The Listening Organisation
Ensuring care is person-centred in NHS Wales

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Foreword

Almost everybody working in healthcare agrees that there is room for improvement. But it can be hard to know how to improve and where to focus our efforts.

The things we find particularly problematic may not be the things that matter most to the people we care for. The ‘solutions’ we find may make life much easier for us, but are they helpful to patients?

Listening to the people we serve as a routine part of the delivery and planning of healthcare helps give us a balanced view. We can learn what it is like to live with an illness, experience the treatment and what it actually feels like to be a service user.

This white paper aims to encourage, support and challenge healthcare organisations in Wales to listen effectively to patients and achieve this ‘balanced view’.

Listening at Board level will help bridge the gap to the frontline and keep patients at the centre of decisions. At individual and clinical team level it will ensure that we focus on what patients want and experience when using services and receiving care.

In ‘Achieving Excellence - the Quality Delivery Plan for NHS Wales’, the Welsh Government has placed improving patient and user experience central to the day-to-day activities of NHS Wales organisations'. It commits to introducing ways of ensuring that feedback on patient and user experience is obtained and published. This white paper will support organisations to move from purely seeking feedback to really listening to and acting on both solicited and unsolicited feedback.

Ensuring that every NHS Wales organisation becomes a listening organisation is an ambitious aim. But it is achievable. It will help us to identify and eliminate weaknesses in what we do. It will identify the wasted time and effort that adds little or no value to the patient. It will enable us to channel our limited resources into areas where they will do most good and ensure that people get the best experience possible in NHS Wales.

It will also mean that NHS Wales is stronger, more informed, more resilient and sustainable as we work together to serve the people of Wales.

Maria Battle
Chair, Cardiff & Vale University Health Board

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The Listening Organisation

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Improving care, delivering quality
1000 Lives Plus is the national improvement programme supporting organisations and individuals to deliver the highest quality and safest healthcare for the people of Wales.
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Executive summary

The Welsh Government has placed improving patient and user experience at the heart of its plans for NHS Wales. There is a commitment that patients will be listened to and that feedback on patient and user experience will be obtained, published and acted upon by NHS Wales health boards and trusts.

Person-centred care leads to a good patient experience, yet organisations often struggle to consistently deliver it. The importance of listening in this context has been highlighted by the Francis Report which investigated the failings of care in the Mid Staffordshire NHS Foundation Trust. The testimony of patients and their families was widely ignored by an organisation unwilling and unable to listen. The Francis Report has raised questions of transparency, openness and integrity in the provision of care and is a wake up call to all NHS organisations to adopt a new mindset of listening to patients.

There is a growing emphasis on ‘co-production’, the partnership between providers and the public and the involvement of patients and citizens in the design and delivery of services. The recent proposed changes to NHS Wales offer a prime example of how re-engineering healthcare systems can be a collaborative effort between the people of Wales and the NHS.

NHS Wales is currently facing a number of different pressures including the need to reconfigure services, operate within budgets and continue to meet the rising needs of an ageing society, but ensuring the provision of safe, high quality and sustainable services are central to decision making at all times. Organisations also need to ensure that changes reflect the interests of patients and the experience that they have. Re-emphasising the importance of ‘listening’ is therefore vital in the current state of flux.

There are also long-standing professional cultural barriers. There may be a belief (from both clinicians and patients) that medicine is something that doctors ‘do’ to patients, something reinforced by traditional patterns of working. However, clinical expertise on a given disease or treatment is only half the picture. Listening to patients provides the balanced view - what it is like to live with the illness or experience the treatment. There is valuable learning for all clinicians from listening to patients. This helps to ensure a focus on the quality of the care experience and not solely the quality of the treatment or clinical outcome.

‘Listening’ must be a planned activity, built into the structures of NHS Wales organisations to ensure it happens. This white paper has been produced to help identify those places where listening skills need to be developed, and provides some high-level guidance on incorporating ‘listening’ as an organisation-wide discipline.

The Welsh Government’s Framework for Assuring Service User Experience identifies three domains of patient experience:

1. First and lasting impressions, including dignity and respect.
2. Receiving care in a safe, supportive, healing environment.
3. Understanding of and involvement in care.

This white paper uses these domains as a basis for exploring how Boards, senior managers, and all those working in NHS Wales can practically gather information from patients and use those insights to inform service planning and delivery and report back to their citizens.
The importance of listening to the people we care for

National and international healthcare organisations have championed, innovated and supported the drive to put the patient at the centre of care delivery\(^2\) and there is growing evidence that person-centred care will lead to a good patient experience\(^3\).

Previous 1000 Lives Plus white papers and the Francis Report into Mid Staffordshire NHS Foundation Trust have referenced the importance of placing patients at the centre of care:

“The central focus in healthcare must always be on the patient. One of the important determinants of quality is what the patient thinks. Do we account for what they want and expect? We need to develop a shared outcome to optimise what can be done for patients.”\(^4\)

The NHS and all who work in it: “must adopt and demonstrate a shared culture in which the patient is the priority in everything done.”\(^5\)

However, despite being seen as desirable, organisations face many obstacles on the path to becoming truly person-centred. For example, healthcare has often been driven by breakthroughs in clinical care, by political priorities and financial pressures, or by adherence to internal policies and protocols that may not be driven by the interests of the patient.

