

One simple thing: Communication in the NHS in Wales

January 2019



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Introduction

This report has been produced by the Board of Community Health Councils on behalf of the 7 Community Health Councils (CHCs) in Wales.

CHCs are the independent watch-dog of NHS services within Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

CHCs seek to work with the NHS and inspection and regulatory bodies to provide the crucial link between those who plan and deliver the National Health Service in Wales, those who inspect and regulate it, and those who use it.

CHCs maintain a continuous dialogue with the public through a wide range of community networks, direct contact with patients, families and carers through our Enquiries Service, Complaints Advocacy Service, visiting activities and through public and Patient surveys. Each of the 7 CHCs in Wales represents the "Patient voice" within their respective geographical areas.

What we asked

We know from our independent complaints advocacy service that poor communication is often a factor when people have concerns about the NHS. It can increase the risk of potential harm from misunderstandings, lead to a lack of confidence on the part of patients and waste valuable NHS resources.

We know from our engagement across Wales that people can also be confused and frustrated when trying to access information about their health or treatment.

CHCs believe that the drive for better communication between patients and the NHS needs a reboot.

We asked people across Wales to tell us about their experience of NHS communication good and bad and to give us their suggestions for how it might improve. By its nature, this report focuses on what needs to get better. This doesn't mean that everyone's experience of communication in the NHS is poor.

We asked for suggestions, based on people's experience of communication in all its forms. We wanted to hear from as many people as possible including those who may have particular communication needs.

We used a variety of ways to reach people. This included social media, a smartphone app, SMS text, Freepost and a dedicated answerphone. CHC members and staff also met with people all over Wales during the summer of 2018. We received 1,306 comments and suggestions and our reach through social media was over 70,000 impressions.

What people told us

People from across Wales shared their experiences and ideas for what could be done to improve NHS communications.

Whilst everyone's experience was different we found that there were a number of common themes.

We have included each theme as a different section within this report. Whilst we have not been able to use every individual response we hope that we have captured all the issues raised with us. All references to specific people and services have been removed.

Attitude, understanding and listening

Many people told us how important it was for the people involved in their care and treatment to listen to them. People told us that this did not always happen.

“Listen and then ask questions. So often I leave the GP feeling as though the doctor has only told me what they have read off a piece of paper - and it could be about anyone. One size doesn't fit all and we deserve to be treated by someone who is interested in hearing our perspective. I would also request that I wasn't made to feel like a pest when I try to get follow up to a big diagnosis or trying to understand a timeline for treatment. Being open and communicative can put minds to ease.”

We heard from some people that staff sometimes appeared distracted or didn't seem to have the time.

“The problem is - people (doctors) do not listen. When you talk to a doctor they are too busy reading / writing on the computer and do not look / talk face to face with the patient.”

“Doctors need to be better at communicating. Seldom see my GP - went the other day as I was unwell. He did not listen to me. I was trying to explain when Doctor said your 10 minutes are up, that's all the time I can give you! He couldn't wait to get rid of me!”

Others felt that staff did not always listen to people because of personal characteristics such as their age.

“Would like GPs to listen to me not with grins, expected to not be taken seriously. Many assumptions about me as a young girl”

“It would be easier if NHS staff could remember to discuss patients' issues with the patient whenever possible. My mother is 98 but has no dementia. She and I regularly experience health staff, particularly those in hospitals asking me or my siblings things that she is in a much better position to answer. This includes really important questions about her future. Like many people her age, she is slightly deaf and yes rather than speaking up, nurses in particular but others besides can be inclined to exclude her and talk about her as though she is not there. Even if she had a certain amount of dementia it would be far more polite and courteous to at least try to include the patient, irrespective of their age or frailty.”

Many people felt that staff did not always put enough importance on what they were saying about their own health or that of their families.

“I have recurrent areas of skin cancer and I am now 98. I attend the dermatology clinic regularly... I know my skin well and have learnt to distinguish between the different types but I do not feel as though my views are taken into account as much as they used to be”.

“I have first had experience of doctors not listening, they assume I know nothing. I know what's going on with my child. Listen to the parent / carer about their condition.”

“My relative was a long term mental health patient with 8 month inpatient stay, no one seemed to know whole situation. Staff can be defensive with families and don't work with families or make families able to have an input. Please listen to patients and families.”

Many people told us it was important that NHS staff not only listen but that they also show they have understood.

“They need to listen to patients and their families. Then ask to confirm they have actually understood fully what has been said to them. Specifically in relation to symptoms, issues, problems, level of debility etc.”

“Doctors actually listening and understanding instead of just nodding.”

Reception

Ultrasound R

OUT OF HOURS
CT / MR /
ULTRASOUND
REQUEST FORM BOX



Accurately recording information provided by people was also seen as important.

