and what decisions can be shared (or not)
- Community leaders and innovators - are there initiatives or projects in the community promoting well-being, or coming up with innovative solutions to care? What could you tap into? Can you help build on them? For ideas and inspiration, see:
 - [Altogether Better site](#)
 - [NHS Smart Guide to Engagement: Community Development, Improving Population Health](#)
- Volunteers - Consider how people might be supported from this stage to taking a more active role as Patient Leaders. There is a considerable amount of material on how to support volunteers for example [Volunteering England](#) provides a comprehensive good practice bank. Also see this report on [Volunteering in health and care by The Kings Fund](#).
- Patients within GP surgeries - Many organisations, particularly commissioners are building on Patient Participation Groups in GP surgeries. Members of these PPGs might become involved in local reference groups for commissioners. Many might also be keen to develop their Patient Leadership skills, beyond that of being a representative. For more information on Patient Participation Groups, see the [NHS Smart Guide to Engagement: Practices and Patient Engagement](#)



Point 29: Get people at the start

The starting point for the patient leader's journey is often their experience of care or services. Ward staff might have ideas on individuals who can offer something back to the organisation - people who are grateful for good care. These people may be interested in keeping in touch with staff groups, or in helping out on a small ward-based or community project. They may be people interested in educating staff or inputting into induction programmes. See case study Ellie Milner on page 43.

You may want to think about other routes, such as PALS or complaints, where these people might offer solutions or where you might harness their skills and talents for joint solutions?

You will need to think through what possible 'first steps' there might be for such people and how they can be supported. The field of personalisation and self-care might also be useful avenues by which to find people who want to be more 'involved' in the field of Patient Leadership. See, for example: [NHS Midlands and East: Delivering sustainable care: A personal approach](#).



Point 30: Be imaginative

Be imaginative. Patient Leaders might act as mentors to staff or professional leaders or they may be able to input into training; see [Anya de longh](#) case study also on page 45 of this Guide. They might play an advocacy role within a particular service. They might act as ambassadors for corporate programmes seeking legitimacy in the community.

There may be new community-led schemes for rehabilitation, the development of prizes for patient-led innovation. It may be about peer-led schemes to support older frail people through to building on volunteering to make more of a difference. Patients can lead education sessions, train staff in use of social media, help with recruitment of staff. See for example case studies of Sue Sibbald on page 42 and Amanda O'Connell on page 44.

Patient Leaders might be the workforce of the future, the list is endless. Get Patient Leaders in to help identify and create the opportunities. Many of these avenues have been blocked in the past for fear of 'allowing' alternative voices in - senior leaders need to make the case for change and argue the business benefits.

In the light of the Francis public inquiry into events at Mid Staffordshire Hospital, things need to change. The conclusions and recommendations starkly show that the patient voice was not heard or listened to. The arrangements for public and patient involvement and local authority scrutiny were a conspicuous failure. Local scrutiny groups were not equipped to understand or represent patient concerns or challenge reassuring statements issued by the Trust. It recommends that the NHS should have strong patient-centred leadership. What better way of achieving this than by embedding Patient Leaders as this Guide proposes.



Point 31:

Widen the pool of talent

People are not 'hard to reach'. Often organisations just have not done enough to reach out. Patient Leadership is not all about having demographically representative populations on project groups - it's about harnessing talent and creativity.

Many organisations are already doing this, but if not check out local voluntary sector and community activity, visit places of worship and local retail outlets. There are many creative projects going on - some will have people wanting to help you, some will be projects where the health and well-being benefits surprise you. See, for example:

<http://www.altogetherbetter.org.uk/amazing-stories-collection>

Be on the lookout for people who show the willingness and positivity that can help tackle dilemmas (e.g. around access to services). For more information on how the NHS is matching up to its equality and diversity ideals, see [Shared Intelligence: Evaluation of the Equality Delivery System \(EDS\) for the NHS](#).



Point 32:

The future is digital

Tap into the huge amount of work being undertaken through social media and digital technology. Check out Twitter for a multitude of patient and community leaders already harnessing digital technology. Get involved in conversations already taking place between innovative patients, staff and professionals.