Ultimately, becoming a listening organisation will ensure healthcare remains focussed on the people being cared for. It will help staff see patients as people, first and foremost, and will lead to a healthier relationship between those who care and those being cared for.

In discussing the failure of care in Mid Staffordshire, Robert Francis QC himself stated that:

“(the Trust Board) did not listen sufficiently to its patients and staff... in part the consequence of allowing a focus on reaching national access targets, achieving financial balance... at the cost of delivering acceptable standards of care.”\(^6\)

In addition to external drivers, two early studies on the barriers to person-centred care, from a medical\(^7\) and a nursing\(^8\) perspective both highlighted the issue of time. From the medical perspective it was lack of time in a consultation and lack of continuity between consultations that was an issue. For nurses it was a lack of time to perform essential nursing tasks, such as addressing patients’ anxieties, fears and concerns and giving patients and relatives information. In this, there are echoes of what was revealed about Mid Staffordshire and nurse staffing levels.

But there are also professional cultural barriers that doctors and nurses may be unaware of. There is a common belief held by both clinicians and patients that medicine is something that doctors ‘do’ to patients. This may be reinforced by traditional patterns of working and the perceived imbalance of power - the patient waits to see the doctor, for example.

One problem with this approach is that whilst healthcare professionals are the experts on a given disease or treatment, the patient is the expert on how they are affected by a particular condition. They will live with it every day. They have to cope with the effects of both the problem and the possible further problems caused by the clinical ‘solution’.

It is also clear that clinicians and patients can both have fears and anxieties which can influence a consultation. Overcoming these fears is essential if patients are to feel more in control and act as partners in their care. For a patient these might include fears about their medical problem, their ability to say what they feel they need to and worries about ‘wasting time’. Clinicians may worry about missing something critical to the clinical outcome or management of the time of the appointment. These fears can have a negative impact on the patient experience.

Following Mid Staffordshire and other highly publicised incidents, confidence in the healthcare system has been shaken. People may no longer feel sure that decisions are made for clinical reasons. Instead, people suspect some decisions are made to reach financial or target-driven goals. Listening and talking to patients can help us to regain that trust and respect. Listening is therefore vital to fully understand what people actually need from their treatment and care.

Listening can also help identify problems and shape future delivery of care. This helps Boards to understand the impact of their decisions on patient experience and can provide assurance that patient experience is being determined and improved. At the frontline listening ensures that the most appropriate care is delivered in the best way for an individual patient.

Listening to patients and the wider public is also an essential component of co-production. This concept requires citizens to take part in the commissioning, design, delivery and evaluation of services so that public services are delivered “in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours.”

Co-production is based on the sharing of information and on shared decision making between service users and providers. Citizens and patients are seen as equal partners whose voice must be heard. The debate about how to deliver the cultural shift required to move from a provider-led model, where the patient has to ‘fit into’ the service structure, to one where the user has an equal voice is continuing.

Mechanisms for co-production have been successfully used to support people with long term health conditions, in clinical shared decision making and in experience led

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commissioning. Whilst this white paper will not explore the role of co-production in detail, the approach to listening described will be integral to the future application of co-production in NHS Wales.

**Who do we listen to and what do we listen for?**

Boards of healthcare organisations are provided with comprehensive data on finance and performance yet the provision of information on the patient experience and discussion of patient experience is often limited on the frontline and is still in its infancy at Board level\(^ {13}\).

In this white paper the term ‘patient experience’ is used to mean ‘what it feels like to be a patient receiving care or treatment from NHS Wales’. Patients are all the people who experience NHS Wales care and services. Alongside listening to patients, organisations also need to listen to families and carers.

NHS Wales needs to listen to the patient experience in an effective, ongoing way. A listening organisation also encourages their staff to engage with patients and others to hear their comments on the systems, procedures, treatments and care they experience\(^ {14}\).

The organisation also needs to listen to and value the views of their staff as there is much to be gained from the stories and experience of those working in the many healthcare systems that co-exist in NHS Wales. This is also true for those who work in partner organisations such as social services and the third sector. Organisations also need to demonstrate that they can identify and address any barriers to the delivery of person-centred care.

This white paper primarily concentrates on listening to patients, but the techniques and suggestions put forward can equally be used to listen and hear the views of staff.

There is already a significant amount of information in most NHS Wales organisations that describes aspects of the patient experience. This may include patient surveys, patient stories, compliments and thank you letters, concerns raised through the complaints and redress procedure, feedback from patient groups, reports against relevant Standards for Health Services in Wales, Fundamentals of Care audits, assessments against National Institute for Health and Clinical Excellence (NICE) patient experience guidelines and from risk assessments. In addition, patient safety incidents, claims and litigation, inquests and recommendations made as a result of them and Ombudsman reports all provide additional intelligence about the patient experience.

However, this information is located in multiple systems and is rarely collected and reported on together. It can be difficult for anyone - from frontline staff to members of Boards - to get an accurate view of what patients are experiencing on a day-to-day basis in the healthcare system. It can also be difficult to identify gaps in the information, with the result that the views and experiences in some services and from vulnerable and seldom heard groups may be missed.

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\(^{13}\) Research carried out for this white paper of agendas and papers of Welsh health boards in December 2012 - February 2013 suggests that the amount of information presented to Boards varies greatly between organisations, and there are no consistent methods for gathering or analysing data on patient experience.

