Patient Champion Report

“To be treated as you want to be treated”

Written by Ashley Brooks
NHS London Patient Champion

January 2011
Contents

• Acknowledgements
• Ashley Brooks
• Background
• My findings
• Recommendations
• The Patient Experience
• Summary
Acknowledgements

I would like to give my personal thanks and gratitude to NHS London for facilitating the Patient Champion pilot role. Without their foresight and willingness to embrace this Department of Health initiative, which had not previously existed, I would not have achieved any of my goals.

With careful expertise they have been instrumental in guiding and introducing me to a cross section of individuals and organisations which has lead me straight into the heart of the healthcare system in London.

With a view to use this report as one of their influencers for an ongoing Public and Patient Engagement (PPE) strategy they have shown that as a Strategic Health Authority they are committed to improving healthcare for all Londoners which is all the more challenging set against the difficult economic climate.

NHS London is working towards goal of “no decision about me without me” as set out in the Government’s White Paper. By working with patients as equals and as part of the “team” great insight and results can be delivered. Mutual respect is essential for this to succeed.

My hope is that the groundwork that has now been laid here in London by this pilot will be the foundations to a new locally lead, national if possible, Patient Champion Network. The legacy or reward for this work should be that patients are listened to as real stakeholders.

I would like to give thanks to Jackie Lynton from the Department of Health and to Stephen Webb Director of Communications at NHS London and to everyone I met who contributed their views and comments to my report.

Ashley Brooks

NHS London Patient Champion
Ashley Brooks

My role as the first National Patient Champion sponsored by the Department of Health began in May 2010. I was appointed Patient Champion following the recognition of my self-funded, self-motivated campaign to reduce MRSA and other infectious diseases within hospital settings and improve hygiene in general across the NHS, www.max4health.com. I became involved following treatment for leukaemia in 2001. My journey as a patient through the NHS had both highs and lows.

I consider myself extremely lucky to have my cancer treatment at St Bartholomew’s Hospital in central London as every part of my six month stay there was nothing less than world class. Everything about my care, the way my illness was dealt with and my ongoing treatment was surrounded in love, professionalism, compassion and dignity. However, once I left Bart’s and was transferred to my local hospital where I was being treated for pneumonia the experience was not the same. As a result of poor hygiene, I contracted MRSA. This near death experience terrified my family and changed my life (subsequently for the better).

This experience showed me that there are huge differences in the quality of care provision within the NHS, between different hospitals and sometimes between different wards within a hospital. This obvious inequality in the system puzzled and frustrated me. What I could not understand then and now is that if National Standards are in operation within the National Health Service why is it that the service being delivered differs so greatly. It motivated me personally to try to make a difference to change this. It was following this work that I was approached by Joan Saddler OBE from the Department of Health to pilot the first Patient Champion role.

This report logs my personal journey and I have included details of my findings and key recommendations with regards to an ongoing approach to PPE based on the views of patients, public and NHS staff.

Most, if not all, information given in this report has been expressed, published and catalogued many times before. What you will read is from an outsiders view point with a fresh set of eyes.

A prominent doctor asked this question of me “when was it that the patient became a burden to the NHS?” by changing this perception we open up the future of PPE in the NHS. I believe that with the proposed changes to the NHS within the White Paper: Liberating the NHS and the emergence of new organisations such as Healthwatch and GP Consortia.
Background

What is a Patient Champion?

The key reasons for piloting and the possible further development of the Patient Champion role was to build continuous and meaningful engagement with the public and patients and to help empower them to shape services and improve health by having firm responsibilities. The key elements of the role were:

- Prepare for significant change through a more local approach to public engagement by building on the impact and to address the challenging conditions facing the global economy and public services i.e. preparing the public early for change.
- Forge lasting partnerships and build on existing local public and patient engagement to improve quality and efficiency.
- Connecting to what matters to patients to improve self care and to improve the system of care.
- Search for the maximum possible opportunities for flexible local implementation.