See: [NHS Smart Guide to Engagement: Using Social Media to Engage, Listen and Learn](#)



Section 6: Finding the right Patient Leaders



Our ambitions for the NHS in the Midlands and East



- Improve patient care & experience
- Significantly improve quality and safety in primary care
- Create a revolution in patient and customer experience
- Make FPM a world leader in patient leadership
- Ensure healthy, empowered partnerships between the NHS and local government





Point 33: Identify and recruit

Patient Leaders need to have clear roles and purposes. Ideally they should be involved in developing these roles and agreeing their purpose with the organisations they are engaged with.

Look again at the location of Patient Leaders diagram. It is clear that there are already well developed job descriptions for some of these roles (particularly the formal roles). Others are unlikely to have formal role descriptions (e.g. community activist).

Use the [Patient Leadership framework](#) to think this through.

Patient Leaders may have one of several roles and purposes. Some patient leader opportunities might need formal recruitment and selection processes. But others may not. Sometimes the bar will be set high, in terms of the amount of content people might need to have. But other times, it's more about ensuring that people have the process skills or attributes of patient leadership.

In encouraging patient leadership you will need to be flexible about which roles require structure and formality and which are looser and more informal.



Point 34: Focus on attributes, not roles

At root, many of the attributes of the ideal patient leader - whatever the role - are around inter-personal skills. Experience has shown that some of the key attributes that you will be looking for can be adapted as part of a role specification or competency framework are the following. They might include the following:

- Leading themselves effectively (e.g. having a clear sense of their drivers, strengths, development areas, beliefs, values, purpose and vision).
- Leading by example – being role models of the values and principles associated with the change they seek to make.
- Building effective relationships built on trust, credibility and respect.
- Ability to successfully challenge, and to manage conflict and disagreement.
- Communicating effectively, particularly using the skills of dialogue (advocacy and inquiry) and coaching.
- Seeing the big picture, act strategically whilst paying attention to results and outcomes.
- Becoming a lifelong learner



Point 35: Work with others

You are not alone. Identify other organisations or partners who can help to identify opportunities for Patient Leaders or work with you to make patient leadership a reality. The people below might already be working with active citizens, some of whom may also be patients; they may be hosting innovative projects that could be adapted or built on; they might be a conduit to identifying Patient Leaders directly. Try the following:

- Local providers of health and social care
- Other statutory agencies, such as housing departments or the police
- Educational establishments
- Voluntary sector organisations
- Private sector organisations

See also section 5 that has more detail on this issue.



Point 36: Get help from internal colleagues

Work with communications colleagues in the organisation or across the locality to raise awareness of the work you are doing, or to call for nominations for Patient Leaders. Patient leadership is a new concept, so it is important that raising public awareness is accompanied by workshops or events where you can explain the concept. Piggy-back on existing service improvement initiatives or public health events in the community. A good relationship with the local media is important.

Try to spot inspiring examples of local people doing things because of their patient experiences. Invite them to events that you are holding to talk about what they are doing and how you can work together.



Point 37: Provide practical support

People need practical support to contribute to activities and to strategic decision-making. Many well-meaning initiatives that seek to involve people in strategic decision-making fail because people are not adequately supported on day to day tasks. Send out information in good time, make papers easy to read, don't stuff agendas full of jargon and acronyms.

You may want to get advice from Patient Leaders themselves about how to provide practical support and how to make their involvement easier. It is vital to provide administrative and logistical support to Patient Leaders - a single point of contact and ways of getting in touch with different key professional leaders with whom they are to work.