Collecting as much material as possible and sifting it for common themes and threads can help build up a balanced picture. Patient stories, for example, have an added advantage in that they ‘humanise’ data – reminding everyone involved that behind the dry statistics are real, living, breathing people with hopes, dreams, fears and anxieties.

**Identifying what matters most to patients**

In order to listen effectively there is a need to know what you are listening for and it is helpful to understand the key issues that are of importance to patients when they are considering their experience of care.

The most comprehensive recent review on this subject in the UK is a project report called ‘What Matters to Patients’\(^ {15} \). It reviews the published evidence on what matters to patients and also contains primary research in the form of narrative interviews with patients and carers, surveys of patient and voluntary organisations and reviews of online postings from two national patient feedback websites.

‘What Matters to Patients’ concludes that there are a number of generic themes which correlate strongly with an overall rating of a ‘good’ patient experience and that, with the exception of a small number of condition specific themes, were consistent across all sectors and care settings.

Knowing the key themes enables construction of a framework to support organisations and individuals to fully focus on what matters to patients. Both the Institute of Medicine\(^ {16} \) and the Picker Institute\(^ {17} \) have drawn on the research in ‘What Matters to Patients’ to put forward frameworks that identify the key themes that patients value most.

The National Institute for Health and Clinical Excellence (NICE) further developed this and other work when it published its Clinical Guideline on patient experience in adult NHS Services\(^ {18} \). This provides clear guidance on the components of a good patient experience.

In Wales, the National Service User Experience Group has adopted a framework which describes patient experience in three domains\(^ {19} \). These three domains are consistent, and can be cross referenced with the themes identified by the Institute of Medicine, the Picker Institute, NICE guidelines and Robert and Cornwell’s work.

The domains are:

1. First and lasting impressions, including dignity and respect.
2. Receiving care in a safe, supportive, healing environment.
3. Understanding of and involvement in care.

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Mapping real experiences against the three domains identified by the National Service User Experience Group allows them to be used as a guide to what to look for and listen to when interacting with patients, carers and families. The knowledge can be used to construct effective questions for surveys and can also be used to stimulate thinking about the focus and content of improvement programmes.

However, it is important that organisations remain aware that even with the framework, it is likely that an individual’s experience may prove hard to classify. Organisations should avoid the temptation to rigidly classify patient experiences into set categories, and lose the depth of insight that an individual experience can bring.

Often, the messages are the same from whichever patient population we listen to. A 7 year-old boy who participated in a project at the Children’s Hospital of Wales commented:

“I want to be seen as a person not as an illness”

When asked to say what he wanted people to know about him a 10 year-old said:

“I would like the doctors to explain what they are going to do before they do anything to me.”
“I want people to listen to me.”
“I sometimes need a break between things being done to me.”

It reinforces the view that in many cases the fundamental things that influence experience for people, of all ages and types are similar and recognising them can allow us to develop strategies to improve experience.

First and lasting impressions, dignity and respect

Listening to patient experiences relating to first and lasting impressions can reveal areas where changes can be made that will matter to patients.

Poor standards of communication can cause patients to be apprehensive about a clinical encounter.

“The appointment letter doesn’t give you an awful lot on what to expect. I called up the day before to ask what was going to happen. I was totally in the dark.”

In contrast, clear communication to patients improves their experience and is valued.

In a patient group discussion, patients who had undergone colorectal surgery commented: “The information received prior to surgery was of a high standard, accurate and comprehensive and that they felt more prepared about the impending surgery and their recovery.”

The way people are welcomed sets the tone for a clinical encounter and this starts right at the reception and continues through the consultation. The contrast between welcomes profoundly affects how patients feel about staff and treatments they receive.

Commenting on an emergency unit: “I think the receptionist that I spoke to could have been a lot more approachable, friendly and helpful, especially considering I was a young woman in distress at the time. It made me feel uncomfortable from the off.”
From an outpatient clinic: “The reception staff are always friendly and welcoming and keep patients well informed of delays and waiting times. Although it didn’t apply to me it reassured me and reduced any additional stress I might have.”

Long waiting times for access contribute to a poor experience. Delays and lack of communication can also occur whilst patients are receiving care. These will impact on how patients feel about the service.

Comment about a rapid access clinic: “The system here is brilliant especially compared to my previous experience in 2002. This time I was seen first by a clinical nurse practitioner. Within 15 minutes I had a mammogram and within another half an hour I had the results given to me.”

Reflection on care from a medical ward: “On the Tuesday the cardiologist explained that Mum would need a pacemaker fitted. On Wednesday we were told that pacemakers were only fitted on Fridays and that the Friday list was full - Mum might have to wait until the following Friday. I expressed concern that a person of Mum’s age shouldn’t be kept on bed rest for 10 days, and that it would be dangerous for her to have to endure a pulse rate of 35 for that length of time.”

Dignity and respect are difficult to define as they often mean different things to different people. This underlines the importance of listening to learn from individual patients what it means to them. There are, however, some useful definitions that can be applied. For example, The Royal College of Nursing helpfully states:

“When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued, lacking control and comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed.”

Understanding the needs of individuals is important in ensuring they feel valued.

“In my practice the loudspeaker system is not easy for me to hear, especially when children are playing.”