The Patient Champion should aim to liaise and engage with as many patients, public and NHS staff as possible. To illustrate and discuss experiences of the NHS and help find areas of good practice and help reproduce those in other areas. This information should then be fed back to commissioners, GP consortia and Healthwatch to help them develop their approach to and knowledge of PPE.

Patient Champions should be able to have a frank conversation about patient care.

On agreeing to become the Patient Champion I asked for three things in return.

1. The Patient Champion must have a passion for the NHS and use this energy to channel news;
2. That the role of Patient Champion be independent to allow for me to make real recommendations and give thoughtful observations.
3. That I would be able to achieve something tangible. The role had to be able to make real change. Not just a simple tick box exercise or a token patient.
Why Now?

The White Paper, Liberating the NHS outlines how the NHS wishes to give the patient more say in their healthcare. This would allow patients more choice in where and when they receive their healthcare. The White Paper also outlines how data should be made freely available to patients to help them make these decisions.

In the new landscape the patient is put into the centre of their own healthcare experience. This transformation will take both time and effort to install. But above all, and a point that should not be underestimated, is that to make this happen, patients must be engaged and involved in every aspect of the new NHS on a continuous basis.

There are many patients groups, forums and charities some organised by the NHS and others which are independent. An issue these groups face is the opportunity to feedback and influence the NHS. The role of the Patient Champion is a unique way of helping these conversations to have a platform that currently is hard to find.

At all costs we must protect the advances that have been made in the NHS. That will be a difficult task in a new era of achieving more for less, managing a way forward without growth and not having an "oven ready" plan of action. It will take strong leadership, structures and a combined effort to make the NHS a world class organisation we can all be proud to be a part of.
My Findings

I have been overwhelmed by the vast number of people who are cared for by the NHS in London (which has a population of almost 8 million), and by the sheer complexity of the NHS and its never-ending layers. The White Paper: Liberating the NHS proposes massive changes to the structure of the NHS, and asks staff to deliver better care as well as putting patients in charge of their own health choices.

I have spent the last six months talking to NHS staff in London and it has become clear to me that some staff are anxious about the proposed changes ahead and the uncertainty surrounding the NHS. This huge issue must be rectified as a matter of urgency. If we don't address this problem of motivating staff, morale may become so low that it could affect the very service changes that are being introduced.

1. NHS Public and Patient Engagement in the NHS across London

The work carried out thus far by the NHS in the area of PPE is impressive. NHS staff are using the tools and resources available to them to forge relationships with patients, communities and the general public. This engagement promotes the local services available as well as creating a two way conversation to get feedback from patients on these local services. However, it does seem that while everyone is heading in the same direction there is not enough opportunity for people or organisations to talk, share and compare their work. It seems sporadic and disjointed.

Patients must be listened to more effectively and then this information needs to be captured, reviewed and then used to inform future strategy. This will take dedicated teams of staff to gather this intelligence. This intelligence then requires direction and action in a more coordinated manner.

NHS London should consider a strategy be put in place that highlights the need for a higher level of commitment to PPE over the transition period. They should then build on this commitment at a local level with both GP Consortia and Local Authorities to ensure that PPE does become a cornerstone of the NHS as set out in the Coalition’s White Paper.

Case Study One - NHS Lewisham

Not all sources of information come from the patients we serve but a great source of current information is that held by staff. You only have to ask and listen.

Lewisham PCT’s Yvette London has been working in Public and Patient Engagement for a number of years. Yvette is an inspiration to her staff and has been to me, due to the dedication she shows to the NHS and her strong work ethic. Her level of commitment to the role of PPE lead goes far beyond her formal duties and she shows a passion for engagement that is infectious. In her role she uses her experience and common sense, the knowledge of her staff, her insight into the local population, her vast contacts in local authority, the community and in Primary Care to align PPE in such a way that it flows through the veins of Lewisham culminating in a network that is wide spread and efficient. It has taken Yvette years of hard work and careful planning to reach such an effective level. To me this highlights the case for locally based PPE.
One particular issue that Yvette has to factor into delivering effective PPE in Lewisham (population 265,000) is that the people she serves have an average reading comprehension age of a primary school child. This is mirrored in many other parts of the country. This highlights that there are real issues around how you communicate the complexities of the NHS to someone with such a young level of reading comprehension.

