

**DeafHealth Champions Conference.**

**Wednesday 11th March 2015**

**Manchester Conference Centre**

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CLAIRE JOHNSON: Is everybody ready?

Good morning everybody. Can everybody see me okay?

Can I just ask the deaf members of the audience can you see Roger okay here where he is stood?

I just want to do a few housekeeping things before we start the Conference. We're not expecting a fire alarm today so if the fire alarm goes off please make your way out of the building following the green exits and please be aware deaf people cannot hear the alarm so look out for everybody the toilets are out the door here on the right. And can everybody please switch their mobile phones off?

There will be a photographer with us today you will see some flashes throughout the day. Any problems with that, please let me know.

My name is Claire Johnson. I am the Chief Executive of an organisation called Genie Networks, based in Greater Manchester and we cover adult and children's services and we're going to facilitate the conference and I will be introducing the different speakers we have today so everybody is welcome.

So why are we here today? Why are we having a Conference today? Most health professionals are not aware about the problems people face, it is published in a report called the Sick of It report, which is very interesting to read.

We would expect places, like audiology for example, to be a bit more aware about the needs of deaf people but they are not aware at all. I remember a couple of years ago I visited my audiologist and pressed the bell to let me in and they said 'If you can hear the buzzer open the door'. I thought 'come on!'

I didn't complain I went straight to the Chief Executive and said come on sort it out. He met me and had a discussion and I complained about the deaf issues and told him they needed to sort them out. We set up the deaf partnership and discussed things and still in years later we're discussing the same things but it was lucky I had access to that person. A lot of people don't have access and struggle with health appointments. They have no access to interpreters and they don't know how to complain. There are a lot of barriers and difficulties for deaf people.

Most of the complaints have to be in written format and deaf people are not very comfortable with writing in their second language. They much prefer using their first language to make complaints with. Also, people say well you can complain in email but they are still using the second language in email to complain. So we're here today to promote the health champions and the great work they are doing in trying to reduce barriers and problems for deaf people that they face in the health services.

Claire Johnson continues: To give an example, I worked with a deaf person recently and he goes to the GP with her mother frequently, her mother was hearing and she was interpreting for her daughter. She came to see me after about a year and she had lots of hospital appointments throughout the year, trying to diagnose exactly what was wrong with her, this person was getting thinner and thinner. She was not very well and her GP couldn't work out what was wrong and her mother was pushing her to get married, have a baby, maybe try for IVF and the lady was not

sure and didn't feel comfortable.

We had a discussion I asked her one question. I said 'what is this problem'. She said I am frightened of food, I don't know what is the right food and what's the wrong food , I don't know what's healthy or unhealthy food. There's a lot of adverts about but I can't read them very well and I am frightened of making the wrong choices. I don't want to eat the wrong things so I don't eat anything.

We contacted the GP and said you are using the mother as an interpreter what did she say? He said "she couldn't tell me because she couldn't sign properly" so the right information was not getting across to the GP. So she had had a lot of unnecessary tests and unnecessary medication, different misdiagnosis because the mistake was the family member couldn't interpret for her. So we had a chat with the GP and brought the interpreter in and it made a big difference the GP was able to explain things to her, she was able to see a specialist dietician and the situation resolved itself and she was a lot better. She could go to the supermarket, pick out the right foods she could eat and slowly began to put the weight back on again. That was a few years ago and she looks very healthy now.

This is a brief example, there are lots more issues here. I think there's not enough really, not enough GPs that sign, the information isn't passed on properly. Also, the family members, especially Mothers having emotional involvement with seeing their family go to the GP. Also, if it is bad news, then how is the relative supposed to pass that on to the patient?

Some cases you need to think about protection of vulnerable adults because the family member could be covering up the fact they are abusing the patient, but covering it up as an interpreting issue. There's also an issue of privacy and confidentiality if using a family member. And also the problem of getting misdiagnosis and different diagnosis or the wrong treatment and wrong tests.

At the end of the day if this happens the deaf person's health is going to deteriorate. Everyday I talk about my experiences with deaf people and their experience in the Health service. It shows how important it is to work with deaf services and the Health service and the deaf organisations that we have here. They are all the same here, they could talk all day about the issues we face in health.

But the deaf organisations are really important, they have their experience, they can share their experience with health professionals and hopefully learn from each other.

I want to add about the value of Deaf Health Champions. We are recruiting deaf volunteers so deaf people themselves empowering other deaf people and teaching and showing their views and sharing the services.

Claire Johnson continues: Supporting deaf people to build their skills and build confidence for them to give presentations about the service and deaf people can be involve in consultations. I know health service rarely give consultations and deaf people don't really access them but with the Deaf Health Champions they can do that and it is really important. Deaf people are involved in the decision making.

We set up groups especially for deaf people, in my area we have a running group. I don't think I will join just yet, I can't really run! But it is very difficult if you have a hearing group, it is very difficult to run and chat with hearing people at the same time, it is too difficult to lipread. However, if it is a deaf group it is a lot easier so hopefully we're giving more opportunities to deaf people.

Especially interesting today is this slide here. This is about access to information. Hopefully it will change the way services give information in the future. A lot of deaf organisations are here today and hopefully they will find that useful to show to people.

It is also useful for hearing mainstream services to see the speakers and how to access services for deaf people, so hopefully I will look forward to hearing a bit more about this if we have more time later.

The first speaker this morning is Jim Edwards. Jim is chair of the UK Council on Deafness

JIM EDWARDS: Thank you, Claire.

Is this the microphone that's working? Is that okay for the loop-system? Great.

Claire, thank you for the introduction. Delighted to be here today. As Claire said, my capacity today is as chair of UK Council on Deafness, but I also want to remind people I have a day job as Chief Executive of Signature, a charity about improving communication with deaf people. My role really is just to introduce Deaf Health Champions as a project, to give a bit of background before we get into the meat of the day looking at why it was created and what it is leading towards.

Critically Deaf Health Champions is a project that is based in local communities; it is based here in the North-West and has a significant number of organisations working in partnership. The organisations themselves have been brave enough to say 'we'll do the right things to work together' and take risks in working together to deliver outcomes to improve opportunities for deaf people in terms of health. The number of partners is significant and that's not made it an easy job for the project co-ordinator, the Project Manager or for any of the staff.

Critically the project is funded by the Department of Health and therefore is a piece of work that is actually embedded in what the Department of Health sees as being a valuable way of contributing to health outcomes for deaf people. UK Council on Deafness was approached by SignHealth just over three years ago and asked if we would work with them as lead partners in the development of this project and help pull together some local partners in delivery. We were delighted to do that because from a UK Council on Deafness perspective, what really matters is the sector coming together in either policy terms to gain and improve things for deaf people or in practical ways to deliver practical outcomes for deaf people.

Jim Edwards continues: The project has a Project Director, Jo Slater who most of you will know. We owe a big vote or thanks to her and all the local coordinators, Simon, Sally and Janice for the enormous amount of dedicated, hard and really well organised delivery within the programme and you will see the impact of that as we go through the day. I would personally like to thank them for what they have done and particularly to thank the organisations that have hosted the local coordinators, - Merseyside Services for Deaf People, Cumbria Deaf Association and Manchester Deaf Centre.

What that gave us as a partnership was some national expertise through SignHealth, consistency of thinking from them and very much local delivery to local people, sensing what was needed, what would work best, how to work in local communities. The final Partner to mention is Merseyside Disability Federation. As a key organisation helping us evaluate the contribution the programme makes to health gains for deaf people, because that is the key message of what the project is about.

It is great to see you all here today but what we really want to see is deaf people living healthier lives, because they get access to health services in a timely and effective manner, that's what the programme is about and someone standing back from the delivery is well suited to help us get that analysis of actually, how well are we doing.

The project, based in the North-West, local charities, established in local communities. Timed very much to work with the new structures within health. All the changes in health over the last few years and the coming changes create confusions for everybody and if as individuals to navigate that well sometimes we need support and knowledge and information to help us too that.

So, 83 volunteers to proactively support those changes, working with diverse populations, across this region, and diverse geography. It really provided a significant opportunity to boost the confidence of individual people personally gaining skills and employability and really building their confidence so they were better placed to act for themselves and for the wider Deaf Community improving health outcomes.

A real focus on access to information, access to services, and patient experience. So the programme is very much a health driven programme. Clearly as I have said already, what we want to see is long-term better health outcomes for deaf people. That's all deaf people. Whether they are deaf, whether they have hearing loss, whether they are deaf and blind. It is really key. The programme has not been excluding any of those groups, whilst it has focussed predominantly on sign language users.

Do we know it is working? How do we know it is working? What we have seen and what we have been told, on that list of organisations who are working in partnership with us, we could have added not just the core partners in the delivery but a significant number of health, social care and voluntary organisations who have really worked actively with us to deliver this programme, because this programme doesn't work by us talking ourselves, it works with us talking to and engaging with people involved in health. We established a number of leaders, 8 leaders, with significant roles within the health sector. That just means we are influencing them, we're talking to them, engaging with them.

Jim Edwards continues: Deaf groups are involved in consultations at local levels to improve services; we have seen an increase in interpreter bookings, an increase in accessible information. Deaf people taking better control of their own lives and their own health and wellbeing; and getting to a point where health providers are more engaged and more supportive.

There are a few quotes from people. The one I like best "I never thought I would be riding a bike at 70". It is a simple statement, but actually, whatever age you are if you engage in physical activity, it can be helpful.