“Staff to LISTEN to what you are saying. I was pre-op for a broken wrist a couple of years ago. Three different nurses asked me about my teeth. I answered correctly but the information was still wrong when the anaesthetist spoke to me. He corrected it when I spoke to him. (It was about a tooth being loose (they kept saying it was a crown and I kept saying it was loose). I know it's only a little thing but it could have been problematic.”

Communicating well, using the right approach and with the right attitude was key for people.

“Having taken my young children to hospital with suspected meningitis, and done all the work talking with the children to make them as calm and as unanxious as possible, a consultant came along and in a record time undid all this work with an attitude & communication method with my children that was completely inappropriate.”

“Some clinicians communicate very effectively with patients and others have very poor skills and use their position of power in sometimes highly demeaning ways. I have experienced this too often.”

Some people felt the NHS needed to invest more in developing and evaluating the communication skills of healthcare staff.

“There needs to be more / better training for GP's and other clinicians on how to communicate effectively in a language their patients understand.”

“Giving healthcare professionals more time and better education in collaboration with the patient so they have a greater understanding of what is required, so they feel listened to and so their needs are met in full - both psychologically as well as physically.”

“Clinicians should have a much more robust evaluation of their communications skills, perhaps including independent selection of patients to provide feedback. I have experienced doctors selecting patients to provide feedback - which is clearly open to manipulation.”

We also heard about the importance of the NHS as a whole working together with people who use NHS services to drive change and make improvements.

“Listen to and act upon what people who use the NHS have to say. Use people's experience and knowledge to drive forward change and to make improvements. Make sure that people are involved, included, engaged and empowered.”

Empathy when delivering bad news

People told us how important good communication skills were when delivering bad news. We heard from people who had good experiences but also from those who felt let down by the way that bad news was delivered.

“Dr amazing in (hospital). Broke sad news very gently in a humane way. Some bad experience with nurse.”

“My brother went for a consultation appointment at the age of 29. He was told point blank that "you have cerebella ataxia and you will end up in a wheelchair" totally stunned my mother and brother left the hospital with no further care. No sign post to any help. No counselling. No explanation, just a diagnosis.”

“Have concerns as to how and the way some clinicians explain diagnosis, procedures and especially how they deliver bad news.”



Keeping people informed and involved

Many people told us that the NHS could and should do more to keep people informed about their health, care and treatment. People told us that it could be difficult to understand what was going on when many different professionals were involved.

“When in hospital, and particularly when seriously ill, there are often many professionals involved. For example, in intensive care there might be IC doctors and also surgeons. The doctors’ rounds often occur outside of visitor hours. My suggestion is that one doctor is nominated to formally (i.e it is recorded) update a nominated ‘lead’ patient relative every two days. This would avoid breakdowns in communication. In my own case, not all the results of a surgical probe were related to relatives and when some of these were eventually discussed they were something of a shock to relatives. There was no intent here, it was presumably the case that someone thought another was doing the updating.”

“Biggest issue is the organisation of care in her home. Never knows when district nurses are coming, has to leave door unlocked, organising & co-ordination between services.”

People also felt that the language used in the NHS was not always easy to understand.

“Explain when given information in normal language, not medical terms. More patience when information given.”

“use simple language - no jargon or unnecessary ‘bumf.’”

We heard that sometimes, staff did not take the time to explain.

“Explain or have fact sheet explaining things to in-patients. I felt sick after my lunch following an operation. When I said what I had eaten the nurse said "what do you expect, you've just had an operation" It was like she assumed I was an expert in having an operation, that I have one monthly and know exactly what to do following one so I should have known this! I don't expect her to be able to strip down a computer to its components, reassemble and reinstall it, I don't see why she assumed I was the expert at her job.”

“My own experience was following an operation the surgeon had little time to explain fully the impact of my breast surgery. Across the board there needs to be better communication.”

“When I was in hospital after I had my baby I had lost a lot of blood & had to have lots of tests but nobody told me why I had to have tests - nobody communicated with me - it was scary. I love the NHS but I wish the nurses would speak to us more!”

“When I was 7, I had an operation, the Drs and Nurses took amazing care of me, although I would like it if I knew more about what was going on. Thank you so much.”

Some people would like more written information to take away with them so that they don't forget what was said.

"I couldn't take in everything that was said to me. It would be helpful to have something written down, even if it was hand written so that I could look at it again later and share it with my family".

"Clear leaflets in good size print"

People shared their different experiences and ideas about being kept updated and informed when they were waiting to be seen in NHS settings.

"Recent trip to A&E - had to wait a long time but was kept updated."

"Signs saying 7 hour wait not changed during whole time in A&E - so unsure if working properly."

"Felt that the communication within A&E department was OK. Had to keep asking for updates on waiting times and some staff were quite flippant but could still find out about waiting times."