An experience of care in a nursing home: “There was a particular problem at night because Mum needed frequent toilet visits. She also often became breathless at night and coped with this by sitting on the edge of her bed. This wasn’t dealt with kindly or with understanding. On the contrary she was made to feel like a troublemaker and we were told she was ‘misbehaving’ at night. On the day after a fall from bed I was told ‘she’d been naughty’.

“Her dignity and control were stripped from her and she was made to feel like an errant child - our mother was an intelligent lady who remained mentally alert throughout which made this even more demeaning and literally soul destroying.”

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It may also be the case that treatment or procedures that are very commonly used by staff are viewed very differently by patients. Procedures which are regarded as routine or simple to staff are often not to the patient - they can be very frightening.

Comment from a patient on a rehabilitation ward: “The hoist was so undignified; I felt like a baby in a romper suit. I still squirm when I see others in it.”

Receiving care in a safe supportive, healing environment

The environment patients are treated in is a crucial aspect of patient experience. It includes both physical comfort and emotional support - a person may be without pain, but experience considerable anxiety. A safe, supportive environment can also help a patient to feel comfortable enough to speak openly and share fears and concerns without feeling rushed or embarrassed.

Healthcare staff can become used to the conditions they work in and simply not ‘see’ clutter, broken fixtures and fittings and buildings in a state of disrepair, but to patients a poor quality environment can cause concern over the quality of the care they receive.

“Nothing could have prepared me for the environment. While on my back on a trolley I noticed there were ceiling tiles falling down. I wondered what my care would be like.”

“As I was being wheeled into the operating theatre and just falling off to sleep, I remember seeing the previous person being wheeled out and thinking, how could they possibly have cleaned that place adequately. I remember feeling helpless and terrified.”

Conversely, a better environment is reassuring to patients.

“I was apprehensive about going in as some people told me it was an old building and quite depressing. Imagine my surprise when I found light, clean corridors and a spacious, light, peaceful and clean ward.”

The Transforming Care and Transforming Theatres programmes in NHS Wales tackle the issue of clutter and disorganised wards and clinical areas. ‘Before and after’ photos published on the 1000 Lives Plus website illustrate the issue 21.

The quality of food in hospitals is significant in aiding patient recovery. There are considerable logistical issues in ensuring the best and most appropriate food is provided to all the patients in a hospital, but the comments of patients indicate that it makes a huge difference to their experience.

“The food was the worst I have ever tried, stone cold and stodgy. Cooked dinners and fish and chips and lasagne were nice but the pie and macaroni cheese was not nice at all.”

“There often wasn’t a healthy option on the menu. Hospitals should practise what they preach. How can you educate people about healthy eating if hospitals serve up unhealthy food?”

The timing of meals and treatments plays a major role in ensuring the experience of patients is positive.

“The physiotherapy staff administer percussive physiotherapy and other chest drainage techniques twice a day. Often this can come soon after a meal has been served. It is tiring, uncomfortable and not the best way to let a meal go down. Sometimes I chose between food and physiotherapy treatment.”

“The drugs round was done after breakfast so my mother was unable to take her Alendronic acid which needs to be taken before food. When she refused to take it after food the nurse wrote on her notes ‘patient refused medication’. My mother asked her to change this as she wasn’t refusing, just informing the nurse that it was important to take this drug on an empty stomach. No attempt was made to change the timing of this.”

It is reasonable for a patient to expect to be protected from infections. Patients are increasingly aware of infection control issues due to media coverage of MRSA and C. difficile infections. If patients feel there is a risk of infection, they will feel worried and question the quality of the care they receive.

“The toilet on the ward was used by all patients, including those with very loose bowels and sometimes it was a real mess. Antiseptic hand wash had been fixed so high on the wall that many of the patients couldn’t reach it.”

Not being too hot or cold, having support for eating, drinking and going to the toilet, and the ability to get help when needed are crucial and are well recognised determinants of patient experience.

“It was a cold day and when I was taken home there was no blanket to cover me.”

“The hand controls for the electrically operated bed were broken for the whole time despite several requests from us and the consultant to get them fixed. This meant that every time she needed to change position to sit more upright she needed to ring for a nurse. The bell was often out of reach or left unanswered for long periods.”

Patient experience is profoundly affected by pain. Being able to tailor pain relief to the needs of the individual should be a priority to clinical teams.

“She wasn’t able to tolerate many drugs and normally managed her pain at home with a heat pack. We were told this option wasn’t available in hospital because of the potential risk of cross infection if we used the microwave to warm the pack. We asked if the physiotherapists could provide a heat pad but this wasn’t possible either. Consequently she was put on Tramadol to which she reacted badly.”

“Ward seating wasn’t suitable for ‘little old ladies with osteoporosis’. She had no support and we would often find her curled up on the edge of her chair in pain. A simple bean bag insert would have solved this problem.”
Understanding of and involvement in care

Patients often feel considerable fear if they do not know what is happening or do not know what to expect. This has a deeply negative impact on a patient’s experience of care. The aim should be to ensure that patients are supported to make decisions about their care and treatment and to manage their own health and healthcare. Patients also need appropriate information, in a way they can understand, about all aspects of care and interventions.

“Having been reassured it was a simple procedure her fears grew as the time ticked by. It took twice as long as originally expected and she naturally assumed things were going wrong. No explanation was given [for the additional time needed].”

Comment from a day clinic: “It’s a lot to take on board straight away when you are in shock and support of the nurses is essential.”