Think about it. The fact you can text your GP to get an appointment rather than go through the myriad of negotiating a pathway down an ordinary telephone conversation. "Feeling comfortable about knowing my own rights". Being in a doctor's surgery or in a hospital, and actually not missing your appointment, because the person saying your name doesn't identify you clearly. So there's a mumble, a voice at the end of a corridor, something that means you don't know your name is being called and therefore a very simple gain for us as deaf people and also a gain for the Health service, that person turned up on time, got to their appointment on time and hopefully they had the communication experience that allowed them to access the service. So "my hospital is no longer allowed to use my grand daughter to interpret any more".

We are confident the programme has had significant impact here in the North-West. We're also delighted there are a number of things happening within the sector to do with health that will really push the boundaries and help this project deliver more in the longer term. You will hear a lot during the day about the Accessible Information Standard 1605. Simply because it is a piece of work that will put 'must' and 'should' in front of GPs, other healthcare providers when thinking about engaging with deaf people and that will make a difference to a lot of deaf people. You must book an interpreter. You should do this. So it is about improving an expectation to that service.

We are expecting the Department of Health before the General Election, touch wood, to launch an Action Plan on Hearing Loss and the key bit about that, it is an Action Plan that has been signed up around services for people who have hearing loss who are deaf, but it's about all departments contributing - employment, education, as well as health. So if you are going to get healthier lives for deaf people you need to think about their employment, you need to think about their education, you need to think about their health. This Action Plan has been long in gestation. Some of us know it has got to about 30 or a 40 iteration and as long as it doesn't slip we should see that launched.

Many of you know there has been technological service developments in the past years, which means deaf people have easier access to services, whether remote sign language interpreting, the new form of text relay, whether it is the ability to have a vibrating device to tell you - these things have changed and are improving services and access to deaf people.

Finally and most importantly for me we have greater consumer engagement, deaf people saying this is what I want, this is how I want you to make it happen. In a positive way and a way that engages health professionals in their service delivery. We think the project has been fantastic, we are delighted with the work the team have done and I

think it has shown a real commitment to excellent service for deaf people and please sign up for 'prescription for change'. Thank you very much

CHAIR: That shows the value of the health champions. Thank you Jim. I will introduce the next speaker, we have Professor Dame Sue Bailey, vice chair Academy of Medical Colleges, Past President, Royal College of Psychiatry. She's going to talk about how the health service fails deaf people.

Prof Dame SUE BAILEY: Good morning everybody. What a negative title. So I will get the negative out of the way quickly. I would like those who are going to have the £6 billion to run integrated health and social care to hear the facts. So that you as deaf health champions will have a better chance to get innovation monies to do what needs to be done if the words which I think are many words of 1605 are going to be realised.

My interest stems from two sources, one I have lived and works at Prestwich hospital and I have lived and worked next to what was until relatively recently the John Denmark unit. I was privileged to work with John Denmark for a short period of time. My best friend's mother was profoundly deaf. I saw what that meant for a relationship with my best friend and her mother the positives and the negatives. I'm now strangely leading an organisation that I'm going to talk to you about, the academy of medical Royal colleges. It's 22 medical colleges, the only reason you need to know about it is because I'm your contact for a route into getting through to 220,000 doctors why the health care of deaf people really matters. It matters at many levels.

I rekindle my interest in deaf people from deaf community through one of your subsequent speakers, because at the academy I chaired the inequalities forum. That's where we put the community of deaf people in the inequalities forum because that's what you are experiencing health inequality. So I learned how many deaf people there are. I learned how you had a poor experience of accessing health care. That your pathway of health care is distributed because our communication with you was poor. We're still from my perspective as a psychiatrist we weren't meeting the mental health problems that people from the deaf community. I know that your fiscal health care is poorer. I learnt that poor communication in a consultation can lead to medical error.

Then the NHS was turning upside down. I have done that and I have no idea what that means in sign language. So if I have been rude I apologise. I must keep my hand behind my back.

This is a real opportunity, not just in Manchester, but how you as DeafHealth Champions and deaf community are going to ensure that the care quality commission expects to meet the need of the deaf community and ensure that you do not experience poor care and even worse premature mortality. I know NHS England are here to speak later, I know there is a huge amount going on.

The next thing I want to say is a confession. I have taken on the role as the senior clinical adviser at health education England for mental health and learning disability. I cannot quite yet find out where the person responsible for improving education, training and work force is within health when it comes to the deaf community. So hats on my urgentlyst to do and if anybody in the uilfts this room knows please tell me.

So there are many places where we can improve. So at health education England its great if we have e learning packages to increase awareness amongst the whole of the health work force but e learning packages do not work on their own. So what we want is people like yourselves to be product champions. So that if in NHS we can get learning to meet safely the needs of deaf people we need you as champions to say that you have the learning, are you putting it into practice, do you need any help, would talking about my story or another persons story help you to make this live. S the so the one thing I learned from doctor Alexander is I must not grow a beard because you will find it more difficult to understand what I am saying.

What I want to finish with, and I do not know whether this is going to happen or not now, yes, I just want to talk about the academy of medical Royal colleges may sound like a group of crusty old male farts, excuse my language, but there are now seven girls there so we're getting there. That's who we are. I do not know what you think of us. I do not know whether you trust us. But that's who we are. A right across all the area of medicine impact on your lives day to day. This is what we too. We bring together expertise to improve health and patient care, through education training and quality standards so use us. Tell us what we're doing wrong. Its essentially to coordinates across this family of MedicAlliance someone, the doctor's and we work closely with the nurses and other Professortions. Our job to promote the R higher standards, and within our equality forum I'm glad the previous speaker spoke about the benefits of fiscal exercise. We have just spdiewith miracle cure, and I'm not sure we have got this through to you as a population, where actually the best treatment for mild mo moderate depression is not talking therapies, its not medication, its taking exercise for half an hour, five times a week, that makes you slightly breathless or slightly sweaty.

Our comms person included sex in this, so I got a lot of unfortunate questions about how much sex and what time. Bout the point is, we need all doctor's to understand the benefit of exercise but are they going to offer that to you as you see lfts Syntocinon a surgery and maybe the doctor notices over 15 years have gained four stone in weight but does he raise this conversation with you? We know he doesn't raise that conversation with the hearing population. So is he raising it with you?

The other things before I finish because I know time presses on, is some of the things we're doing where I need your help. In the academy. So we're carry on working to ensure that 16O5 becomes a reality. I will help at health education in England in any way I can. We're working with the Secretary of State, whoever he may be in the the future, or she, to choose wisely. Because we can't afford the cost of health care at the moment. As doctor's we need to be able to have a conversation with our patients about the best choices for your particularly disease, or what I want to call, dis ease. That's how we can communicate.



We have been involved in something called the accountable commission. So now when you go into hospital you should throughout your stay in hospital know your named nurse and doctor. Is that working for you as part of the deaf community? If its not let me know. I will let the Secretary of State know.

Voidable mortality I struggle with this. I find it difficult to get Government to believe that people with mental health problems die 15 years longer and that people from the deaf community die younger and go through more illness needlessly and suffer longer. So help me with this. We're now starting accountable commission in the community. What's that going to look like for your coordinated path way of care, so that you get your appointments transmitted to you in the way that you can receive them. You have a care coordinator doctor who will understand you. You will inevitably be put in a complex group. I wunpt worry about label if it gets us to the end accept it.

Sustainability is another thing the academy is doing and you are saying, we're not here to talk about green fields and open spaces. But sustainability is about disease prevention at patient empowerment. So please join me in that.

The last thing I really want to emphasise, my research is in the feel of building rely sly's in communities. We can only do that through social scaffolding. That's about communities that come together to care, to work together, to make a difference. The basis of all forms of productive social interaction is shared social identity. I know that the deaf community have this, but it is still poorly understand by those of us who are not deaf. Good social identity includes good communication, leadership, motivation, cooperation and rust. So I want you to use today to eat leave me on bits of paper the things you think the academy medical Royal colleges could be doing.

Finally for my family I'm part of the social enterprise in the rest of my life. Both of my daughter's work in mental health, community engagement at arts. My son in law runs unity radio which is a project to get young people out of gangs. Thats the sound bit. But what the young people who are in gangs can do, they can't hear the radio, but they can do the graffiti and they make their views H clear through the graffiti work they too. If there is anything as a social enterprise we as a family should do in Manchester to support the young deaf community, particularly the deaf community where the young people have got other problems like attention deficit hyper activity disorder at autism and learning disability, please tell me ant we will do our best because we're not a family of shrinking violets. We will speak out. We want to help you as a community to have a better voice. So thank you to for listening, I promise to hear. So thank you. (applause).

**CLAIRE JOHNSON:** Thank you. I am sure you will all work together to give the feedback we need for the future and it is important to keep the communication open. I am going to show a video, it is about five minutes.

( Sick Of It video) I would like to introduce and welcome now Dr Andrew Alexander he is going to talk about the video.

DR ANDREW ALEXANDER: Thank you for the invitation to be here today. Last year, I had the opportunity to work with Deaf Champions, Janice and Shelagh. I am also involved in the CQC Inspection and it nicely links with the Deaf Health Champions and it is part of the CQC inspection. I have worked in hospitals for 30 years, before I joined SignHealth. I have two daughters, one is hearing and one is deaf. My deaf daughter has grown up using sign language.

For my presentation, I will revert back to speech.

I have been asked to speak about the deaf health study, the Sick of It report and how it fits into the context of the health of deaf people and also a bit of mental health and also a bit about where we go from here and the Accessible Information Standards.

I have been Medical Director of SignHealth for two years but I was involved with the deaf health study from the start in 2008. This study is the largest and most extensive study of the health of deaf people in the world. We set out to investigate four main things. Deaf people's experience of healthcare; whether deaf people have poorer health; to suggest reasons for any inequalities; and to identify practical measures to reduce them.