"Knowing how many people were in front of you in A&E - a visual screen display, after having been triaged."

"Should be a message board in A&E to inform patients of their anticipated time to be seen."

"Long wait in minor injuries but no communication about why."

"Doctors waiting room - if running late there should be a message to let you know. That way you have a timeframe and can go and come back later."

Some people told us they were happy with the communication from different parts of the NHS.

"Good communication with GP being referred to mental health department. Have been under mental health care for one year, had good help from both and good communication with all services involved."

We also heard from a large number of people who told us that communication was particularly poor when waiting to hear about treatment or where care had been handed from one part of the NHS to another.

"When patients are discharged [from hospital] they don't know what to do. Can be a couple of weeks before any care."

"Wound care - nurse hasn't turned up for periods to dress wound - no communication. You don't want to ask as someone might be in a worse situation."

"No communication or communication very late, i.e. told on morning of operation that it is cancelled."

“Have been waiting six months to see two different consultants, yet have not been told who or when. How about being transparent and informative? Send an e-mail to the patient telling them who they have been referred to and when they can expect to be seen.”

“Referred to ENT Specialist in October 2017. Hearing check December 2017, no communication until July 2018. Group session July 2018 which resulted in finding out that I had been removed from ENT waiting list without any consultation with myself or GP.”

“Tell people the truth. Including waiting list times. Was told 1 year (in fact 2.5 years). Doctors / director of IVF Wales - no-one gave realistic time, reduces options available. Might have chosen another route had we known the realities.”

“Not being told when appt. will be - cataract op & oestoscopy exam. Not explaining possible waiting time or what will happen during procedure.”

“I am currently awaiting surgery on my knee - a reconstruction. It is frustrating not knowing when the surgery will be done, especially when you have a young family to cater for and arrangements to be made.

Some people told us it could be difficult to find out what you needed to know when you needed to.

“Not enough information available in community informing people "what is out there", "who to contact to avoid going to A&E", "what do Community Hospitals have available and when".

“Clear lines of communication as to who to contact when you have grave concerns about a family member’s mental health?I have been going around in circles.”

“There is no communication when services change within GP's e.g. times of opening, how to book emergency appointments etc.”

We heard there was a lot of information available on NHS websites but that it was often difficult to find what you needed. It wasn't always easy to recognise which websites were designed for people living in Wales.

“GP surgeries should have websites that are designed by actual web designers and adapt to screens of different sizes.”

“It would help to have clear communication of referral pathways. I have found it very difficult to find out the appropriate referral pathway and couldn't find this information online.”

“My doctor couldn't even find this information. An online resource to help patients see referral pathways so that they can understand how their treatment will proceed would be extremely useful.”

"The "Health in Wales" website is terrible. It's like an information dump where everything and anything is placed with little concern for how difficult it is to navigate."

"Lumping services with research & statistics, information about the history, etc., all in one place means there is information for every kind of audience yet it's useful for nobody."

"I recently tried to get information about clinics using the search function and was given 1089 listings in an order I couldn't work out - first result a clinic nowhere near me, second result was the name of a consultant in a different Health Board."

"The whole site needs an overhaul to streamline and make sure people who need quick info - so they don't have to phone up - are able to get it!"

"NHS Choices is good communication and I often use it. But when I have spoken with specialists doctors and nurses within the NHS they are not aware of the content relevant to their subject that is on the NHS Choices which seems a bit silly and not a joined up service - patients see themselves as treated by the NHS (I think), not by their particular Health Board. e.g. Midwives should know what advice is on NHS Choices relevant to childbirth and post-birth care."

"14 years in Wales, only seen GP few times. My personal experience is brilliant. I am from South Korea and love concept of NHS. Now as a proud Briton, I am most proud of the NHS system. Only problem - if I need any advice I don't know where to go because the NHS is complicated. People coming to the country would benefit from better, easy accessible information."



Appointments

Many people told us that communication with NHS services to book and change appointments was often difficult.

"GP is a nightmare 2 week wait (name) Surgery, online referral process via symptom checker ineffective & restrictive & impeding access, useful tool but impeding access."

"I had to cancel my surgical appointment at the last minute due to a medical emergency. I phoned the number on the letter and left several messages on the answering machine saying I was not going to be able to attend. I was then contacted by the ward asking why I hadn't turned up. It turns out the number on my letter was for the central booking team and nothing to do with the ward. This should be made clear and a contact number for the ward also provided."

"Carer cancelled the patient's podiatry appointment as they were unwell themselves and unable to bring patient. They were then told off and the patient put to the back of queue for the next appointment. Very little empathy."

"They should answer the phone when patients call to cancel or change an appointment. I've been ringing for a week but my calls are not getting answered. Now I will probably lose my place for missing it."