Point 38: Provide incentives

Be sure to value people, in part at least by providing reimbursement for their time and expertise. See, for example:

- [Department of Health: Reward and Recognition](#) - website
- [Department of Health: Reward and Recognition Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care - document](#)

For examples of a model payment and incentive policies, see:

- <http://www.invo.org.uk/posttypeorgpub/involve-policy-on-payments-and-expenses-for-members-of-the-public>
- Model of [Service Users and Carers Payment and Reimbursement Policy \(full document\)](#)
 - [Cover page and contents](#)
 - [Part One: Guidance for Employees and Provider Organisations](#)
 - [Part Two: Guidance for the Coordinator](#)
 - [Part Three: Guidance for the Service Users and Carers](#)
 - [Part Four: Templates and Payment Rate Tables](#)

But money isn't the only way to reward or incentivise people. It may be that training can be provided, or other mechanisms set up such as TimeBanks:

- [Timebanking UK](#)
- [TimeBank](#)



Point 39:

Provide Opportunities for Learning and development

Learning programmes for Patient Leaders are still in their infancy. The Centre for Patient Leadership provides bespoke learning and development opportunities, and there are other organisations that provide training for particular types of activities. See for example:

- [Altogetherbetter: Community Health Champions](#)
- [Turning Point: Community Commissioning](#)

As a general rule, for learning programmes to be useful, they should focus on the 'skills' of patient leadership (the attributes mentioned above) rather than overly focus on providing knowledge and understanding of the way the system works - this is because these process skills of patient leadership are themselves applicable in a variety of different contexts.

For a recent example of a programme that integrated the above principles, see [Patient Revolution Patient Leader programme for the Midlands and East SHA](#)

For further examples of patient leader programmes, see: <http://centreforpatientleadership.com/aboutus/ourclients/>



Point 40:

Keep it going

Keep the dialogue going and have deeper conversations. This is about sustaining and supporting rich conversations and building trusted and ongoing relationships. Think about setting up and developing a network of Patient Leaders. This can provide a community of practice for Patient Leaders for sharing of ideas and resources. It can also provide a pool of talent, from which an organisation can draw.

Instead of slotting people into fixed opportunities, there may be merit in providing learning and support to a broad pool of people, and working with them to create opportunities for their skills to manifest. Contact the Centre for Patient Leadership that hosts a Patient Leaders Network. Sustaining this sort of 'people bank' may allow for 'fresh blood' to emerge and different collaborative opportunities to come about.



Section 7: Case Studies



Our ambitions for the NHS in the Midlands and East



- Improve patient care, experience and safety
- Significantly improve quality and safety in primary care
- Create a revolution in patient and customer experience
- Make every patient, carer, family, community, partner and organisation responsible for their own health and wellbeing
- Ensure locally co-ordinated partnerships between the NHS and local government



Case Study: Sue Sibbald

My name is Sue Sibbald and I'm currently a self employed trainer and a bit of a social media geek. The area in which I work is Mental Health particularly around Borderline Personality Disorder (BPD) of which I have a diagnosis.

I currently carry out work for Sheffield Health and Social Care training staff in the Community Mental Health Teams and on the wards educating them about BPD and how they can help.

I also run education sessions for people with a diagnosis of BPD helping them to understand the diagnosis and giving some ideas around how to manage. At the minute I'm looking at setting up parent and carer education and support groups and DBT skills groups with my colleagues at the Trust. I'm also on the Personality Disorder strategy team for Sheffield Trust.

Something else that I do is on line peer support and last April set up BPDChat on Twitter with a friend, where people with a diagnosis of BPD come to chat around a topic every Sunday.

The reason I do all of this work is because when I got a diagnosis of BPD, I discovered there were no services and I felt really motivated and determined to try to set up something for people with BPD. I think anger at the lack of services was a motivational factor and I felt a need to do something to help, that included getting help for myself.

I think the key to managing to get where I am today was sheer bloody mindedness, and hard work and having the support of some key people within Sheffield Trust. Tim Kendall who is the Medical Director believes really strongly that people who use services should be involved at every level and be paid.

Also my psychologist colleague and I have worked really well together and learnt from each other along the way. A mutual sharing of knowledge which ultimately helps people with BPD.

I think the impact from me initially writing letters to then becoming involved has been quite substantial, I came with ideas and so much enthusiasm and things have changed for the better for people with BPD in Sheffield.