So I am going to speak about why we did it, what we did, what we found, and what we need to do next. So why? Because we heard from deaf people that healthcare was full of barriers and problems. Awful stories such as having major surgery and not being told why. Or being admitted for an emergency operation and then being in the Ward three times without being told why and each time that person thought they were going for their operation.

This is a quote from a complaint from a deaf BSL user, "making sure an interpreter is present is an important as providing lifts and ramps". It doesn't matter what the adjustment is, whether a deafblind communicator or lipspeaker, what doctors and nurses need to realise is that the adjustment is not just for the deaf patient, it is also for them to enable them to make a safe diagnosis. It is also the law.

Providers should make reasonable adjustments under the Equality Act. If a doctor doesn't arrange an interpreter, then they are not fulfilling at least two of the duties of the doctor as set out by the General Medical Council, to listen to patients and respond to their concerns and preferences, and give patients the information they want or need in a way they can understand. So lip readers may get up to a third of what's said and then use guess work to fill the gaps. Dr Andrew Alexander continues: Writing notes doesn't allow a full medical consultation. It may not be at the level of English accessible to the deaf patient, so not only is reading and writing notes not accurate but it is not safe because they are prone to medical error, and that's why interpreters are needed.

Back to when we set up the project, what was the evidence at the time? Well, we knew access was poor, booking appointments relies on the phone, deaf people left in waiting rooms because people simply call out their name, we knew communication was poor. When deaf patients finally got into the consulting room having overcome the access barriers, a third left the consultation unclear about their condition. Often, booked a repeat appointment just to clarify what was said at the first. A third of deaf people were unclear about their medication or had actually taken the wrong medication. There was very little health information in BSL. Despite the fact there are leaflets in dozens of foreign languages. So deaf people had to rely on reading leaflets and reading subtitles which again may not have

been at a level of English which was accessible so they are likely to have lower understanding of healthcare.

There was, however a lot of research into mental health. We know common problems are about such as anxiety and depression are about twice as common in deaf people. There are higher rates of physical and sexual abuse and domestic violence. There's patchy access to psychological therapies and counselling services in BSL. So deaf people are being prevented from self referring to the appropriate BSL IAPT service which pushed them back to their GP who we know acts as a barrier, rather than a Gateway.

The mental health provision for BSL users used to be in BSL. As Sandra said, having a third person in the room disrupts therapeutic alliance and also can lose nuances of language. If the professional doesn't have a good understanding of deaf awareness and deaf culture, they can also make incorrect diagnosis. So there's a double disparity for deaf people in mental health.

Sandra's awful story illustrates so many of the barriers. Communication breakdown with the GP; not getting the appropriate therapy; getting medication but no adequate information about it; delay before correct treatment. It also shows the importance of the interpreter in the GP consultation, the importance of not having an interpreter but having a BSL using mental health professional in mental health provision. And the need for more health information in BSL.

At the moment, very sadly the BSL IAPT service is under threat and there are fewer practitioners than there were because of the failure of CCGs to commission the service properly and SignHealth is working with the ministers and the Department of Health to try and rectify this awful situation.

So do deaf people have worse physical health? Well, there are a lot of risk factors - poorer access, poorer communication, poorer physical health, linked to mental health, less employment rate, also linked, and there has been masses of research into deafness but none into their physical health We wanted to look after at the overall health and wellbeing of the whole deaf person, not just their hearing, and their experiences across the whole NHS.

The study was in three parts. In phase 1: 533 BSL using deaf people answered questions which were in BSL and English about their access to healthcare, their lifestyle and health. This was carried out by IPSOS Mori, funded by SignHealth.

In phase 2: 298, BSL users under went standard BUPA health assessment with BSL interpreters and deaf advisers present to give us quantative clinical data including blood pressure and blood tests and also further questions on access. In Phase 3: 47 of those people went on to have in depth interviews in BSL by BSL using deaf interviewers about their experiences of healthcare. Phases 2 and 3 were carried out by deaf and hearing researchers at the University Bristol with considerable help of half a million pounds from Big Lottery.

Huge thanks to the members of the research advisory group which include Herbert, the research team at the university Bristol, to deaf advisers, to Big Lottery and in particular more than 700 deaf volunteers. I am going to talk

mainly about the results of phase 1, the online survey, and phase 2, the medical.

Starting with lifestyle. Deaf people have generally healthier lifestyles than the rest of the population, with less smoking and less alcohol. Activity levels were similar, as was intake of fruit juice and although there was slightly high consumption of vegetables there was more fried food.

Moving on to communication, most deaf people wanted to communicate in a medical consultation in BSL with an interpreter - 86%. In practice, nearly half were forced to write things down when none wanted to communicate like that. A quarter were forced to use spoken English and lip-reading when none wanted to.

So there's a clear mismatch between how the deaf participants would prefer to communicate and how they actually have to. There's a clear mismatch between what they need and what they get. So not surprisingly, this affected deaf people's access to healthcare. Two thirds of the deaf participants who had not been to their GP recently, had wanted to go but have not. It was not that they did not need to go but something got in the way. More than half the time, this was a lack of interpreter. A third of the time, it was difficult to arrange an appointment, but most worrying, in over a third of the cases the deaf person did not think it was worth going to see their GP because communication was so poor. So deaf people are being put off visiting doctors and nurses, which is simply unfair.

There were two main findings from the medicals. The first was that the deaf volunteers were more likely to have conditions that had not been diagnosed. For example, high blood pressure. Twice as likely to have high blood pressure as the rest of the population. The second main finding was that even when conditions such as high blood pressure or diabetes or heart disease, had been diagnosed, the deaf participants were less likely than everybody else to be adequately treated. So three times more likely to have poorly controlled blood pressure, twice as likely to have poorly controlled diabetes, and only half the deaf participants with heart disease were on the right treatment.

So there's under diagnosis and under treatment of potentially serious conditions. It is more common in the deaf participants of this study than in the general population and these are conditions that bring with them disability and premature death.

The economics analysis of the Sick Of It study, carried out by University of East Anglia, showed this under diagnosis and under treatment of deaf people cost the NHS £30m a year. Not surprisingly, deaf people have low levels of Trust in health staff and low expectations of healthcare.

So, what should we do next? How are we going to address this awful situation?

How are we going to address this gap between health staff, doctors, nurses, receptionists and deaf people? In my view, all NHS staff need to reach out to their deaf patients and read them better. The NHS as a whole needs to reach out to the Deaf Community to target this marked health inequality. The bad news is, this is a serious problem. It is unjust and unfair that there's a group of people who should receive worse healthcare and have worst health just because they can't hear and at a cost of £30m a year. The good news is that the solutions are simple, such as don't call a deaf person's name in the waiting room, walk up to them. It all boils down to awareness that deaf people face barriers and to stop making assumptions. Just ask the deaf person how best to communicate. There's a lot of good

work being done by the deaf communicated, by deaf charities and deaf and hearing professionals but that's not enough, all NHS staff need to treat their deaf patients better. Although this study is about BSL users that applies to all deaf people. There were two Sick of It reports. This is the longer one, the full one, it has a section towards the end on recommendations and advice for different groups of NHS staff - primary care staff, secondary care, public health, NHS England, commissioners - on things they can do better. Many of these were already NHS policy, such as on line booking of appointments, and ordering repeat prescriptions.

By targeting health inequality we'll improve the health of deaf people and save money. This is the shorter yellower Sick Of It report, how the Health service is failing deaf people and this also has recommendations for different groups of staff, such as this prescription for doctors, nurses and support staff. There were two medical publications last month on the medical results on Sick of It, one in British Medical Journal and one in the British Journal of General Practice. And the BMJ one has ten top tips of how to treat deaf patients better, things that are really simple things.

I am going to finish by talking about action, action that can be taken by the local provider, Commissioner or practice or Trust. And then national NHS actions. I thought it was more appropriate for this audience to talk about local providers. I am going to talk about the hospital, my local hospital. Not because it is better than anywhere else but because that's the place I will know best and I am sure we'll hear more from Deaf Health Champions later today about work they have done with local providers.

The first thing we did was deaf awareness training for staff, provided by Roger Hewitt and Sarah. Because if staff are not aware there's a problem they are not going to work to improve things. We also improved BSL interpreting provision by setting up a register of agencies, including out of hours cover, setting up online interpreting, rewriting the hospital policy for interpreter provisions and separating that from the foreign language interpreting provision. We wrote guidance on how to book an interpreter, how to use an interpreter, how to communicate with deaf people, which is visible to all staff in any hospital in three clicks.

There's no point having these developments if staff don't know about them so we publicise them as often as we dare. This is one of two computers on wheels, which live in the emergency department which can be taken to a deaf person wherever they are in the hospital and then using wifi and a webcam connect a deaf person and a health staff member to a remote interpreter. We also set up links with the local Deaf Community including consultation meetings we had a 'see it my way' event where four deaf users at the hospital came and told their personal experience of the hospital to over 100 staff in BSL.

We work with local commissioners, primary care, social services and out the providers such as Action on Hearing Loss to improve care locally. We did two very simple things. If you were admitted to my local hospital as a medical emergency the doctor fills in a 12 page form. This is the front sheet. We put on communication needs box next to the allergy box, so for example BSL user book an interpreter.

When a nurse admits a patient to a Ward they have to go through a series of on screen tick boxes. One of these is

'does the person wear specs or hearing-aids'. We put in another box 'are they with the patient'.

I used to despair on a Monday morning Ward round and elderly patients who came in Friday night or Saturday and 2006 specs and teeth and hearing-aids were still at home, that was not making for good communication for safe diagnosis and it would make the whole experience of hospital more awful.