We heard many examples of letters arriving by post too late.

"My daughter often receives a letter with an appointment and, only a few days later, receives another letter cancelling the appointment and giving a new date. This has happened for almost every appointment she has had in the last two years. The bookings system needs to improve so that appointments don't keep getting re-scheduled."

"My elderly father received two letters from local hospital; the first saying he hadn't attended the appointment, the second arrived later with the appointment details. I phoned the hospital and it was sorted. I was told there was a glitch in the system, but very frustrating and worrying at the time."

"Letters could also be uploaded to the NHS Appointment Portal and an email sent to the patient informing them there is a letter waiting for them to view."

"In terms of letters, these are sometimes sent out just a few days prior to the appointment. Letters could be provided by email for a quicker delivery to the patient."

We also heard that letters didn't always contain all the information they needed. This included a lack of information about which clinic the appointment was for. This was particularly difficult for people who were receiving treatment for more than one condition.

"I was waiting for 2 different appointments and when a letter came I couldn't tell what I was going for"

"Put room numbers and/or a mini map on hospital appointment letters as half the time I find myself walking around endless corridors looking for a place which should be obvious to find. Would be less stressful and save time and late appointments."

People told us that when appointments were cancelled new ones were not always made automatically. Several people told us that they felt it had been left to them to follow up or chase for a new appointment to be made.

"I am a long-time diabetic, all is OK but I also need to see a consultant re skin cancer issues. On two occasions appointments have been cancelled and unless I follow it up, I am not sent a new appointment. Computer says I have had one sent out to me, but none have been received."

Using technology

Many people felt that the NHS could use modern technology better to make communication in the NHS quicker and easier. Extending the use of on-line booking of appointments, improving phone systems and using text messages as a reminder were common suggestions.

“Why not have a website where you can see if there are last minute cancellations?”

“Use modern methods of communication. You should be able to cancel appointment by text or email.”

“On the back of 'Hello, my name is...', I would very much like the NHS to devise a method of calling one in for an appointment which doesn't involve bawling one's name from the other side of the room. It is most demeaning and clearly shows that the staff have no conception of politeness. They are too used to treating patients as a herd and not individuals with feelings. My name is my own business & should not be given to people I don't know. GDPR apart from the small matter of courtesy.”

“Online booking of appointments at surgery. For those working full time, having to phone at a specific time on a specific day to then have to call multiple times before getting through isn't practical.”

“I have helped my mum and dad to register on 'my health on-line' - great idea. It makes it easier to make appointments on-line for those who work.”

“A telephone call or text or email to remind people about their appointments whether at hospital or GP would be useful. I can get this service from my hairdresser and dentist so it shouldn't be a problem for the NHS!!”

“I find being sent emails and texts for appointments and reminders a lot better than receiving paper ones in the post, especially when appointments need to be changed. As a patient who is blind with a guide dog, this makes it also easier to transfer into my calendar so I cannot miss an appointment.”

“Better use of email for communication - as it is not always possible to find a place to have a confidential conversation when speaking with a doctor.”

“Increase the number of incoming phone lines to my GP so that's there's a waiting system instead of hearing the engaged tone for up to 3 hours when trying to call the surgery.”

Some people felt that the use of technology should go further. Suggestions included using text, email, on-line portal or 'app' to access test results and medical records as well as appointment details.

"Access to online records to be able to communicate with a variety of health professionals.”

“Every patient should have a personal file to keep at home - to log details given by health professionals and ensure appointments are followed up as these are sometimes missed by the health board. Important information should be given in layman’s terms that could also make the patient more involved and responsible for their health. Of course, an app could be developed for those with the IT skills to follow their health care.”

“I like the text system at the doctors, it would be nice to be able to book by text for appointments or to request a call-back on a non-urgent matter, especially in the night with the children.”

“NHS needs to use more Technology resources - that's the future. My Health Online - create an appointment, get test results...”

“Long way to travel to hospital for 5 min app with heart surgeon - skype appointment would be better?”

“My brother was called from one town to another to see a Neurosurgeon. It ended up being a 5 minute interview. Why make people travel so far – it could have been done with a Skype call.”

“Following recent tests I had to wait 2 weeks to get my results from my GP. They were all clear. The appointment lasted no longer than 5 mins. I had two weeks of worrying when I could have just been sent a text or phoned.”

“Some consultant appointments could be done via phone...Go and queue for an hour to be told your thyroid levels are fine and see you in a year? Just phone me. I will save the bus money and free up an appointment for someone else.”

Some people told us it didn't work for everyone and there needed to be a range of options to suit people's individual needs.

“Too much reliance on Technology - not always suitable for the elderly.”

“In my GP practice I am told I can only book an appointment on-line. I don't have a smart phone or a computer. How am I supposed to make an appointment when I need to?”