Patients often want to know what is happening, and importantly what might not happen, for example if a scan or test has been cancelled. It is important to consider what information a patient would find valuable.

Comment on a surgical ward: “I was waiting for a scan which never happened which increased my anxiety level, all I wanted was to know if it was going to happen or not…”

Patients also value being involved in decisions about choice of treatment options and care plans. There is a strong evidence base to support the use of shared decision making. Patients involved in shared decision making had increased knowledge, more accurate risk perceptions, reduced internal conflict about decisions and a greater likelihood of receiving care aligned with their values. It also ensures clinicians feel confident that the care they prescribe is the best for the patient.

Patients appreciate the involvement.

“I was really chuffed to have choices and options discussed. It felt like I had made the right decision.”

Families and carers also have a significant role to play in ensuring patients receive the best care possible. Patients may express different wishes to families and carers than to clinicians and therefore should be included in care.

Comment from a rehabilitation hospital: “I am able to be completely involved with the care of my son. I was able to feed him; wash his hair and not made to feel I was in the way.”

Comment from an emergency unit: “There was a lack of information given to friends and relatives and no advice given on discharge of what to look out for if symptoms worsened. There was also a lack of information on blood tests and what to expect.”

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22 Lee, EO. & Emanuel, EJ (2013). Shared Decision Making to Improve Care and Reduce Costs The New England Journal of Medicine 368;1
Acting on what we hear...

There are three levels at which it is vital to keep listening to our patients:

- At the frontline among clinical teams directly working with patients.
- At department or ‘middle management’ level to listen to what is happening on the frontline in a range of services.
- At Board level to get a whole system picture, to gain assurance and ensure departments are working together to provide one, fluid, excellent patient experience.

At the frontline

Staff at the frontline who deliver clinical care and support services hear patients every day. This should lead directly to the improvement of patient experience on a true real time basis. At this level, listening fundamentally relates to identifying and meeting the needs of individual patients.

Intentional rounding is a system approach to ensuring that a patient’s needs are listened to, identified and met. Experience in the USA and the UK has shown that rounds are associated with significant increases in patient satisfaction and with equally significant reductions in the use of call bells and in the frequency of falls, pressure ulcers and complaints.

Patient and family shadowing is another approach which uses direct, real time observation of patients and families as they move through the healthcare system. The principle is to allow sight of what really happens through the eyes of the patient and their family. Those who have used it report that it opens their eyes to the impact of the whole care experience on patients and creates an urgency to drive improvements.

Medical and nursing students in Cardiff have tested an approach where they have been asking patients after they have had a teaching or learning encounter with them “If there was one thing I could do to improve your stay here today, what would it be?” The responses give a snapshot of what patients think would improve their stay in hospital.

The majority of requests made are for the most basic of care needs such as “Please can I have a drink of water?” They correlate well with the three domains of patient experience, further reinforcing what contributes to a positive experience for patients. This approach could be further developed and used by all frontline staff.

1000 Lives Plus has championed the use of patient stories and recommends the inclusion of frontline staff in the collection and analysis of material relating to patient experience. The experience of clinical teams highlights the need for frontline staff to be involved in collecting patient stories, and show the energy patient stories can give to improvement efforts.

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24 Patient and Family Centred Care (PFCC) Patient Shadowing http://www.pfcc.org/go-shadow/


Patient-centred care means organising healthcare around the needs of the patient. This includes ensuring that the behaviours and the processes that we put patients through are patient focused. An understanding of patient-centred care is important for all, as is the way in which improvement methodologies can be used to deliver improvements. In Wales, this is being introduced to all staff through the Improving Quality Together framework.

There is also a strong link between staff welfare and morale and patient experience. To ensure that listening takes place on the frontline, managers and leaders also need to be aware of issues related to staff working conditions. Bullying, harassment and abusive management can lead to a high turnover of staff and closely aligns with poor patient experience.

At department or ‘middle management’ level
At this level in an organisation an ongoing flow of information and discussion about the patient experience is needed. The will ensure that frontline listening (wards, clinics, community services or in a general practice) is actively heard by those who can influence the resources, systems and processes that have a significant impact on patient experience and who can stimulate and deliver system wide change in response to concerns.

In order to ensure that improvements are put in place, the management team also need to provide an environment where patient-centred care is the standard and in which the Improving Quality Together framework can be implemented and sustained. This will ensure that all teams are equipped to introduce improvements as a result of what they have learned from listening to patients.

At Board level
There is guidance available for Boards to ensure they know what patients experience in their organisation. There are a number of ways to build up a picture of what it feels like to be a patient and Board members should ask themselves whether the picture of care that they see in reports actually correlates with what they hear from patients and relatives.

To listen to patients effectively, Boards can do the following:

- Agree a cycle of regular and periodic reports (such as Fundamentals of Care audits and assessments against Standards for Health Services in Wales).
- Invite patients, relatives and carers to present their experiences to the Board.
- Ensure patient experience forms an integral component of quality reports and discussions.
- Give close attention to staff feedback.
- Be transparent about patient feedback and publish analysis of both positive and negative feedback.
- Ask how patients’ experiences have shaped decisions.
- See if there are some services which never feature in reports.
- Ensure that decisions made are influenced by knowledge of patient and service user’s experience.