Every Ward and care home needs a proper stock of hearing-aid batteries, not a few random ones at back of drawer, so the patient does not have to wait two weeks for an audiology appointment for a battery change.

There's still a great deal to do. All staff need deaf awareness training, not just a few. We tried to set up a network of deaf awareness champions, so there's least one on every Ward or clinic who staff can go to for advice on communication with deaf people. We need to make better use of SMS and email for booking and communication with hospital staff and video relay services in the future.

We need better flagging of preferred communication method and better delivery of communication support. Think ahead when booking an interpreter. Book a double length clinic spot. When there's a deaf patient on the Ward they don't just need an interpreter for consultant Ward round, what about drug rounds, procedures, consents, and so on.

My last two slides just looking a bit more broadly, NHS wide. In my view, the main problem is ignorance. Most NHS staff don't realise the extent of the barriers deaf people face. I also think that until there are national standards of care which are mandatory, and monitored, and where necessary enforced, nothing will change.

So it is very timely that NHS England's Accessible Information Standard, 1605, is due for publication in May or June this year and it is great to have Giles Wilmore from NHS England speaking after lunch.

But for anyone who is worried about the cost and time implications of implementing 1605, please bear in mind that the under diagnosis and under treatment of deaf patients costs the NHS over £30m a year and more than £20m a year in missed and wasted appointments.

If deaf people have proper access and communication, that will reduce chronic disease, fewer exacerbations and complications and if we take diabetes as an example, the national diabetes audit says 24,000 people with diabetes die avoidably early every year because of poor management of diabetes. A deaf person with diabetes has all the barriers I have just been speaking about as well, so they are even more likely to get complications which include blindness.

I want to leave you with this deaf diabetic. If providers provide a BSL interpreter for doctors and nurses and better health information in BSL, then he is more likely to have better diabetes management, fewer complications such as kidney failure and blindness, and that will well save the NHS time and money and is also nicer for him. Thank you

CHAIR: Thank you for your presentation. I agree, there is very simple solutions to help access to health services.

If you haven't seen the video it made interesting points. Wit like to show you another video with somebody else's experience from the health service. (Video)

It's Healthwatch about the interpreter service. Hopefully that will spread out a bit more. I recently I have to contact the hospital service because I knew someone on boxing day that wanted an interpreter. When I rang the hospital, they couldn't get through the the agency to book the interpreter so I said I would book myself. They said they wo closed Christmas day I do not think they are thinking about deaf people's health. Its very restricted use for interpreters if you want to do that.

Just before we have a break, I found some lost priority. A simcard. It was left in the exhibition room. It's for a a memory card for a camera. I do not know if anybody has lost that. We will keep it for later. We're going to take a break. If you can come back at 1140. Thank you very much. (Break)

CHAIR: Are we ready to start again? Are we ready to start back now? Okay. Can everybody get ready to start again after the break please. I hope you had a good break. I would like to introduce you to Dave Nunns, the Chief Executive for Healthwatch Wigan. Thank you.

DAVE NUNNS: Thank you very much Claire.

I have been asked to speak and tell you a bit about the experiences throughout the health Healthwatch network nationally of some of the local health Healthwatch working with the deaf communities at finding out their experience. I will highlight of examples from round the country. And before I do I will do a some slides to explain about Healthwatch.

Healthwatch, the national network of Healthwatch was established in April 2013 along with all the other kind of upheaval within NHS. I would like to think that we're one of the better outcomes of the changes that were in the health and social care act of whatever year it was, 2012.

The name for the new section that helps children and young people and families speak up about local care locally the photographs tell you that we have in interest in dotors, GP, dentists, care homes at with young people and old people its our job if you like to make sure that the people who run, who a fund, and who over see health and social Care Services find ways to listen to the people who use their services and importantly that they think about what those people say and they use that information to improve those services. We're not just isn't business of listening to people for the sake of listening to people.

There are I think someone who knows more about these things will tell me different, I think there are 152 in the country, rather help there is 152 fs that we do things. Seeing health Healthwatch from my perspective in Wigan we operate differently from Bolton and Bury and Trafford and elsewhere. So we do things slightly different, but at our core we're listening to people's experience and views of health and social care issues.

In terms of, there is map up here. I wanted point out there are 10 cross Greater Manchester. The first speaker talked about Manchester and the integration of health at social Care Services across Greater Manchester. I will be interesting in the next year that we need to step up a gear I get out of our locality and work better across the whole of Greater Manchester. If you are not from Greater Manchester, you will have a local health Healthwatch and I if you do not know where your local one is I will give you web site where you can find your nearest one.

What we found, we have been operating for two years, a number of local Healthwatch have priority issues of local deaf people and want to find out more. I want to give you examples from across the country if that okay. Examples from Yorkshire. If anybody is here from Leeds, I do apologise I have missed you off the slide. Colleagues in health for Kirklees produced a report called welcome to my world. Important point to make around the reports I will mention, and any of the BSL videos they are available via the local health Healthwatch website. Similarly York you will find their report and the BSL videos.

I might sound like I'm going to repeat myself, because what we found is there is an awful of similarities in the people across the country I will try and pull that out without repeating myself. So in Kirklees they had concerns about a lack of BSL interpreters and an about in consistency over BSL interpreters. Some people finding they were okay for GP appointments and hospital points and they were differences in the skill levels and the experience levels of the interpreter being used. Kirklees had a series of recommendation. Some of these we've heard already.

Recommending about the use of text at e mails for booking appointments. Confirming appointments. They were calls for greater deaf awareness training or health and social care staff. Patients records to flag up when someone is booking an appointment with someone it flashes up what their communication needs are and issues like double appointments should automatically flash up.

Need to be system to tell deaf people that a interpret tlr has been booked. There is a difference between requesting one and trying turning up to find an interpreter is not there. One of the interesting things is around deaf people knowing they rights when it comes to these things. Quite often we found that they were rerequesting interpreter and being told we do not do that, they are too expensive. A greater empowerment for deaf people to know their rights.

In terms of York they found similar experience of as people in Kirklees. York turned their report into a BSL video, so not just written in English. They found a lack of appreciate that for many deaf people BSL is their first language and not English. They found GP surgeries refusing to book BSL interpreters. Telling that they were too expensive. There were a number of cases where medical staff asked whether members of the family could interpret for you. In our own experience of working in the deaf community in Wigan there is sometimes when that's appropriate at there are times when that is not appropriate.

We had examples of patients being left in waiting rooms because they had not heard their name being called. Some frustration in the York report that many of these issues had been raised multiple times over many years, and the



people who had been involved in campaigning on deaf issues to realise that and the changes have not been implemented yet. They made a series of recommendations round training forefront line staff. Promotion of the fact via posters and leaflets that interpretation services are available and that would be empowering for the deaf patients but also the staff within surgery, they would know which agency to use.

Colleagues in Leeds did a piece of work, so apologies for not mentioning them on the slide. Similar experiences. Appointment systems that weren't accessible. Lack of awareness among staff round deaf issues. And confusion over who was responsible for paying for interpreters. Quite often that is seen as the reason why an interpreter is not booked because there is confusion over who is responsible for booking that person. Similar to York, Leeds found that deaf people didn't feel confident enough to make a complaint or to insist on their rights.

Going down south, a bit further revealed colleagues in Oxfordshire were aware of there was an increase in discussions and grumblings about the situation for deaf people were getting worse over the last couple of years. They did take a piece of research, and they produced their report in English and BSL. Again the links are on the website.

Interestingly, they undertook their research using deaf researchers at you used film company using deaf camera operators, producers, Edinburghers at those kind of things. They found that many people felt that health staff talked down to deaf people, treated them like children may they feel small

Like Yorkshire they find mixed experiences of BSL interpreters, both in the availability and quality. They found frustration in the use of telephone booking systems, being left in waiting rooms and medical staff using relatives as interpreters

Many people in Oxfordshire said that the practice of their GP, their experience of their GP was better than the hospitals. Quite often if a GP knows you, they will know to book a double appointment, and interpreter but the systems there are not necessarily in place when you went somewhere other than a regular place.

Done some interesting work in London, there must be 20 odd local health Healthwatch in London, a lot more experience than I know about but I have examples where health Healthwatch is, they were invited to give evidence to the greater London assembly and Mayor about deaf people's experiences. So again they some of the things that we have heard the lack of BSL interpreters, lack of information, they made recommendation to the greater London assembly and we heard it in speakers before already this morning, the health service should be responsive to the needs of deaf people, health professionals shouldn't assume that all deaf people need the same and that everyone will need the same communication support.

Staff training is key. But one of the things that they pointed out is that staff training can't be a one off. Partly because of the churn of staff this needs to be kept on going, needs to be a regular cycle of deaf awareness training for all staff.

They had some good practice examples of GP practice using pagers that would vibrate when someone's point was ready and they thought that would be a simple solution that could be replicating practice.

Some interesting where north central and east are working together to train deaf people to interview visitors. This is something that we talked about in Wigan. We're at the case where I can't get my head round that. It's really complicated to understand. The fact that colleagues in London have done it we can learn from that and we might see more examples of deaf people being trained as volunteers and do some of the enter and view visits.

Moving on, Healthwatch Leicester, working in partnership with Leicester deaf forum and they produced a report at BSL reports as well. Some of the interesting things was that 96 per cent of deaf people used emergency services because they didn't have confidence in using primary care. They went to an A&E for an issue they should really have used their GP about. But their experience over years of using primary care was so poor they ended up pitching up at A&E which we know is at a great strain. Similar to the SignHealth report 77 per cent of deaf people didn't understand NHS leaflets, website, and the letters that they received from their doctors and clinicians and not enough care had been taken in the production of those leaflets and letters to bear in mind people's communication needs.