Coordination of care and communication across services

We heard some good examples where people had received joined up care. However many people also told us about the issues they had experienced when the NHS failed to communicate properly between its different parts or with other services.

“Spent 5 months as inpatient at (name) hospital last year. Was very impressed with communication between hospital, GP and District Nurse.”

“Discharge planning & support for home services could be improved in rural areas. Support for carers to provide home care, including teaching for home medication provided in a timely way. Welsh language support services required for dementia patients.”

“I was told by the GP to go outside and make my own appointment to see the podiatrist. I didn't know what a podiatrist was - I know what a chiropodist is. Why could the GP not make the appointment for me?”

“Referred to neurologist symptoms not typical. Was told they would refer to someone else but that they would talk to them. Then out of the blue got a letter from the MS clinic. Also had a range of letters using jargon etc but mentioning things like motor neurons symptoms.

“Test in March - mid July before could see anyone to discuss results. Asked for email to confirm appointment so that they could arrange time off work - they couldn't but could fax to whole others. Referrals kept getting lost. Only to be told in the end someone would 'walk it over”

“Better joined up thinking in respect of clinic times on different days. Letter sent to deceased person 3 weeks after death from same hospital!”

“Had to take my brother for an MRI scan. Got a call to say it was cancelled as the MRI machine had broken – understood, fine. They said they could re-arrange for following day – again fine. As they were talking to me they suggested that I could go to a neighbouring hospital instead. Great - went to the alternative hospital. When we got there I was told that we were the only patients they had seen this week and they hadn't seen anyone the week before. Why is the service overloaded in one hospital and under-used in another?”

“There needs to be more inter departmental communication. The NHS has lost sight of what is being offered within their area.”

“Improve cross border and cross boundary communication. I had an x-ray taken in a Welsh Hospital but they were unable to access it at the English Hospital.”

“Transport can be an issue - missed an appointment because volunteer ambulance was late. I paid for a taxi next time £10 so my parents were there on time.”

"Communication - events in one hospital, reported to another - one would expect the record system to flag-up to the consultant in the second hospital what had happened. He was appalled when I reported it to him myself!"

"I am waiting 12 months after 2 operations for a follow up, I was referred by physio back last April and again last September and I am still waiting - yet trauma and orthopaedics do not have any paperwork from physio, yet physio have shown me the 5 e-mails they have sent. If you cannot manage the basics how can you manage the rest?"

"Unfortunately my hospital has not digitised it's records - one London hospital had already digitised its records in 2003. Why is [my health board] so far behind? I have complex health issues and I'm cared for by a variety of health professionals & paper records make it an absolute nightmare to manage appts and transfer documents between health boards. I have witnessed paperwork going astray due to the absence of digitisation."

"Better communication between GP and consultants. Where more than one consultant is needed they should confer patients illnesses and treat together, rather than treating each symptom separately with different consultants - share diagnosis."

"GP & appointment systems - had to have tests & consultant appointment but consultant appointment came before tests - consultant needed the tests first. Duplication of letters for same appt."

“Waited 18 months for a hip operation - then 3 weeks ago got an appointment. I ordered a hospital car - message not passed on from the hospital to the car service – car never arrived.”

“Hospital didn't assess what would be needed at home. Never saw an occupational therapist about what would be needed. Didn't contact Social Services about care. Dozen times cancelled operations - never told until after hours of waiting. In and out of hospital for 18 months.”

“Poor communication between hospital & community heart care team, on discharge waited 5 months for team to visit. Had to chase up visit with GP to ask why delay. Breakdown between GP & community heart care team.”

“I left hospital with both legs in plaster, they were supposed to arrange an appointment for two weeks later – nobody did. When we chased I got an appointment, I was told I needed a brace to start walking. They were supposed to order a brace and they told us they had but then we found out they hadn't. When they went to organise a brace they had lost the measurements – they asked if we had them! Information just doesn't flow between departments; you have to tell the whole story every time.”

“Disappointed at lack of communication between services / departments e.g. turned up for mother's appointment at hospital - her notes had not arrived! Had to rearrange time - totally inconvenient.”

We heard about referrals not being picked up or getting lost between different parts of the NHS.

"My daughter had issues with her stomach, constantly causing her pain. Dr said it was ideopathic and nothing could be done. I pushed for her to see a paediatrician, eventually she was put on the waiting list, apparently, but the GP forgot to send the referral so she waited a further 6 months to be seen. Turns out she has IBS so needed to see a nutritionist. She has now and is doing well."

"I felt generally weak - blood sugar high. I only got to know I had confirmed sleep apnoea, when I was asked to join a survey by the university. A referral was supposed to be made in Sept 16 but it got lost - Was eventually seen in April this year [2018]. Consultant has been exceptional - time when she explains things, empathetic, does things when she says she is going to."