28 For more information see the Improving Quality Together website: www.iqt.wales.nhs.uk/home
31 1000 Lives Plus (2012) Patient and Person Driven Care Case Study - No. 3. Face to face storytelling at a Board meeting. Cardiff: 1000 Lives Plus
Always include patient experience as one of the outcome measures to assess the impact of any changes in service provision.

**Gathering feedback**

There are many methods which can be used to gain intelligence about patient experience. Intelligence can be gathered specifically to assess patient experience or as discussed earlier, can come from other sources.

The National Service User Experience Group has identified a framework which balances real time, retrospective, proactive and balancing information. The intention is that organisations should never rely on one source or type of information to listen to patients but should use a variety of methods to achieve triangulation.

It is essential that organisations design their feedback strategies to ensure that all their service users and patients can be included. This will include those with communication difficulties, those with sensory impairment and those without English as a first language. The requirements of the Welsh Language Act, for Welsh organisations, and the 2010 Equality Act, for all UK organisations, will also need to be met.

It is also important to ensure that appropriate methods are used to obtain feedback from all clinical settings, hospital and community.

There also needs to be staff skilled and trained in the methodologies, including survey and questionnaire designs, data analysis and presentation and patient story taking.

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<td><strong>Short surveys</strong> used to obtain views on key patient experience indicators whilst patients, carers and service users are in our care.</td>
<td><strong>Postal surveys</strong> used after discharge or any clinical encounter in any setting to gain in depth feedback of service user experience. They can also incorporate outcomes measures such as the EQ-5D health questionnaire.</td>
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<td><strong>Patient stories</strong> provide rich detail. <strong>Patient groups</strong> can provide advice on service delivery and developments. <strong>Third party surveys</strong> by external agencies such as Community Health Councils, voluntary organisations, etc.</td>
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</tbody>
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There have been several studies outlining the benefits and potential uses of the different methods that can be used to obtain patient feedback. In marketing, it is recognised

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32 See [www.euroqol.org](http://www.euroqol.org)

33 Robert G and Cornwell J (2011)


that feedback is usually either extremely positive or quite negative and rarely in-between. Yet the ‘silent majority’ will have much potentially useful experience that can be used to assess how well the system copes with demand, how well dignity is protected and how effective the treatment process is.

Identifying the ‘minor’ issues that would rarely be considered important enough to complain about, may help spot wastage like delays and inefficiencies. Similarly, talking to satisfied customers can help organisations identify what ‘little things’ make a patient’s journey through the system flow more smoothly.

Healthcare organisations are advised to make use of as many different avenues to gather information as possible. These include:

- **Surveys** - with a combination of questions and space for narrative feedback. There are several types of survey:
  - Real time short surveys collect views whilst patients, carers and service users are still receiving treatment.
  - Retrospective surveys seek in-depth feedback of service user experience.
  - Online surveys can be permanently hosted on organisation’s websites.
  - Commissioned surveys can address areas of interest and importance, sometimes in collaboration with other stakeholders.
- **Social media** - using emerging tracking metrics to collect ‘mentions’ (available from commercial media tracking services, for example).
- **Rating websites**, e.g. Patient Opinion and iWantGreatCare36.
- **Patient stories**37 - these can be used to significantly improve care for an individual, and also be used to highlight general areas of concern, examples of good practice and should be at the heart of any ‘listening organisation’.
- **Patient groups** - there is advice available on how to establish and run groups, which, although aimed initially at primary care, can be applied in other settings38.
- **Partner organisations** - several agencies, including Community Health Councils, may survey patients, carers and families about the services they receive. These survey results can be very useful as people may be more willing to talk openly about their experience and feelings to a ‘neutral’ third party.
- **Voluntary organisations** can collate and share feedback from the people that they work with and support.
- **Informal feedback** - talking to patients, families and carers about their experiences39.
- The “mystery shopper” approach has been used in some settings40.

Other sources include:

- Standards for Health Services in Wales, NICE patient experience guidelines, Fundamentals of Care audits.
- Transforming Care and other improvement initiatives.
- Concerns, complaints and compliments.
- Risk assessments, incidents, inquests, claims and litigation.

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36 See [www.patientopinion.org.uk](http://www.patientopinion.org.uk) and [www.iwantgreatcare.org](http://www.iwantgreatcare.org)
Creating a patient experience report for Boards

Some NHS Wales organisations currently have a patient experience report at their meetings and reports vary widely in their content, depth and presentation, as is also the case in NHS England. A small number of English organisations present their feedback in a way that is aimed specifically at the general population.

Given the range of sources from which patient feedback can be obtained, compiling and summarising patient experience data which may be in a variety of forms and from a diverse range of services into a comprehensive and comprehensible report can be challenging. Some information may be available real time and some may be produced on a monthly or quarterly basis, six monthly or annually.

A good starting point is for Boards to map their feedback from all sources against the three domains in the National Service User Experience Framework and to be clear about their improvement priorities. Information aligned to the three domains can be used to provide a triangulated assessment.

Organisations should be explicit in their operational and quality delivery plans about what aspects and parameters of patient experience they wish to monitor on a regular basis. They should agree a programme of gaining regular feedback against each theme, in a way which meets the needs of the individual service and organisation, and their objectives for improvement.

An organisational feedback strategy, structure and report should be built up in such a way that the same data collected at the frontline can be used at multiple levels, aggregated as appropriate. Feedback could be collected at team or individual clinician level and shared quickly; it could be aggregated at directorate, divisional and locality level monthly and aggregated to organisation-level to fit with the schedule for Board meetings.