It is important to understand that without making information available in a way that is easy to understand and communicates with the audience it is aimed at then we will fail to engage with people to improve the NHS. NHS Choices is good but is it aimed at primary school children?

We must remember that education breeds responsibility and the NHS Constitution calls for its patients to become responsible to the NHS – let’s educate through well thought out communication.

One of Yvette’s many achievements to date was her “Smile Dental Campaign” that aimed to increase the numbers of people visiting their NHS dentists and break down barriers and change attitudes towards dentists. Feedback gathered from local people was incorporated into the campaign which was so successful that NHS Lewisham’s dental access targets were achieved a year early.

Yvette also involved Lewisham patients in designing a very successful community anti-coagulation service, which involved moving patients out of hospital into a community based service.

2. PALS - Patient Advice and Liaison Service

PALS exist to help patients navigate their way through the NHS – a process which can feel quite overwhelming. Their role is to help patients resolve issues, advise patients about how they can get more involved in their healthcare as well as linking patients with agencies and support networks outside of the NHS.

One issue that is a concern is how little is known about the PALS service in the wider community. It is such a great resource for people to use but without knowing it is there to be used it does not make the most of its potential as a PPE tool. Therefore I would suggest that this service be explained more to patients on arrival into a health care setting with a community wide awareness campaign that advertises this service. I would also suggest that clear guidelines are given on the future role of PALS in light of the forthcoming changes.

3. LINKs

LINKs (Local Involvement Networks) were set up to work with the local authority and to act as a watchdog for local NHS care. They serve the public and are perfectly placed to challenge report and question local issues facing patients as well as providing patient feedback on local issues and service changes. LINKs also question how services are commissioned, giving power to local patients.

A LINKs group is only as good as the membership of their individual group, its leadership and management team. Naturally, there are some stronger LINKs teams than others. Pooling together ideas and learning how the more successful LINKs groups work and sharing good practice is crucial in establishing a successful Healthwatch.
The White Paper suggests that LINks are transferred into a new organisation called HealthWatch. My hope is that by establishing HealthWatch, all local groups will be able to have high quality leadership. This will enable them to be a local force for change. It is crucial that London groups work together and support each other in the future. I hope that HealthWatch will benefit from dedicated local teams to coordinate a marketing campaign, explaining what HealthWatch offers the local community. I believe that LINks have suffered from lack of investment from an awareness campaign. Almost everyone I have met either did not know of the LINKs organisation or what its purpose was.

Lessons can be learnt by some of London’s truly outstanding LINKs teams. For example and not in isolation, I attended the Richmond LINK to find an organisation which had great direction, leadership and motivation that involved the correct stimulus and drive. This created a forum that actively forced debate and change, the very point why LINKs were put in place. Bonnie Green and her colleagues have created a truly patient focused LINKS organisation.

4. Patient forums and groups (charities and third sector)

These groups are the backbone of public and patient NHS engagement. Without these organisations, patient pressure and feedback would not be as powerful. There are many organisations and they vary in size and scope. While acting on behalf of their members they highlight the inconsistencies in the way the NHS operates and serves patients. They also provide a valuable support network for patients as well as an opportunity for the NHS to gather feedback and help vulnerable individuals have their voices heard.

A point worth thinking on is that not all people are able to make their voice heard as individuals and they need a platform to express their views which is something that these organisations can support.

Again it is obvious that a patient forum or group is only as good as its membership and these vary from group to group. However I have witnessed many that are well managed, always have a good membership attendance and work in tandem with their GP surgery or healthcare partners. When this happens strong relationships are formed that culminate in a synergy that creates change. A concern is that funding will be withdrawn in the future for these forums or groups or at very least the importance of them will be overlooked.