Referrals that get lost. Been waiting 20 months for a cataract operation - referred in February 2017 - not even a letter - referred again in February 2018."

"I had an experience where a consultant wrote an expedite letter but [it was left] on his table waiting for two months. I spent a whole month chasing it up and speaking to different people. In the end it was passed on. It was very frustrating, there needs to be better communication between different departments - rather than asking the patient to call one person after another."

“Referred by GP with accompanying letter to present at A&E. A&E took no notice and sat in reception for 4 hours before being admitted for emergency surgery.”

Lots of people told us how frustrating it was to have to repeat information to different people.

“One shift doesn’t speak to another - handover inadequate. Patients have to repeat their story/ experience so many times it is frustrating. The key worker system does not work because there is no continuity in care.”

“If Doctors and nurses talk to each other about what the patients need for their care at that time. Patients will appreciate and feel less like a 'number' if they did not have to repeat what's wrong every 5 minutes.”

“When I was in the local hospital recently, I had to keep repeating myself every morning. Could there be some way that the notes could be digital? on ipads? Make it more modernised. To make sure that everyone is constantly and officially updated.”



Using Welsh

We heard from many people about the importance of being able to access services through the medium of Welsh. People shared experiences both good and not so good:

“Everything is working well. It is great to have Welsh speakers in the surgery - it is a big help.”

“Have more Welsh speaking. People should always be offered the option of a Welsh language speaker.”

“Where I live there are a lot of older people who are unable to get an appointment with a Welsh speaking doctor. They struggle to explain their problems in English.”

“I receive bilingual letters but when calling to confirm an appointment and choosing the Welsh option, the 'Welsh' on the phone system is awful! Make everything bilingual is my one simple thing.”

“In my town only one GP speaks Welsh despite over 50% of the community being Welsh speaking. Please ensure adequate staff and doctors, dentists etc., that can speak Welsh.”

“Make fairer use of Welsh language in NHS provision. Translators need to be better.”

“Plenty of Welsh - have had good experience this year!”

Appointment letters - good information bilingual
- really good. Opportunity to ring and have a
conversation in Welsh - positive intention."

"Text message reminders are brilliant, but
they don't do it in Welsh"

"Should be a better response time to Welsh
language line when booking patient transport"

"Would like to see more Welsh speaking
GPs - have had experience where the GP
was having difficulty diagnosing due to a
problem with communication"

"It's completely important for old people to
speak their first language [if] Welsh - especially
for those with dementia."

"I live in (town), there are a lot of older
people who are unable to get an
appointment with a Welsh speaking doctor.
They struggle to explain their problems in
English."

Meeting individual needs

Many people told us how important it is that the NHS considers and responds effectively to meet individual communication needs when delivering its services.

"92 year old father with early diagnosis Dementia. Community visit very welcome and staff very professional. Hadn't known what help to ask for or even if visit needed so very assured by their leaflets, phoned lines and follow up call. Helpful when initiative is taken by the experts because such an unknown situation for the relatives and of course very emotional. Visit was relaxed and not rushed very impressed."

"My brother is completely deaf and finds difficulty getting an interpreter when he turns up at A&E. He tends to become confused and frightened."

"Nursing care for elderly - don't think of what patient is capable of - Welsh speaking & hard of hearing, it was assumed he had dementia. Were not overcoming background noises. Need to up communication for elderly because they have different communication needs."

"Someone to talk to who isn't the Doctor / Nurse. Our nan was in hospital and as a family dealing with the reality of her having dementia we feel not enough help was given. Often our nan was left with no water to drink and she is unable to ask for water / loo."

"I believe there is a lack of communication across the board. In hospital, my mother who was blind was not told what nurses, doctors etc. were doing to her despite my asking them to explain to her on numerous occasions."

"Take time to listen especially those with dementia and the elderly, treat as equals."

"My mother needs someone with her to explain what the doctor has told her as she cannot always hear."

"As a care home manager I feel that NHS services need to improve their communication with people that either have learning disabilities and / or mental health issues. Particular skills are needed to communicate with these particular client groups and more speed of hospital appointments is needed and a lot of adults with learning disabilities would not understand the wait for appointment or would become anxious and stressed knowing a treatment is needed but have to wait."

"Communication is always a struggle particularly when patients are unable to take in all the information and family cannot get to see doctors to discuss the needs. More availability at visiting times would help."

"It's great to get details / communication from the GP / nurse / dentist through a text. I'm hard of hearing - this makes life easier for me."



"At reception I had to press to say what language I wanted but did not have glasses, pressed wrong button and could not understand what they were saying."