As for BPDChat it was a phenomena on Twitter when it launched it trended on the first one, a chat run by people with a DX of BPD who would have thought that possible. It has grown from strength to strength and is now co run by a few people, it's wonderful, watching people share and learn from one another.

I would say to anyone thinking that it's impossible to change things in your area, that's not true, I think as long as you remain positive, come with some ideas and not just negativity, then things can change for the better.

Sue

Case Study: Ellie Milner

I started off as a patient and was regularly admitted to Birmingham Children's Hospital. When I was 16 I was told about the Young Persons' Advisory Group, otherwise known as YPAG. YPAG appeared to be a great way of giving something back to the hospital and saying thank you. When I went to my first meeting it was so much more than I expected, not only did the group give something back to the hospital, we were also given so many different opportunities to get involved and make a difference.

Throughout my time as a YPAG member we took part in consultations, feedback sessions, interviews and so much more! As time went on I felt my confidence growing and that I was able to say my true opinions without being worried they would be laughed at. Each YPAG member respected the others opinions and the facilitators made sure that we all had an influence.

About two years ago the position of Chairperson came up and I decided that I might actually be a good chair! If I hadn't been part of this group and developed my communication skills I definitely wouldn't have applied for the role. To my surprise I was chosen as Chairperson and started choosing what was going on the agenda and what chair the meetings. Opportunities were coming in thick and fast, I was asked to speak at our AGM, sit on interview panels, sit on judging panels and represent the young people of Birmingham Children's Hospital.

In 2011 the Chairman of the trust came to our YPAG meeting and spoke to us about the role of Patient Governor, she went on to tell us how much she valued YPAG's input and opened up the application process to the members. I decided that I would definitely put myself forward for this role as I believed that it could help develop my skills further which I could then transfer between two roles. I was lucky enough to be voted into this role and now sit on the Council of Governors, representing the views of the patients. This is such an interesting role as I get exposure to all sorts of individuals and environments, the combination of both roles allow me to have a really good link between children and young people and the Council of Governors and Trust Board.

Having done these two roles for a significant period of time, I am now in the process of stepping down as Chair of YPAG and my term of office for Patient Governor is coming to an end. Although I am reluctant to let both of these roles go, I have now progressed further and through continuing to develop my interpersonal skills and taking up every opportunity thrown at me, I am now working on the Trust Bank as a Patient Experience Assistant. This position allows me to be a champion for Patient Experience and allows me to help others who were in a similar position as I was in a few years to flourish and progress, just as I did. I cannot be thankful enough for the doors that have been opened through patient experience. I truly believe that there is an opportunity to get patients involved everywhere and you never know what it will lead to!

Case Study: Amanda O'Connell

My name is Amanda O'Connell and I am a mental health patient. I live with clinical depression and borderline personality disorder. I also deliver mental health first aid training courses and do peer support work.

I have been unwell for a number of years. 2011 was my worst year. I spent most of 2011 severely suicidal. That year I attempted suicide a number of times. I had two short-stays in psychiatric hospital. I overdosed 9 times. I didn't think I would make it through. But I did. And I am still going strong. In late 2011 I also decided that somehow I was going to make some good come out of my mental illnesses. I didn't know how, or when, but I knew it would happen.

Just over a year ago I set up my first peer support group for those living with depression and anxiety. It has continued to flourish and has a number of people who attend each meeting. I have just set up my second support group, and hope to set up a network of peer support groups with time.

Shortly after setting up my first support group, I found out about the Scotland's Mental Health First Aid course. I did this course because I wanted to learn how best to help others. I was really inspired by the course and later trained as an instructor to deliver the course to others. Recently I left my full-time non mental health job, to set up a business in mental health. The main focus of my business is making Scotland's Mental Health First Aid as accessible as possible to the public, and increasing public awareness about the course. I have been setting up and running courses all over Scotland, many at evenings and weekends when there previously were few courses available.