Case Study Two - Karen

I attended a disability forum and was the guest speaker. At the end of my talk I asked the audience, “If you were in charge of the NHS for one day and you could change just one thing about the service you receive what would it be?”

A severely disabled girl tried to raise her hand to be heard. With difficulty she introduced herself as Karen, and in that one word a million were spoken. Her “wish” was that when she visited her hospital along with her mother or carer and was in the presence of her doctor that the doctor would talk to her directly and not to the person accompanying her. She explained that it was hugely frustrating and patronising and would normally reduce her to tears.
When she asked the doctor why he acted in this way, the doctor replied that he did not have the time to converse directly with Karen. This lack of sensitivity demonstrated by the doctor had a huge negative impact on Karen and her experience with the NHS.

In no way is this an isolated incident of the apparent lack of communication skills that are so important to a good patient experience. In the future, by taking time to talk to their patients all NHS staff could significantly improve patient experience.

The charity sector provides the NHS with support both nationally and in the local community, but often doesn’t receive credit for the work. I have been very impressed with all the charities I have met. A very good example is National Voices, a coalition of more than 200 health and social care organizations, who work together to provide a stronger voice for all those who come into contact with the NHS.

Jeremy Taylor, Chief Executive of National Voices, has set out a clear agenda entitled “Share the Power” that has many parallels with the White Paper Equity and Excellence. His vision is to include patients as the decision makers and leaders of the new era of NHS.

5. Public & Patient Advisory Group - PPAG

In response to the creation of Healthcare for London the PPAG group was set up as part of this strategy with elected members allowing patients across London to have a more powerful voice, to help create change and to highlight issues in their healthcare. A key strength is that it is expertly chaired by Rudi Page, an independent facilitator to keep the focus on what needs to be achieved. From the beginning the group has been responsible for many achievements across the NHS in London especially with the success of the Stroke & Major Trauma consultation showing that with a well thought out agenda and structure a patient body can be both respected and be used as an invaluable resource.

6. Public consultations

We have recently gone through a period of consultation for the NHS White Paper: Liberating the NHS. This engagement work has included both good examples and some bad practice. I have been involved in some areas of the consultation with members of the public and the third sector. These discussions produced some really good responses to what the White Paper is outlining. However, I was concerned that the consultation is only engaging with a small percentage of the population as it was only available online, in English and without a version with larger type for those with visual impairments. Also, the ‘easy read’ version was published many weeks after the main report, not giving some groups enough time to become informed or to be consulted with fully.

Case study four - Public Consultation

I was asked to speak at a LINK meeting along with NHS staff, local residents and the PCT Chief Executive. I was impressed by the way the meeting was conducted and the by the interaction with the audience.

The main topic of discussion was around a decision to move a service historically based within a hospital out into the community. The Chief Executive was there to discuss and defend the decision
for the move. The audience was made up of the patients, LINK members and some of the very people who would be directly affected by the change and primarily they were unhappy with the decision for two main reasons:

1. The department in the hospital had already been put on a six month notice of closure.

2. A large section of the audience felt the consultation had not been adequate and they had not had the opportunity to give their feedback. Others had not heard of the consultation.

During this meeting, the Chief Executive admitted that the PCT had not been good at this particular consultation in consulting the public. The Chief Executive committed to the group that lessons would be learnt from this for the future. He also added that dwelling further on the process would overwhelm the good work that was happening locally.

This is just one way that proves that the existence of LINKs is warranted and works as one positive experience is that it raised the issue of the importance of patient engagement with the Chief Executive who is now committed to learning from the experience in the future.

Public consultations need to open and transparent. In this case, the consultation only gathered opinions from small sections of the local population and the PCT missed the opportunity to gather feedback from local service users.