Like other reports, they make recommendation for deaf awareness training, deaf friendly point of contact, better communication arrangements. The comment was made that the Commissioning groups haven't got their heads round, they are brand new, but they haven't got their heads round Commissioning appropriately for deaf services and they need to. Healthwatch Leicester were also encouraging people to sign up to the BSL charter to improve the access to BSL interpreters and the provision, the quality of those interpreters.

I want to finish with examples closer to home. In the North West, I know there are colleagues who are in the room that are not on the green but there is good work going on. There is the in mercy side. They are working together on an out patients project that patients from the boroughs do not say in the boroughs, they use hospitals in each other boroughs. Experience of deaf people using out patients in the boroughs. If you are in one of those boroughs if you want to get in fact have a chat with me and I will put you in touch with a relevant health Healthwatch.

I'm not deaf and I'm the person in the room that knows the least about deaf issues, but it's something that we have looked at in Wigan. The next bit speaker following me is one of my Committee members. She's she will introduce your self in a minute but she's a deaf champion on the board. So from day one we that deaf issues at the forefront of our attention. We have done some work with the deaf club. We're playing unwilling focus groups with the wider users and the issues we have been finding coming to our attention and communication issues, GP appointments, hospital

and A&E. Bridgewater is the community trust so there are things about health visitors and those kind of things. Difficulties in using choose and book round the mental health services the difficulty round social care, around social workers working with interpreters.

Just check what the next slide is. I haven't got a next slide. I only given you a snap shot. There will be a lot more going on within the health Healthwatch net work working with deaf communities. There are Healthwatch in the room that haven't been on the slides I know Trafford are doing work with a deaf community and Cumbria as well.

If you are not already involved in your local health Healthwatch, I'm sure they would like to know the experiences that you have had locally and the Healthwatch England website is the place to go to find your local Healthwatch if you are not already aware Sick of It. If I can plug a website, Healthwatch.co.uk. There is a search click and map that will tell you where your nearest one is. You may find that there is also a group of deaf people involved in that Healthwatch, it maybe that they are interested in finding out more about your experiences and those of other deaf people locally. Thank you. I was only asked to speak for a short moment.

Thank you. Thank you for listening. I am happy for anybody to grab me and ask me questions about how to contact their local Healthwatch. Thank you. (applause).

CLAIRE JOHNSON: Thank you Dave for great examples of how Healthwatch can work with local communities. The next person I would like to introduce is Deaf Health Champion Annmarie Stone. Anne Marie is the first Deaf Director of Healthwatch.

ANNMARIE STONE: Hello everyone. Claire, thank you for the introduction. My name is an Ann-Marie Stone and as my Chief Executive mentioned I am one of the Healthwatch Directors. Before I speak to that I have been asked to present what I have experienced. Prior to 2012 I have experienced a lot of health problems that led to frustration, difficulty in booking interpreters, a lot of time wasted, I couldn't access, I was constantly ignored and it was so problematic, I didn't know what to do, very frustrated.

Now when I became well and I was better I had time to reflect on it. I looked at the frustrations and worry and I went 'what can I do? I felt powerless to help until I was told 'well why not set up a project, do something about it?'. I sat down, thought about it and did.

I set up my own project called ' Deaf Awareness' looking at the range of difficulties and listening to campaigns, making sure the professionals understood what was going on so it was mediating with and also working with the Greater Manchester Coalition of Disabled People.

Making sure they had deaf awareness and making sure there was a deaf voice present, working with Salford Royal hospital, the Wrightington, Wigan and Leigh, hospital, and talking about lack of access and working with Greater Manchester Police; it was about being proactive and about being positive and about making a difference and to the benefit of the Deaf Community.

Having the opportunity to work with deaf individuals to talk about their problems and through that I met with Jo Slater. She came to a meeting and became absolutely fascinated at the work I had been doing and said can you see us about the Deaf Health Champions project and because of that I became interested.

I was asked to become a leader, being a Deaf Health Champion and it was about working within that as well as my own project. Obviously, it is hard work it requires initiative. Then along was Healthwatch. There was an interview for a Director. I became interested. I said to Jo 'I want to show them we can do something, we can support the Deaf Community'.

Now, through the interview, the filling out the application form, can you imagine my nervousness, I thought I was going to fail at that interview to get it but it was the first time I had been for an interview. When I got a text to say yes, you have got the position, I could not believe it. It took me quite sometime to actually believe I had actually got this position. It was like a 'wow' moment.

So now I am a Healthwatch Director and as far as I know I am the only deaf person on the board of directors on Healthwatch nationally so we can be very proud of having a deaf person on board. We do work hard. We want to ensure that the local Deaf Community are involved, such as the Leigh Deaf Centre, hearing their complaints, sharing their complaints, ensuring the deaf voice is heard, that issues are being challenged. I have to say I love it!

I know that we are making a big difference for deaf people, as well as education for the professionals about deaf issues at the same time. It is so worthwhile. I would recommend to all of you that I would like to see more deaf champions in your local area and be part of the board, I would like to see that happen.

On that note, thank you. And thank you, Claire.

**CLAIRE JOHNSON:** Thank you AnnMarie. That was amazing! Thank you. The first deaf Director in England, that's brilliant! I think every Healthwatch in England should have one.

I would like to open a question and answer session. Can I ask the speakers from this morning please to come up on to the stage and take a seat? The aim of this session is to give an opportunity for you to ask questions from the sessions we have held this morning. If you use BSL it is very difficult for deaf members of the audience to see each other so if you want to ask a question please can you come to the front and ask a question so everybody has access? We'll also have a roving microphone so if you can put your hand up.

So we have the Panel from this morning, thank you for your speeches, it has been great. Does anybody have any questions? Would you like to come to the front?

### **Q&A Session Morning**

**AUDIENCE:** My name is Janice. I am a Deaf Health Champion's Volunteer Co-ordinator in Merseyside. I recently I had an idea about how to resolve some of the issues we spoke about and I spoke with Arrow Park Hospital within the Wirral area and spoke about how to resolve some of the problems.

It is okay to deliver training to staff but once it is delivered they leave to a new position and you are left with new members of staff. So if you have a new person coming into position, let's say an induction day a briefing session, so as part of that, why not bring them into deaf awareness training right from the very beginning and that could solve a problem earlier rather than training and then they leave and then you have to appoint a new member of staff who is unaware of the issues. So why not introduce the training on an induction day? So that was an idea that we came up with and it makes it easier. So that's just a suggestion.

CLAIRE JOHNSON: So let's present that to the Panel then. What do you think?

ANNMARIE STONE: I can answer that. I would like to answer Janice's question, that's a very good point. It is about, we work very closely with Wigan and Leigh and those hospitals because what we're finding is hospitals around the area have the same problems, and that's an issue, regarding training of new staff. We thought what is the best method of providing training? What we thought was a DVD, a DVD that doesn't just talk about deafness but talks about disability and the wider inequalities. That would be in an information pack. What it would be would be film clips of actual people, people who are disabled or deaf, who have been affected by the lack of service. It has taken about two years to get that done. Finally, we have it done.

That is being disseminated to all members of staff being recruited in the health trusts. So the information is there. Have a look on line. It is NHS Wigan and Leigh website. But that's a very good point but we have a solution!

CLAIRE JOHNSON: It is very interesting to see how different staff vary in the same department. Some staff are very aware and some not aware. There does not seem to be any consistency. So that's a good point, thank you.

DR ANDREW ALEXANDER: I think the accessible information standard will expect staff to have training in implementation of the standard but not deaf awareness training---- the accessible information standard will suggest that staff have training in how to implement the standard but there's no deaf awareness training as part of that so I think there needs to be separate deaf awareness training, it should be part of induction, it should be perhaps revised, staff should have to repeat it every year or two. It should be part of appraisal that if they have not done that, they fail the appraisal. Even further, it should go back, it should be every medical student, nursing student and every I physiotherapy student. In my view it should start at school there should be BSL on the curriculum and, kids should be aware of BSL and deaf people at a much younger age. It needs to be something repeated, not just because of staff turnover but because of staff forgetting, particularly if they don't see many BSL users. So it needs repeating.

AUDIENCE: My name is (inaudible) volunteer with Deaf Champions for Liverpool. I want to ask two questions. The first is is, a simple thing, 1605, what is that, can you explain what it is?

DR ANDREW ALEXANDER: 1605 is the accessible information, it is the number, it is shorthand rather than saying to have NHS accessible information standard all the time, 1605 is just easier. .

AUDIENCE: I have got another question, this one to AnnMarie Stone about Healthwatch. I tried to get on Liverpool Healthwatch but they can't get interpreters for me so how did you get round that?

ANNMARIE STONE: Good point. When I first joined Healthwatch Wigan, now prior to Dave's arrival, at the interview, I had to admit there was a problem there and I had explained the importance of a deaf person requiring an interpreter to be involved with Healthwatch, to be part of it. It was a slow process. Slowly built it up. I am pleased to say Healthwatch understand the importance, they know that an interpreter is required to be present. They had ensured that I had an interpreter present with me within Healthwatch and externally. So far, I have not had any problems with this particular issue. Does that answer your question?