"Lady 88 living alone. Family living at a distance. Can't breathe very well, can't walk very well, can't see very well - brain still quite sharp BUT interaction with medical profession - someone to be the 'daughter' - accompany to specific appointments - available to explain in own environment, slowly, what has been explained during short GP appointment - make things less 'scary'. Change for elderly people is magnified greatly."

"If patient is hard of hearing look at this fact and speak clearly."

“Braille - did not have information i.e. pregnancy. Signs & warnings - was told 'we can't do it in all community languages so how can you expect it'. Pro-active campaigns in Braille.”

“The practice doesn't use language line, it means that people are relying on friends and relatives – sometimes children. That means no privacy or confidentiality for the patient and for the person translating it can also be really difficult.”

“Any form of communication by health professionals should be RESPECTFUL and professional. Always use appropriate language that is tailored to the recipient to aid understanding and avoid mis-communication and conflict.”

“I am autistic so when I see people like doctors I talk too much. They don't have enough time in appointments, I need longer. Dentists etc., don't send letters any more. I find it helpful to have things written down.”

“Non-neuro mental health staff to receive training on communication problems after an acquired brain injury. Problems with communication exacerbate distress, anxiety and do nothing but reinforce already present feelings of worthlessness. Extra time is needed and written communication must not be ignored. Headway UK produce many advice booklets, costing only £3.50, and I believe this is the minimum that should be mandatory for mental health wards, GP surgeries, Community Mental Health Teams and others.”

"They should listen to me - I have visual & hearing disabilities - must face me so that I know they are listening. My friend needs carers who do give her enough time."

"My mother has Dementia. Many health professionals are very poor at communication i.e. District Nurse was not able to arrange time of visit, she visited mum, left no information. It took four phone calls to sort out who had visited and what had been said."

"Some health professionals need better awareness of mental health service users and how to deal with them."

"Problems when making a telephone appointment when you suffer with hearing difficulties. Can adaptations be arranged? (for when no family to ring for appointment)."

"Better education & understanding about mental health. Being told to look forward to the future when you're dealing with a bad bout of depression isn't helpful."

Raising concerns

People told us that it was not always easy to raise a concern about NHS services or to have concerns heard and responded to quickly without making a formal complaint.

“Need a simple way to express opinions without making a complaint e.g. if the ward visited is dirty - who do you tell to clean it up?!”

“Make it easier to speak to the right person. Make it easier to complain or get something sorted. Get the outcome from speaking to the right people.”

“Be open, honest and to the point. Be prepared to have a face to face conversation with patients when there is a complaint. Be prepared to say "sorry" when things go wrong”

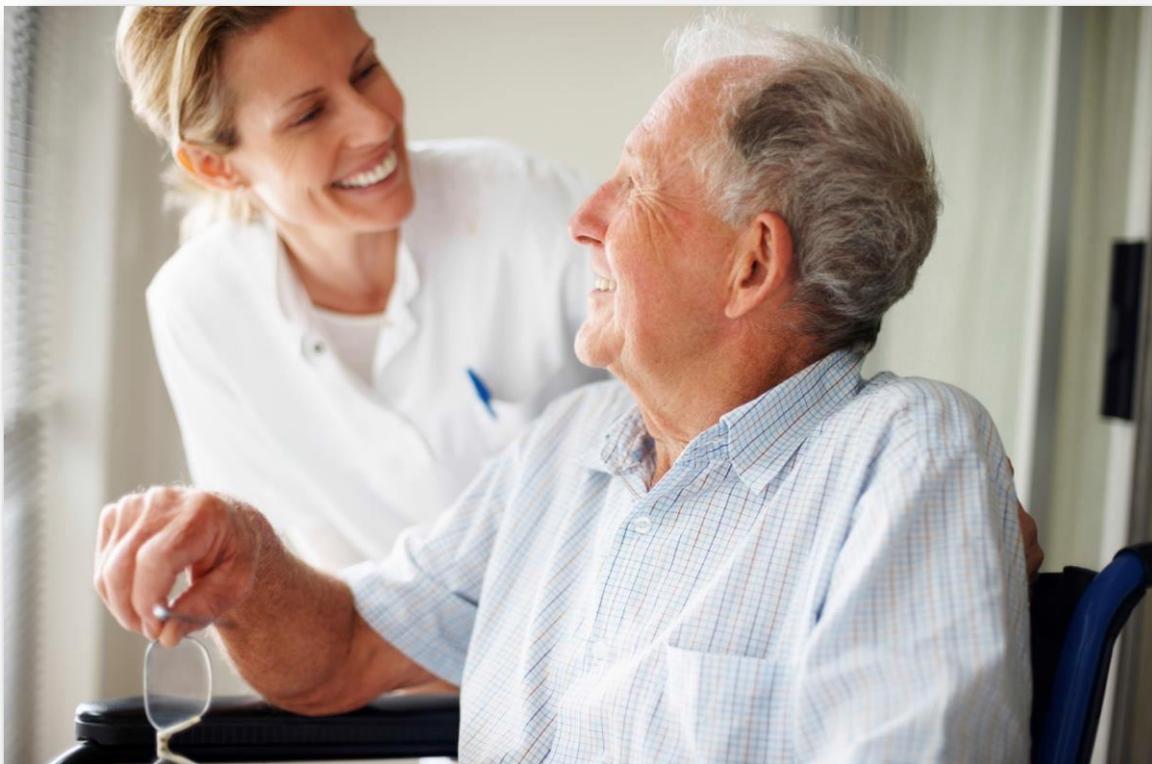
“Have an open door for complaints, make the process easier.”