### 7. Those who we need to engage

As I begin to understand more about PPE and the NHS, it has become clear that at one end of the spectrum you have many focused individuals (both paid and unpaid) working with and on behalf of patients, patient groups and charities. We should all be hugely grateful to these people. At the other end of the spectrum are those who do not want to engage with the health service or help to make changes – they will not complain, praise or attend a public meeting. It’s within their nature to be this way and this is something we have to accept.

So the representation being offered and received at the moment is not a true representation of the entire population of London. There is a huge amount of our population “the middle” whom do not interact with the NHS.

I believe more can be done to engage with people who fall between these two groups. Many people don’t know that they can give feedback, how important their views are and that there are opportunities to join local patient groups. Meetings are often in the evening or during work hours that do not suit all people. Also it is possible that people who don’t feel very confident might not feel able to speak out in a local LINK meeting or patient forum especially if other members of the group are educated or particularly vocal.

This is where Healthwatch or the Patient Champion can have the greatest influence. By using these channels to broadcast information it would be possible to develop a relationship with the middle.

I would recommend implementing a campaign to inform and prompt this section of society to get involved. The key messages would be:

- That the NHS is there to help everyone
• That without public feedback service improvements cannot be made

• That “your voice counts” and that all or any comments are valuable to the transformation of the service. All feedback is good feedback.

• That we all own the NHS so why wouldn’t you want a say in “your” NHS

8. The Patient Champion

It is important that an open rapport is alive with all of the groups mentioned in this report. If the Patient Champion role is to exist at a local level it will enable the Patient Champion to engage and inform patients, helping us all to improve the quality of care delivered and overall patient experience within the NHS.

A pivotal part of the Patient Champion environment will be the sharing of such information, a gatekeeper for anyone to access. A person who listens to both sides of the story and uses information to translate messages and stories that can be used to influence change.

There is nothing quite like a personal story to translate a persons experience and perception of the NHS. Everyone at all levels and in all areas of the NHS should on an ongoing basis sit and listen to its “customer” and to keep reinforcing the importance of engagement to all NHS staff regardless of their role.

The following case study, if nothing else, highlights the need for a more “customer focused” lead NHS.

Case study Three - Annie

I met an elderly lady who was well into her late eighties named Annie. Annie mistrusted the modern world with its televisions, telephones, computers and even her burglar alarm. But Annie was amazingly coherent and informed. Her only means of communication was the radio and by post.

Annie had just had a spell in a large inner London hospital. She had a few comments about her care but one thing upset her (and me) more than any other. When in her hospital bed and due to her operation she had little or no movement. At meal times her meal would be put on a tray at the bottom of her bed. The meal after a time would be taken away untouched by Annie, by staff who presumed that she was not hungry. Unfortunately Annie was hungry but she just could not reach her food, she could not move so she just had to look at her meal instead of consuming it. Annie would be the first to admit that she should have said something or complained but like many elderly people she didn’t want to make a fuss.

I thought such an obvious, simple piece of communication or customer service would have been common sense. After all of the great care she did receive this experience tainted her perception. Her outcome was spoiled by the lack of putting the customer first.

What is even more concerning is how many other people are too afraid to speak up and make a fuss whilst under the care of the NHS. What else are we missing?
Recommendations to NHS London

1. Improving NHS Public and Patient Engagement

I believe PPE needs strong leadership to help bring PPE leads together. Engagement is now seen as an essential cornerstone of the future of the NHS. Local Authorities and especially GP Consortia will be tasked with building on the work carried out to date.

Patients must be listened to more effectively with their views captured, reviewed and used to inform future strategy. Gathering patients’ views will take dedicated and experienced teams who can ensure that is used to inform PPE in the future. This cannot be left to organisations that do not prioritise PPE.

NHS London needs to develop a strategy to highlight the need for more support for PPE over the transition period and beyond. The NHS needs to build on this commitment at a local level developing the skills of PLNs, GP consortia and local authorities to undertake PPE.