I also do some peer support work for a mental health organisation. I don't want to be just involved in training. I know what a difference it makes to someone struggling to be able to connect with someone who understands what they are going through because they themselves have also been there. I want to continue to make that difference to people. I also do lots of other things in mental health – such as writing a mental health blog and running a weekly twitter chat for those with BPD.

Doing all I do, while living with my illness is hard. Most days my depression just makes me want to curl up in bed and never get up again. I stand up and deliver training courses on suicide wondering 'I wonder what these people would think if they knew quite how often I feel suicidal, how often those thoughts creep in'. I train about depression wondering 'what would they think if they knew how long it'd been since I last showered, how I've actually worn these clothes for the past few days, how difficult depression actually makes these things for the trainer standing in front of you?'

But I believe it is that lived reality that makes me really good at what I do. I'm not saying that you need to have experienced mental illness to make a difference in mental health, but it certainly does help.

The motivation I have to help others, to make a difference, is very strong. The urge to curl up and never get up again is also very strong. But as long as the motivation to make a difference is stronger than the need to curl up, then I'll do just fine. For any other patient thinking of doing anything along the lines of what I have done, my advice is simply to 'follow your heart'. That's all I have ever done and it has gotten me far.

And for organisations – see beyond the mental illness diagnosis. It does not need to make a person any less able. In fact, it can actually make them *more* able. Remember that.

Thanks for reading. I hope that my story gave you some insight ☺
Amanda O'Connell, March 2013 www.amandamhscot.com

Case Study: Anya de longh

I am 23 years old and live with a number of neurological long-term health conditions. Before my health deteriorated, I was a medical student, and it is suffice to say that my perspective on things has changed significantly! Having completed the first three and half years of medical school and amassing quite an collection of experiences as a patient, I want other people (namely healthcare professionals and students) to be able to learn and benefit from it.

There is so much about chronic illness that now I wish I knew when I was a medical student, and I want other medical students to learn about it. I have returned to my medical school and delivered lectures to the students on the patient perspective of disease and the later two components of the bio psychosocial model of disease (the emotions and social impact) which are so important but often neglected in the teaching. I have also given talks to other health and social care students as well as prospective students who want to apply to such courses.

We talk about co-production a lot with healthcare services, but the doctors, nurses, physiotherapists, occupational therapists and pharmacists that deliver those services are essential to the success of the services. If we want our services to developed in true co-production, shouldn't patients be involved in the development of the key asset to any service, the staff?

And if you can't teach an old dog new tricks, we need to be getting the puppies to be doing the rights tricks now, i.e. getting the future healthcare professionals to understand the patients' perspective and role from day one!

I initially approached my old medical school, but have been lucky to be given additional opportunity through the Expert Patient Programme (EPP) since qualifying as a Service User Mentor. Through that, I have spoken to a range of healthcare students from nurses to pharmacists. I am an accredited EPP tutor, delivering their self-management courses for people with long-term health conditions. I have also been involved in reviewing syllabuses for healthcare professional degree courses, to comment on the quality and quantity of patient involvement and perspective included.

The talks and workshops that I have delivered so far have been well received by the students, but also by staff who recognise the importance of the patients' perspective and content in relation to the students' development and learning.

I have received a lot of support from my old medical school and encouragement from those I have lectured, and other patient leaders who have been excellent role models and inspired me (and proved it is possible) to use my experience more widely. On a practical note, ToastMasters has proved very useful in helping me feel confident enough to stand up and speak about some quite personal experiences. The Expert Patient Programme supported me in providing training for the mentor role in their Service User Mentor scheme working with universities.

I still feel enormously privileged every time I have the opportunity to talk to our future doctors, but it has been a steep learning curve, and I am only just beginning my journey! It is a continual process to distil my experience into episodes that have the most relevance for my audience. Stories are great, and it is always the personal bits that people always remember, but the main points still need to be general enough to apply for most patients.

It is a real privilege and very exciting to have a role like this! For anyone else thinking about it, my advice would be to find good role models and make sure you don't lose your passion and belief as that is the most effective fuel! For organisations wanting to develop these people, value them as more than tokenistic patient perspectives but as equals, in every sense.