DAVE NUNNS: If I could add to that, it has not been easy, has it? We have made mistakes along the way, we have booked too few interpreters sometimes, we have booked the wrong types of interpreters sometimes and we have - because sometimes it is a meeting that we have arranged, so we take responsibility for covering interpretation costs and sometimes it is for attending an external meeting. We sometimes clash against some of our NHS and social care partners around the discussion around who is responsible for picking up those bills and I am sure many of you in the room would recognise those. From a management perspective, it is not something we really question, we have set aside a budget for it. It is not like 'we can't afford that meeting, there's a budget there for it and it is part of the support package we have in place to support AnnMarie as a Director.

AUDIENCE: My name is Sue, I come from Derbyshire. Over the years I have worked with a number of champions as you call them. I have presumed the champions are not paid, they are volunteers. AnnMarie, it is the first time I have met a deaf person actually paid to do their work and I just think it is really important that public health look to employ more deaf people to do this direct work with the Deaf Community. I went down - I don't know if anybody else went - to action on hearing loss in London a few days ago where we asked Members of Parliament to implement the BSL Act and there were four on the Panel. Not one of them agreed to implement the BSL Act. It has been implemented in Scotland, they said they want to wait. I am old now, I am ready to retire. For many years I got a BSL interpreter myself, I have hearing loss. Why aren't more members of Deaf Community employed to do this work? It makes sense all the way. If you are losin 30m, employ some of them to do the work

JIM EDWARDS: The deaf health champions are volunteers, they are not paid. There are three or 4 people involved in the scheme who are paid to do the training, to do the coordination etc, but the volunteers themselves are not paid. I think your other point, the wider point, it is important to say deaf people can really contribute to either the provision of deaf awareness, vocalising rights being involved in advocacy and where that's appropriate if anybody else is being paid deaf people should be paid just as well so it is about saying to be arrested equally and the access is on the same basis as anybody else in that situation. That's one of the things the BSL Act or that direction of travel is about trying to say deaf people should be treated equally in society. And not just BSL users, it is anybody who needs some form of communication support, lipspeakers, notetaker of deafblind communicator. .

AUDIENCE: I am Carolyn fair, Director of operations for SignHealth. Over 60% of our staff delivering services are deaf. We run the only deaf IAPT service in the country and it is important we're training deaf people to deliver services and we have run the only training course for deaf people in counselling and in IAPT and we have also done that with advocacy so the trainer course was in BSL and the assessments was in BSL and we are trying to move forward with the employment of deaf people.

AUDIENCE: It was mentioned from the Panel about accessing GP's surgeries and them providing vibrating pagers. It is an on going problem and it is awful and it is not just in particular regions, I would say it is nationally. The idea of a pager is very good but you can't give everybody a pager so you need a system where the deaf person turns up for the appointment and the receptionist gives them a pager. But what happens with emergency services? It is fine in the GPs hen they know you are coming but what happens in an ambulance if there's an accident of whatever. What happens out of hours if you are very ill and you can't communicate very clearly without an interpreter, what would you use there?

CLAIRE JOHNSON: Anybody like to answer?

DR ANDREW ALEXANDER: I think providers should be a register of interpreters, a register of agencies and what I often find is they have one contract with one agency and they may or may not make one call and if they get 'no we can't make two weeks on Thursday at 14.10' they tell the patients there's no interpreter. What they should do if the agency they are contracted with can't supply an interpreter, is to phone every other agency in the region. It may not be there's not enough interpreters and there need to be more. There needs to be a register of out of hours interpreters. On line is a back up for if there isn't face to face visible and the choice between on line or face to face should be the patients

JIM EDWARDS: To add to what Andrew said, it is almost like the deaf awareness training point as well, that there's going to be such a variety of different solutions to meet the wide range of needs of people who are deaf and have hearing loss , that what we want is deaf people to keep saying 'actually, what about this, what about that' so that people involved in healthcare and Health service provision start to recognise all the different situations where a deaf person might put at disadvantage. The pager might work in one situation it might work in another situation, but people need to be creative and come up with different answers to suit the needs of deaf people in different situations. It is your ability to keep saying 'what about .... what about ....' and it is the health service's responsibility to keep saying 'we'll try and find an answer to that'.

ANNMARIE STONE: Responding to the GP issues. Yes, some GPs do provided a vibrating pager. When I went I had to ask them please tap me on the shoulder to let me know when it is my turn. But it is having to constantly remind them and saying to the practice manager, saying 'I am deaf, you need to make improvements. Why can't you have the Board that shows the name and room number ?' 2 weeks later when I was back, it was there. The board was there. So it is worth it. If it you are having a communication access barrier, talk to them, say access needs to be improved. Give them a card, a leaflet or a number. Whatever it makes a. Whatever different ways that are there, lot

them know. Also, what do you do in terms of an emergency. I agree with both Jim and Aleks, at the end of the day staff should know, they should know about arrangements to book an interpreter but it is knowing how, working with and encouraging them. But there is the issue between GPs and hospitals so there's a gap between those two services that needs to be resolved

DR ANDREW ALEXANDER: The information standard that will be spoken about after lunch will include a duty on providers to ask deaf patients how they wish to communicate in all the various situations - booking of appointments, during an appointment and they should ask a range of questions like How do you want to know your x-ray results and tests whatever. So that should all be a duty now. The concern I have is that the providers may try and shape the provision according to what they can provide, not what is best for the deaf person, so it will be very important to test that out. Everything should be logged so every time you go to that provider, whether GP or hospital - and the two should talk, that's another provision that should be happening. I hope a lot of those things will be addressed. Provisions of interpreters is a different thing and there needs to be a decent register and hospital and GP policy.

CLAIRE JOHNSON: There are a number of questions now.

AUDIENCE: Caroline I work with national deaf services down in London. I can assure you down south the problems are identical and the work you are doing here is very impressive. I want to ask the Panel how they think the work to primary level IAPT services can be improved. Caroline mentioned sign off provisions. In national Deaf Services we had a psychological deaf provisions as well. The relationship between us perhaps has not always been perfect I don't know I am not in that branch of the service. While things have improved for us in terms of the community team for national commissioning through national health England, now we can work with anybody but they have to be second level care already,. Now there's no unfunded access to deaf psychological therapies. We used to provide it unfunded but I know---- now we need funding as well. I wonder if you thought there was any way forward for the Deaf Community to get access to deaf IAPT services without the demand for funding which is very difficult to get?

DAME SUE BAILEY: I think this is problematic across many parts of the IAPT services and I think what you have just said is are there ways of doing it without funding, to which the community in this room would say 'no, we want funding'. I think you have got to then push all the buttons that are likely to take that happen and sadly those are the buttons of inequality, patient safety, all the things ministers don't want to go wrong. I think to say we will have to make do and mend because the funds are not there, if you start from that point, nothing will happen. You have to push with solutions. This will require funding and the best way to do it is .... I think you can't afford in a community that is facing increasing inequality to start from a position 'we'll do what we always did and try to sort it out without any funding'. They will have you on a list that says 'they won't cause too much trouble so we'll concentrate on another group that will demand funding'. That doesn't sound very nice but I think that's the reality

DR ANDREW ALEXANDER: Please can I add one point? After the Lords debates on BSL and mental health, last month the Minister agreed to set up a working party to try and coordinate national care because obviously primary, secondary and tertiary, there's no proper care pathway, there's a million areas where it could be improved. The



working party maybe in the long grass but it is better than what was there before.

CLAIRE JOHNSON: Any other questions? .

AUDIENCE: My name is Jessica from Northampton. (Inaudible) spoken appointments rather - rather than national service, one provider

DR ANDREW ALEXANDER: I am sorry I couldn't hear the question. (Inaudible)

NEW SPEAKER: Would somebody mind voicing over again please

NEW SPEAKER: The question was I am from Northampton and when we book interpreters locally it has to be booked through NHS, a national service and that doesn't meet the needs of people locally in terms of interpreter access. Why is that?

JIM EDWARDS: I think it is a really good question. I am half tempted to say there maybe something in this afternoon's content that will partly answer your question and maybe one of the Panel this afternoon maybe in a better place to deal with it. I am looking--- I am getting a nod. Do you mind holding on to your question and I am sure people here will contribute as well but I think someone who is speaking this afternoon will be in a better place to answer you directly. Thank you.

CLAIRE JOHNSON: Would the next contributor like to come up please.

AUDIENCE: I am Richard Jones from Manchester deaf centre I am not sure if I have actually a question. It is about raising awareness. It is important today is not lost. We're looking at how to improve access to services for deaf people. When we talk with deaf people at grass roots level they don't want to use interpreters, they want family and friends to go with them. I met somebody two weeks ago who was quite annoyed, they had received a letter that an interpreter was going to be provided and she said she didn't want an interpreter and wanted to use her husband. She asked me if she had to use one. That put me if a difficult position. I was trying to explain about misdiagnosis, if you wanted to sue the doctor, who would sue the husband? It creates a bigger problem. What we need is strategies and those strategies would be for teaching the Deaf Community about using interpreters and working with interpreters.

AUDIENCE: I am Neil Ridley work in Derbyshire County Council. Recently I had a conversation with CGG locally because we have concerns about how to access on line appointments. If you talk about phones, texting and on line. Yes, you have them but what you find with GPs is that they do not access the on line so it is all well and good to say you have that but if you have a deaf person that's wants to cancel an appointment how do they inform them? You know if you miss your appointment three times in a row you lose your place. All the GPs, there's no consistency, it is

up to local individual practices to decide if they want to use the phone or text. I think there should be consistency across the Board where deaf people have a choice. Also it talks about the human right and the DDA, they should provided it. It shouldn't been an individual decision. At the end of the day it is about giving deaf people the right to communicate that way

DR ANDREW ALEXANDER: I hope the information standard will address that as part of the logging of how the deaf person wishes to communicate. It is a really important point to flag up when the provider is asking all the questions about how to communicate.