NHS London should continue to develop their involvement with the public and patients. At the moment, they do not talk to patients enough in London. I have been able to provide NHS London with feedback from patients in my role as Patient Champion but in the future and with the abolition of the Strategic Health Authority, more needs to be done.

Recommendations

• To decide how existing regional PPE work will translate into the future Commissioning Board and GP consortia. This should include a summary of previous work and lessons learned.

• To assemble a ready made panel of PPE experts from all the areas mentioned in this report. This expertise should be offered to the pathfinder GP consortia to enable PPE to be highlighted on the agenda from the very beginning. Other GP consortia would be able to learn from their colleagues and share best practice.

• To produce a suggested framework of PPE requirements and a “top ten” of patient engagement tips.

2. Information, communication and education

As a member of the public trying to understand the changes ahead in the NHS, I understand that we need to be well informed about our own healthcare and about how, where and when our healthcare takes place.

The Information Revolution, where healthcare associated information and data are now easily available online, goes some way towards helping share this information. However it is not a solution for everyone as it relies on patients being online. The detailed data is too complex for patients to analyse and relies on a third party to translate it into something which patients can use. At the moment NHS London has released data on maternity services, trust performance and Quality
Accounts. They are also publishing data on stroke, trauma, cardiovascular, cancer and aspects of mental health care.

If this Information Revolution is to continue then charities and patient groups need to translate this data for patients. NHS London should develop further partnerships to ensure this is the case and to allow patients to make those choices about how and where they are treated.

Communication should be the number one priority for the NHS. Without this none of the important changes being made to the NHS will effective. Communication should always be a two way process. Whatever channels are used to communicate, the message must always be clear and simple to understand. It is important that communications to the public do not contain jargon or NHS acronyms. Patient engagement should be linked with communications to ensure that these messages are delivered to patients clearly. Without good communication, we won’t be able to change the NHS.

It is my experience that many people are not informed about large areas of the NHS. We simply don’t know what our patients know about the NHS, and what their expectations are.

What is required is an ongoing, simple communications campaign for the public to use the NHS efficiently. We need to work in partnership with the NHS, GP consortia and local authorities to get the messages right. It could also be used to highlight PPE. It should be cost-effective and educational, and could ensure the public know how, where to have their say about the NHS.

Without immediate action we will miss the opportunity to get patients excited about the changes to the NHS.

**Recommendations for NHS London**

- To support GP consortia, especially the pathfinders, in communicating to patients. Particular attention should be given to suggesting how messages are relayed in an easy, uncomplicated manner.

- NHS London (and the wider NHS) should run a simple public communications campaign. It should include messages about the wider NHS, GPs and local authorities. A joined up approach would be cost-effective and it would ensure that the public know more about the NHS in general and know where and how to have their say about the NHS and use the system in a more cost effective way. This campaign could build on the Choose Well campaign which was run on a large scale across London last year.

- To reassure the public and patients that the changes to the NHS will not affect their healthcare provision and that services will remain as they are with further explanation if services are to change not leaving this to the PCT or Trust. NHS London should offer support in this area.

- All communications and message should be aimed at the level of comprehension that the audience understand and identifies with.
3. A cultural revolution

This initiative (currently in its early stage of development at Imperial) is solely focused on boosting staff morale. It will pinpoint what measures recommended from a cross section of NHS staff should be introduced to help motivate them on a daily basis to be more patient focused and attend to the customer care side of healthcare.

We must listen to the recommendations of staff and ensure the ideas and measures are realistic, achievable and sustainable. All staff need to be acknowledged for their role as individuals or as part of a team. In addition be involved in hearing the feedback not only from colleagues but also from the patients they care for they should also be involved directly in the feedback, good or bad. Staff must be empowered to take ownership for their work.

If we are to make these changes, organisational and financial, one of the area’s that requires most work alongside PPE is Staff Engagement, Enthusiasm and Motivation (SEEM), an immediate and continuous programme that promotes staff wellbeing. If we are to have happy patients we must have happy staff. This will take more thought and effort than is currently being invested. It will have to come from within and be pitched locally, a social movement, a Cultural Revolution.