In addition to the routine reporting through real time data, Boards should be specific about other areas that they wish to see reports on over a given period. In some cases this will be department based, such as the Emergency Unit or clinical service based, such as diabetes, or focused on specific groups, such as carers. In these cases more in-depth feedback should be given incorporating methods from two or more quadrants in the National Service User Group feedback framework.

In all cases Boards should expect to see an assessment of the data and plans for improvement which can be monitored through subsequent reports. In addition, feedback which is obtained as part of national standards, NICE guidelines etc. could be presented in line with their own reporting schedules.

Boards should also develop an effective way of sharing patient feedback and actions taken as a result directly with the public.
Feeding back and using the information

If patients are being encouraged to give their feedback to organisations it is important that there are effective methods in place to report back outcomes in a meaningful way. The design and routes by which this is done requires careful consideration.

Some key points to be considered include:

- Ensure transparency and candour, telling the good as well as the critical.
- Use multiple communication methods including social media.
- Avoid using healthcare and management jargon.
- Share the information received (You said), what we understood (We heard) and what the outcome was (We did).
- Illustrate the results using ‘infographics’ to communicate data in a visual way.
- Explain clearly what was done as a result of the feedback or explaining why not, or when it will be done.
- Demonstrate behaviours at all levels which correlate with the feedback received.
- Use run charts and data over time to clearly demonstrate improvements.
- Take steps to ensure that policy and strategy is adequately informed by patient and service user experience.
- Publish local data as close to care delivery as possible and develop ‘Patient Experience Zones’ - specific places where patient feedback is displayed and opportunities given to provide further feedback.

Delivering care centred on people

Patient feedback can be gathered and used to enable NHS Wales organisations to become person-centred. This can be at an individual patient level, to improve their care and outcomes, at an individual and frontline level to improve the patient experience and by the direct involvement of patients in improvement programmes (co-production) to ensure they are person-centred.

At an individual level

Listening to an individual’s story can help to fine tune treatments to increase the likelihood of longer-term success for an individual. It is not sufficient to treat symptoms alone. This is particularly important for long-term medical conditions. We are more likely to achieve longer-term success if symptoms are considered within the context of that person’s whole life - the whole person. We can only do this by listening to the patient.

Even if we listen successfully to patients, patients themselves need the confidence, skills and knowledge to participate effectively. Self-management programmes such as those developed through The Health Foundation’s Co-creating Health patient skills programme\(^{41}\) and the Education Programmes for Patients (EPP Cymru)\(^ {42}\) can provide this support.

Common themes from patient accounts suggest several issues contribute significantly to wellbeing and are closely intertwined with medical symptoms and how a patient responds to treatment. These issues include:


\(^{42}\) See [www.wales.nhs.uk/expertpatient](http://www.wales.nhs.uk/expertpatient)
Social isolation and loneliness.
Stress and negative emotions such as worry or fear.
Low self-esteem, poor self-confidence and feelings of worthlessness.
Loss of identity and identity issues.

Healthcare organisations therefore need to take these issues into account and tailor and individualise treatments for patients, to maximise treatment benefits. The most effective way to account for these issues is through hearing and acting on the patient’s story.

The Picker Institute has developed a principle called ‘Always Events’ which will ensure that the right things are always done every time to improve the patient experience. Always Events are defined as “those aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the delivery system.”

Without being prescriptive about the exact methodology, the aim is to encourage organisations to work with their patients to identify their key Always Events and explore ways of embedding them in clinical and organisational practice.

Through co-production

Directly involving patients in improvement work can be challenging, however the MAGIC (MAking Good decisions In Collaboration) programme on shared decision making in Cardiff and Vale University Health Board is attempting to do this and can serve as an example of good practice.

Despite the evidence base, shared decision making still isn’t widespread in clinical practice. One way to overcome this is to ensure that implementation programmes draw on patient experience. In the MAGIC programme patients are being involved at three levels:

- In the design of the overall programme as key members of the steering group.
- In design of interventions at clinical team level - advising on materials, approaches and supporting training.
- In the promotion of shared decision making - by supporting patients in clinical settings and encouraging patient involvement in general.

The principles could be applied in other programmes and the outcomes in the MAGIC programme will be reported at the end of the programme in early 2014.

The Health Foundation’s Co-creating Health programme approached the challenge of engaging patients in improvement by using lay tutors alongside clinician tutors to deliver training programmes for patients and clinicians.

Although these are new ways of working, it appears that actively listening to patients and taking the lead from them in setting clinical priorities has an impact on the effectiveness of treatment. These methods appear to indicate that listening to patients has a direct outcome of better, more holistic care that meets patients’ needs.

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43 Picker Institute, Always Events http://alwaysevents.pickerinstitute.org/
44 More information about the MAGIC programme in Cardiff and Vale University Health Board 2010 - 2013 is available at http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/
Conclusion

A central tenet of this white paper is that organisations exhibiting a genuine willingness to listen will be in a position to provide better care to their patients and will identify ways to improve more quickly.

Listening needs to take place at all levels of an organisation - from the Board responsible for the overall strategic direction of the organisation, through to the frontline where care actually takes place. Listening to patients as individuals will help staff treat patients as individuals, thereby maximising the impact of treatment and resulting in better outcomes for patients in terms of recovery, condition management and improved health.