“Don't put barriers up when patients wish to complain. Many services will only accept a complaint in writing and refuse to log dissatisfaction unless written complaint is received. All complaints should be logged and dealt with and taken seriously, whether they are verbal or written. It appears that most GP surgeries won't even allow you to complain via email, you have to send a written letter.”

“My complaint was never followed through about my wife's treatment in hospital and finding out why she never had a care plan or why they wouldn't even tell me why she died when, two weeks before they told me that she was fine and practically "bed blocking" but couldn't tell what was wrong with her after she had been in hospital for ten and a half months.”

“Well I was in hospital for few months and had to make several complaints... this was met with being threatened by ward staff that treatment would stop if I complained again... nice when you are paraplegic and find things like syringe needles in the bed !!! .. then tried complaining when I returned home.

They made it impossible so much so they constantly cancelled meetings so I gave up trying ...left me disgusted.”



Summing up

The number and nature of the responses we received shows how passionately many people feel about the importance of good communication in the NHS.

People told us that good communication made difficult times bearable, helped to build trust in NHS care and made people feel safe.

Some of the best examples we heard showed how good communication led to people in vulnerable situations feeling involved, empowered and in control of their own health and care.

On the other hand, we also heard about how poor or no communication left people feeling frustrated and scared. People didn't always feel that they had any say or control over their health and care and were not able to voice their concerns easily.

There were many examples where people tried and failed to find the information they needed to access NHS services or look after themselves. This included no available information as well as inappropriate, out of date, unclear or conflicting information.

People told us the language often used in the NHS made no sense to them.

We heard people's frustration that simple things that make things easier in everyday life such as text messaging and email were not routinely used across the NHS. We also

heard that where these things had been introduced this often completely replaced more traditional ways of communicating. People told us they could no longer pick up the phone and speak to someone when they needed to.

One area that really confused and frustrated people was when different parts of the NHS did not speak to or share information with each other. People could not understand why, with today's technology, it didn't seem possible to get this right most of the time.

People shared some encouraging stories about their ability to communicate in Welsh where they wanted to. We heard too that this is not consistent and that translation services needed to get better.

We heard that whilst technology was starting to improve communication for some people with sensory impairment, access to British Sign Language (BSL) and Braille was very poor.

People with sensory impairment and those who spoke other languages told us they found it difficult to communicate with the NHS themselves and often relied on friends and family.

Overall the NHS in Wales needs to get better at adapting its communication to meet individual needs.

We know that the NHS in Wales has committed to making things better in its plan for health and social care "A Healthier Wales". This plan sets out 10 principles to drive change, including:

- **Voice** – empowering people with the information and support they need to understand and to manage their health and wellbeing, to make decisions about care and treatment based on ‘what matters’ to them, and to contribute to improving our whole system approach to health and care; simple clear timely communication and co-ordinated engagement appropriate to age and level of understanding
- **Personalised** – health and care services which are tailored to individual needs and preferences including in the language of their choice; precision medicine; involving people in decisions about their care and treatment; supporting people to manage their own care and outcomes
- **Seamless** – services and information which are less complex and better co-ordinated for the individual; close professional integration, joint working, and information sharing between services and providers to avoid transitions between services which create uncertainty for the individual.

The Welsh Government has set up a Transformational Programme to help make this happen. Everyone involved in this programme needs to recognise that improving communication must be at the heart of the changes the NHS needs to make.

The recent report ‘Informatics Systems in NHS Wales’ and the people we heard from shows how technology can be a key part of this – if it’s done well and responds to what people have told us needs to improve.

Simply put, the NHS in Wales needs to prioritise and invest in:

- **developing and valuing the communication skills of its current and future workforce**
- **catching up with the use of technology to make communication quicker, easier and simpler**
- **systems that respond to the diversity of people in Wales and enable good communication with everyone**
- **making good quality information available in a range of accessible ways.**



Acknowledgements

We thank the people who took the time to tell us about their experiences and share their ideas. We hope they influence everyone in the NHS to recognise and value what they do well and to make improvements so that the things that cause very real frustration for people using the NHS are improved upon.

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