The NHS has a steady stream of “patients” pouring through its doors on a daily basis. It has the infrastructure, buildings, equipment and research centres that in many respects are the envy of the world. However, these assets are worth nothing without the experience, dedication, cooperation and professionalism of the staff that work in and around them. Making staff the biggest asset the NHS holds. How many times have we heard the quote “staff are our biggest asset” but yet they often get the least attention. More importantly the experience these staff members hold is the real asset of the NHS, so why not acknowledge and cultivate it?

Motivation is the key to improving efficiency within the NHS to making the NHS work. Let’s put it at the top of the agenda. Without the dedicated staff the NHS would fail.

It will take great locally based leadership to create and sustain a happy, enthusiastic and motivated workforce and is not impossible to achieve. The right motivation to make it happen is the beginning.

**Recommendations to NHS London**

- To support the pilot of the Cultural Revolution and to supply resource as so it has the best possible chance to succeed.

- To assemble a panel of NHS staff from a cross section of area's. Porters, cleaners, clinical staff, office staff, senior management and the CEO. This would help gather information about how to motivate staff and what the priorities should be in that organisation.

- Based on this information build a SEEM strategy that would encompass the findings of the Cultural Revolution and staff panel feedback to enable a pan London movement.
The Patient Experience

The patient experience is such an important part of today's healthcare agenda that it sometimes can seem to be an impossible task to get right within the current culture. However the underlying message I have heard from patients in London is that it is possible, and in fact very simple. I have summarised below:

A - Easy and timely access to their local GP. Plus friendly and approachable staff in the surgery with booking of appointments made with less stress and fuss.

B - Patients should be cared for with dignity and respect in clean, safe environments.

C - Following treatment, patients should be consulted with every step of the way, educated and given the correct information and knowledge about where to access ongoing support. This echoes the White Paper sentiment of “no decision about me without me”.

This should be a set of standards defining how patients are to be treated and how healthcare is administered. But it seems that the NHS struggles at times to deliver this even though it is highlighted and defined within the NHS Constitution.
Summary

Taking into account that the future structure of the NHS is not yet fully formed or functional and allowing for the large number of NHS and social care organisations including: GP Consortia; HealthWatch; NICE; the Quality Care Commission; Health and Well Being Boards; the Department of Heath; NHS Commissioning Board; local authorities; Monitor; Foundation Trusts; PALS and the third sector to name but a few! I ask myself is there anymore room for another body or organisation? My answer is yes the Patient Champions Network.

At the moment none of these organisations focus entirely on PPE. It may be on their agenda or they might have powers to investigate but no one leads the way, uniting the patient voice. If we are to believe patients are to be treated as equals in regards to their healthcare decisions, then engagement and experience must play a major part. It is not justified that someone might carry the baton or implement a plan depending on whether they have the funding. The new legislation currently going through Parliament must allow for this.

What is needed is a Patient Champion Network (PCN) that builds on the work in this report. Patient Champions would get involved with the emerging organisations and infiltrate the new NHS system. This is the only way to mobilise a patient lead PPE agenda for the future NHS.

The creation of a new Patient Champion Network must recruit and consist of passionate, professional, elected, impartial, truly independent and focused individuals that have structure and purpose. Only then will the work that has been documented in this report and communicated in so many papers of late become a living entity. Is it too much to expect a member of a PCN to sit on the board?

This Patient Champion Network fits perfectly into the Big Society agenda and the Public Sector reform which is being carried out. It will empower communities at a local level allowing voices to be heard.

My personal experience of being a patient of the NHS and then of being a Patient Champion it only reconfirms all of my thoughts and passions about how the NHS can improve its service. Is it too late to introduce the Patient Champion organisation? No! It will never be too late.

Ashley Brooks

Patient Champion

For further information or to discuss this report in more detail please contact me at ashley@ashleybrooks.co.uk