CLAIRE JOHNSON: Next question, please. Can you come forward.

AUDIENCE: There should be a cross on here so we know where to step!

I had an experience. I am not sure who on the Panel on this afternoon but it is a recent experience had two years ago. This is an issue about home access and my daughter. My daughter had epilepsy and when she had a fit it was about how to contact the ambulance service, so I had to run outside, get a random person, plead my case, try to communicate with lip-reading and asked them to phone for an ambulance. It was horrible thinking, if you are looking at a local connection, be it the ambulance or local GP, in terms of an emergency, when you look at the GPs that we have been talking about, how do you make that connection? Because in my situation for me it was horrible and for my daughter. So it is about getting access to services when you are in the home, because an interpreter won't always be involved either. So can I ask that question of this Panel: are there any ideas what do I do in a situation at home?

ANNMARIE STONE: Are you aware of the text service where you text 999? What you need to do is register, text 999, say I want to register, so in future if you have another emergency you can text 999 and they will respond to you. The other concern is that it is not one hundred per cent reliable. I had tried my damndest to have a meeting with the North West ambulance service regarding this particular issue and also the deaf centre said the same thing, there's a problem accessing 999 or 101 service. So there are problems within those systems but my hope is week will be able to move forward somehow in finding resolution for deaf people to be able to access the emergency service. But for now, it is worthwhile to register with 999 through the text service, and that is for your own personal safety

CLAIRE JOHNSON: I am aware of the time. I think - well there will be another opportunity this afternoon. If you have any questions, hold them for this afternoon. I can take one more. Let's take one more.

AUDIENCE: My name is Mel, I work at the John Denmark unit. A brief comment and a brief question hopefully. Professor Bailey's presentation's referred to us 'used to be based at Preswich' we are based at Preswich hospital and cover the North West, Merseyside, into Yorkshire so we're one of the three adult mental health services. The question, I don't know whether to Dave or the Panel really in terms of I don't know whether there's a way of capturing Healthwatch on a regional basis just to provide some information, it is about the Pathways from primary to

secondary to tertiary specialist mental health services

DAVE NUNNS: By all means there's a north-west network of managers for Healthwatch and we meet once a quarter. If you and I catch up we'll swap detail and try to get something on the agenda for a future meeting. Thank you

CLAIRE JOHNSON: Are there any other responses from the Panel?

DR ANDREW ALEXANDER: A quick comment about texting for 999. That was an important development but it is still not real time. It needs to be DRS video relay service so the deaf people have the same real time communication with ambulance staff as hearing people.

DAME SUE BAILEY: I won't be here this afternoon. I am a bit reticent to do this but can I leave a challenge with you? I work with young people so for those young deaf people who are going to be born in 2025, what should the future be like? While we're pre-occupied in getting it better, that generation is born into the generations of Facebook. How do we get it right and bear in mind whatever generation you come from there's a generational perspective. I apologise, I know John Denmark is there and alive and well. Can I leave you with that thought, I don't think there's anybody in the room here under the age of 18. I know there are parents. What will it look like for young people born deaf in 2025, what will their needs be? Whilst you are going to get it right you might as well get it right for the future generations. I will leave that with you. I apologise if I have offended anybody but I can't leave the room without talking about what young people might need in the future.

AUDIENCE: I would like to ask this Q of the doctor and the hospital. I had an operation back in October but the attitude was horrendous. How do you change attitude within a hospital? Get the deaf awareness. I mean I am oral as well but the staff should change their attitude. I had an interpreter present. Once the operation was finished, it was the interpreter that said the attitude of staff was awful. How can that be changed?

DR ANDREW ALEXANDER: Two ways, I think. One is deaf awareness training being mandatory. And the other is to complain. It should be possible to complain in BSL. The information standard will include an accessible complaints policy so it would be possible to send a video in BSL, as you can with the health Ombudsman now. It doesn't have to be a written complaint. There will be a duty to make complaints of accessibility. When I started to work in my hospital in 2008, two things made that work possible. There were two serious complaints of poor treatment of deaf people that arrived with the Chief Executive just as I put my hand up and said I wanted to try and improve things. Those were really powerful. So complain, complain and keep complaining and the standard will encourage complaints. So although it is useless to have extra time after being treated badly to have to campaign, that's how the system will change.

CLAIRE JOHNSON: Okay we now draw to a close and we will have our lunch. During lunch time I hope you will take the time to sign up to our prescription for change so please show that you are committed to change for deaf people's

health. Please sign up. Looking at time it is now quarter past one - no no, please be back for quarter past one. Thank you.

## Afternoon session

CHAIR: Are we ready to start back again? I hope you all finished having your lunch and we're ready to start afternoon programme the first person I would like to introduce to you today is Giles Wilmore. Giles Wilmore, Director of Patient and Public Voice & Information, NHS England.

GILES WILMORE: Thank you very much for the introduced. Thank you for the opportunity to come I speak today. Apologies for those of you who can hear I have a cold but I will do my best to try and make it an interesting presentation for you.

What I'm here to talk to you about which I believe many of you will already be aware of, it indeed will have been involved in I believe is a piece of week we're doing in NHS England round a standard. I have a few slides to go through, what we hope I will achieve at what the next steps look like going forward.

So the accessible information standard the intention is to provide a legal basis that defines the way in which information and communication support for people with sensory impairments, disabilities or other kind of sensory loss are recorded and implemented and used in health and social care across the NHS and social services. Its quite a bold and radical programme of work that we've been working on for about the last 18 months. I struggle with desk top microphones being so tall as well.

So we have been working on this for the last 18 months. Will take you through the process in a moment but the intention is to have a legally defined standard round information accessibility at the way in which information is communicated and recorded.

Why has this come about? Well as you will know per than we there are expectations created in legislation and the equalities act about reasonable adjustments but our experience, in the NHS, because of the feedback many of you have finance us and because of our own research that we have under taken is very much that say the NHS fails to meet the standards and I know that the experiences of people who are deaf, or have other sensory loss or impairments its often poor and way blow what you would expect for NHS and other public services to be able to offer. So we felt the way to address this was to look at defining more precisely what good accessible information standards would mean in practice so there was no real reason why public services like the NHS at social services shouldn't be able to meet those information standards. Therefore, we set about a project which we hoped supplements I reinforce says at builds on the duties in the Equality Act. As I will explain more as we go through the presentation, we will be using new legal powers that are enshrined in the twenm 12 health social care act. NHS England has legal powers to set information standards now. This I will be the first time that we have exercised these legal powers.

So there is lots more information that I have included on the slides which you will have in the packs and you can take away so I'm not going to read through all of the slides. I have got more information there on background but to try and keep the presentation moving I will pick out the main themes.

We've done about this work very much working with organisations and individuals, many of whom are in the room today, across a range of different groups of people with different disabilities. So as well as the deaf community we've been working with people with visual impairment and blindness, with learning disability, a range of other people and organisations that really work on behalf of people with sensory impairment or other kinds of disability that means that their communication needs are different and have to be met in a different way. The defining characteristic for us was to try and exercise this principle of coproduction. We set up a steering group with representation of services users with a range of different disabilities and organisations, many of you here today, that work on behalf of those groups because we weren't the experts in this. We knew that this was an important issue but we didn't know what kind of information and communication requirements you have. So we have had that process in place for just over a year. All our papers are published on the website six minutes after the meetings and there is documentation that is required to set legal standards so we've been trying hard to do this in a transparent way including a wide range of engagement events and activities to gather views and a formal period of public consultation which has concluded as we're going through the process of analysing the consultation.

Some of the organisations that we've been working with particularly in relation to deaf service users are on the slide, this is by no means an exhaustive list.

The scope of the standard is quite complicated but it falls into five different areas. Firstly identifying what an individual's communication support needs are. So what formats are used to communicate, what type of material do they need to be able to access and understand, particularly health care information that's often quite technical. It has to be in a format that people can readily access and is understandable the first thing is to allow people to express their communication needs and identify those. The second thing is then to record them to make sure that if the health care system understands what your communication needs are. I know this is particularly challenging because we're not yet in that kind of ideal world where we have fully integrated health and care records. I have colleagues in the technology part of the directorate who are working to try and move us towards linked health and care records. So we can pass your health care and treatment to other parts of the system. We're not there yet. So what that means is when you have a new appointment or new interaction with a different part of the NHS or care system you have to tell your story or making your request again and that something that we want to try and address through the statistics so that whatever record keeping system the hospital, GP practice, health services department, etc., as in place they will record in a prominent high profile way your information requirements so that other people providing services to you would be able to see what those are.

Obviously this is information you provide yourself about your communication needs and preferences at therefore there is appropriate consent implied within that. You wouldn't be providing information that you didn't want to share the purpose is to increase your communications accessibility.

Third area is flagging. Once recorded to make sure it can be accessed by people in other organisations that might also be providing health and Care Services to you to make sure that they are aware in advance ideally of somebody coming for an appointment or being seen in a consultation, etc., that they have certain communication needs or require information to be provided in a way that makes it accessible and understandable.

Flagging and sharing really to reinforce that point and that means you wouldn't be having to repeat those request time and time again.

Finally, meeting of those needs. So it's all very well to identify your communication needs, to record them and share them with other parts of the health and care services that you might use but there is something about how organisations meet those needs. They are equipped to provide interpreters, to provide letters in different format, to provide information into the different range of media so that people can access them in different ways according to their communication needs. We're currently piloting how they do this and surprisingly we have been pleasantly surprised that when organisations concentrate on this they find it's not that difficult. But the culture that it's not been as a priority. So it's going to be really important that we support the NHS and social care organisations to provide information in different formats so that your needs are met within the remit of an accessible information standard.