There are various methods and mechanisms that healthcare organisations can use to become ‘listening organisations’. All these methods can prove useful - what is important is that organisations are using at least one method. It is very likely that a blend of approaches would be the most useful and provide a more rounded picture of patient experience.

The sooner these proven methods of listening are adopted and become normal practice in NHS Wales, the sooner the benefits will be felt by both the people of Wales and the people who care for them.
Appendix - Questions to ask in ‘real time’
The National Service User Engagement Group is currently testing a small range of questions that could be used on a real time basis nationally and which are aimed at the key domains of patient experience.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Covers (examples only)</th>
<th>Draft National Service User Experience Group Core Questions</th>
</tr>
</thead>
</table>
| First and lasting impressions              | Being welcomed in an appropriate manner. Being able to access services in a timely way. Being treated with dignity recognising individual and cultural differences. Ongoing support and monitoring of long term conditions. Good co-ordination of care. | • Do you feel that people were polite to you?  
• Do you feel that you were listened to?  
• Do you feel you were given all the information you needed?  
• Do you feel you were given enough privacy?  
• From the time you realised you needed to use this service, how long did you have to wait?  
• Were you given support you needed to help with communication needs? |
| Receive care in a Safe, Supportive, Healing Environment | Receiving care in a clean, clutter free environment. Receiving good, nutritious, appropriate food. Having rigorous infection control practices in place. Being free from pain, being warm enough and receiving prompt assistance. Being helped to the toilet when needed. Having drinks when wanted and needed. | • If you asked for assistance, did you get it?  
• If you asked for assistance did you get it when you needed it?  
• Did you see staff clean their hands before they cared for you?  
• Did you feel that everything you needed for your care was available?  
• How clean was the place where you received your care? |
| Understanding and Involvement in Care       | Receiving appropriate, timely information. communicated with in an appropriate, timely manner. Being involved in decisions about choice of treatment options. Being involved in decisions about care plans, including discharge. Recognising the knowledge and support of carers and families. | • Were things explained to you in a way that you could understand?  
• Did you feel you understood what is happening in your care and treatment?  
• Did we meet your individual needs?  
• Were you involved as much as you wanted to be in decisions about your care and treatment? |
Further white papers available from 1000 Lives Plus include:

1. **Accelerating best practice: Minimising waste, harm and variation**
   Addresses the questions: “If quality and patient safety are the priorities in an organisation, what would this look like?” and “How do we embed improvement in healthcare services?” Includes input from Professor Don Berwick, Sir Ian Carruthers and Gerry Marr.

2. **1000 Lives Plus and the NHS Agenda - Lessons from Systems Thinking**
   An introduction to Systems Thinking from Professor John Seddon, author of ‘Systems Thinking in the Public Sector’.

3. **Are Bevan’s principles still applicable in the NHS?**
   A study of the NHS in Scotland, England and Wales looking at how well each service reflects the ideals of the founder of the NHS, Aneurin Bevan

4. **Quality, Development and Leadership - Lessons to learn from Jönköping**
   An introduction to the approach of delivering health services by Jönköping County Council in Sweden, and what can be learnt and applied to Welsh healthcare.

5. **Is healthcare getting safer?**
   What has been the result of over a decade of national and international work to improve safety in healthcare? Professor Charles Vincent attempts to answer this crucial question.

6. **Attaining Peak Performance**
   Canadian and NASA astronaut Dr Dave Williams addresses issues of working safely and effectively in high-risk operational environments, including a look at achieving excellent team and personal performance.

7. **Person Driven Care**
   A study of the Esther Network in Jönköping, Sweden, which is an acknowledged world-leader in focussing on the needs of patients and involving the public in planning healthcare services.

8. **Improving Quality Reduces Costs - Quality as the Business Strategy**
   Examining the close relationship between high quality care and the efficient use of financial resources, and how genuine partnership working between clinicians and finance managers can enable transformational change, better patient experience and optimal clinical outcomes.

9. **Achieving High Reliability in NHS Wales**
   Drawing on technical theory and practical work from the NHS and other industries subject to catastrophic consequences when things go wrong, this white paper explores applying the concepts of ‘high reliability’ to make NHS Wales a better and safer place to both work and be a patient in.

10. **Providing Assurance, Delivering Improvement**
    Gathering together learning from the use of mortality and harm reviews in NHS Wales, this paper highlights methods of using mortality reviews to assess the quality of services and identify priorities for NHS Wales organisations.

These papers are all available at [www.1000livesplus.wales.nhs.uk/publications](http://www.1000livesplus.wales.nhs.uk/publications)
About the author

Allison Williams was born and brought up in Swansea and graduated with a BSc (Hons) Nursing in London in 1989. Her early clinical career in women’s health led her to take up a lecturing post in Southampton University from where she returned to Wales in the early 1990s as a Genetic Counsellor.

She combined her clinical practice and lecturing activities with an expanding general management portfolio before deciding to step into a full-time management career in 1995.

Her career includes director and chief executive roles in NHS Wales and working in the Strategy Unit of the Welsh Government’s Department of Health and Social Services.

Allison has led a number of clinical change programmes at organisational, regional and national level, and has played a key part in developing national strategy for NHS Wales. In 2011, Allison became Chief Executive of Cwm Taf Health Board. She is passionate about high quality patient care, clinical leadership and empowering staff.