The process that we're going through is new in that there is new legislation, to set information standards that would be binding law. With the regulations in place it would be a breach of law for NHS organisations in future to fail to meet the standards set out.

This is quite a complex and long-winded process and for any of you that have been on the website you will see there is a large amount of documentation that has to be prepared to take people through the process. It culminates with a Committee for the standardisation of care information which approves standards on behalf of NHS England and the Secretary of State for Health at our expectation is that the final version of the accessible information standard will go to this Committee later in the year, probably in late spring or early summer. We're at a point where formal consultation closed just before Christmas. We're nearing completion of the analysis of all the responses and views and comments and suggestions to make refinements and changes to the accessible information standards to formally take to the Committee and say here is the standard, and obviously part of the evidence they will be looking for in approving it, it is that there has been appropriate and proper public involvement and consultation in setting the standards and that why it's important to engage and to have a process that's got lots of views and input.

Hopefully it will be adopted by summer time. Then there will be a period of 12 months before it becomes legally binding in organisations. That's to allow them to time to set up systems, process, have in place facilities, such as access to perhaps a greater number of interpreters, all the different types of in a interpreters than they have at the moment so they have no excuse when the standards is illegally in place for not meeting it. We would expect if this el process runs to plan, that the accessible information standard will become legal requirement by the summer of 2016. So the impact of the standard. I think there is a number of things. I will do all the things I have already talked about in terms of being able to make it easier for people with sensory loss impairments or disabilities to access information in a format that works for them. But the consequence of that is not just about the process in itself, as I'm sure you are far more familiar than me, its about the quality of health care, the safe tied quality of health care should improve because you are less at risk if you have access and can understand the information being shared with a, it will also very importantly, I hope, promote a shift in culture and tutors in the NHS so that if this is seen as a much more mainstream activity is the norm, its the expectation that a range of formats are available for different types of information that we will start to see a change in culture attitude in terms of health care professionals and other officers admin colleagues within the health and social care system having a much more open attitude to meeting police communication and access information needs

So the other kind of impact of the standard, are around the support that people need as well so obviously accessing information may well require support, not only to for example, use an interpreter to help you understand what's being said but also support in terms of advocacy and other functions that allow you to make more informed decisions. What the information accessible information standard won't do is if you like make those provide a framework for making those decisions for a. Its there to support at enable and the emphasis is on empowering patients thorough better information and support to be able to make much more inform decisions and be confident in discussions with doctors and nurses as they understand the issues in front of them a lot better because the information has been presented and explained thorough various understandable and accessible ways.

Se just a couple of web links to finish. The website address there is where all the information on the accessible information standard is posted on the NHS England website. Its available in BSL and easy read and a number of different for mats or in standard word or PDF documents. There is an e mail address fewer can contact us if you have queries. As I say, I know many of you have been involved in this work. I would like to an thak you profereuse for that and in the absence of my two colleagues Sarah and (Inaudible) who have been leading all this work at nif of you have met hos two ladies you know they are not to be turned back and they are doomed press ahead. Its been a long and challenging process but I feel we're now three quarters of the way there I hope that next time we come together we will be celebrating first legally information standard as accessible information for people with disabilities, sensory imimpairment. So thank you very much for your time. I think there is going to be a question and answer panel at the end so I will take questions now but I'm returned for the afternoon and I will be able to take questions at the end when we gather. So thank you very much.



CLAIRE JOHNSON: Thank you Giles for the interesting presentation. Someone said this morning they had not seen the report before so hopefully that makes it clearer for you and you can look at it on the Internet yourselves.

Is someone in the audience whistling, I am not sure if you have your hearing-aid in your bag or pocket if you can just check? Now I would like to introduce Jo Slater, the project Director for the DeafHealth Champions

JO SLATER: Hello everybody. I just want to start by saying that this project makes me incredibly proud to be a part of it and that everybody who has bothered to come here today is a deaf health champion. Thank you. I really wanted to focus in on our volunteers because there has not been that much said about our volunteers to say and the contribution they have made but most importantly the value that this project has had for those individuals involved. DeafHealth Champions can best be described as bitter pills and best remedies because we started at a point with a disillusioned immunity, disengaged, disinterested in getting involved in this project. It was not an easy sell. We felt it was important to give people choice of how they wished to engage.

JO SLATER: We're going to hear voices around social prescribing and quotes from volunteers about the impact of being involved in getting access to information has made to them. Finally some positive interventions. Louise Barry at the top from Merseyside disability federation kindly set up some groups for us and I will be reading out quotes from our volunteers. Where do we start from? I find this quote really interesting because it is true and I found it in a research paper. Despite policy emphasis on social inclusion current services and legislation fail to provide a firm basis for the full participation of deaf and hard of hearing people in British Society". we see that everyday.

In my first week of setting up this project, I went into Manchester deaf centre and I spoke to Terry, who happened to be in the centre that day in an activity. I hold him about the project and what we were trying to achieve and he shook me hand laughed. He said 'from the bottom of my heart we wish you the best of luck but we'll never do it. We tried and tried and things will never change' I said Terry what do you have to lose, I need people like you and Terry signed up. Because really, deafness is only the first hurdle. When we're looking at equality and diversity and looking across the 9 protected characteristics the health inclusion group, there's deafness in every single one of those groups and the people that are signed up to our project are from all of those groups. So to consider deaf people as a separate entity while it is important, is not actually the reality. Because we have deaf people in every community with every need. Then we're looking at literacy levels of some people and that's down to access to education and further education. There's barriers around volunteering, as we found, although we have had some amazing partners, a lot of partners say you can't accept a volunteer, we can't have a deaf person on our training course because we don't have the budget to supply an interpreter. So from a deaf persons perspective why bother?

So we give people a choice. It is absolute testament to my team of Simon - make yourself known Simon. Come out where we can see you. Janice. Stand up. Sally. Stand up. This is the team that is out in the regions, this is us, four people, out across the north-west, engaging deaf communities. It has been there passion because they all work remotely, it has been their passion that has got these people ranged and believe me they can make a difference. Because we started with a culture of empowerment and ownership, this was never our project, it absolutely belonged to the Deaf Community. You can sit down now.

So the three main things we were looking to do, because we were set up alongside Healthwatch CCG and the launch of new NHS structure, we wanted to get people involved in healthy activities and events and getting access to information, we wanted people to be involved in community consultation with their local Healthwatch organisations or hospital CCG, and maybe some of those individuals want to give case studies about their experience which we have passed on to organisations and got results from. We always want to move people to strategy representation, those people who sit on joint assessment panels, that was really important to us but what we found was not everybody wanted to volunteer, a lot of people just want to participate and you need to understand that that is where people are at. We have had volunteer who have said I have not worked for 20 years, what can I do. There's a lot of work to do engaging communities in that basic confidence and capacity building and Janice will tell you that she had one lady who sobbed the night before a community consultation because she was so terrified she might not understand, or she might be asked to say something. At the end of that event she was really confident and felt yes I can go to the next one. That's a big leap for that person.

So some quotations. All the pictures above are just a snapshot of the kind of community activities because as I said we have two roles a strategy role and community based activities. Here are quotes 'being a member of a joint strategy needs assessment groups meant I could contribute making sure clear and improved access is put in place for all deaf and hard of hearing aged from birth to end of life in a wide range of health services. This is why I value going to DeafHealth Champions courses because I was able to know what it is like, not just for deaf people who use BSL, but also for hard of hearing and deafened'. This is a lady who I believe is in her 60s and Janice might correct me if I am wrong. Cook and taste, love it very much, I learned how to cook from raw foods. I tried at home and my husband and son love my cooking. This is a lady who never knew how to cook before going on one of our courses.

I have achieved to help Kendal deaf people campaign to improve services like discussing with CCG what happens with services and how deaf people are feeling. Finally: "the walking group is a response to what people asked for. I joined a two mile walk to new Brighton. Feel healthier and at the same time involved in/out door activities, meeting a people and sharing information".. We also allow people - not allow, it is led, it is a community led activity, it is what they want. But people request information sessions on certain subjects and we'll bring health professionals in and work in partnership with different people to give that information. Again, some quotations on that impact 'I know how to interview a deaf victim of domestic abuse. I know about different types of domestic abuse which made me think about my family and friends and positive praise for the interviews and focus groups and the way we adapt to the needs of clients, these are individuals volunteering for South Liverpool domestic abuse service and Janice has joined the Board as a trustee as a deaf professional woman.

As a deaf gay man, this was the first opportunity I ever had to discuss these things. I now have a better understanding of the issues linked to LGBT HIV and aids. Because of better access, DeafHealth Champions has made for all levels of hearing loss, we have the opportunity to access better information on a wide range of health services and awareness training like cancer, healthy eating, COPD.

If we look at a few statistics we might say 'so what. We have 120 people registered as volunteers. So what my local hospice as 750. When you drill down into that number, they are all deaf people. Around 95% use British Sign Language as a first language. The three regional charities we Partner with did not have this many deaf volunteers prior to our project starting. Deaf vision in, Cumbria has said this has built trust and good relations in their communities, and a lot of excitement because it belongs to deaf communities and it is all back to culture and ownership. 63% of women - again so what? A lot of women we work with have no confidence or belief in their own skills or abilities and we believe everybody has skills and abilities and they all should have the opportunity whether through volunteering or work to fulfil and develop those.

14% of our volunteers are from ethnic minority communities and we have done a lot of work to support those people and been quite innovative. Not to keep highlighting Janice but all my team is fabulous, Janice translated a written English document into Mandarin for a deaf person in Taiwan who had beautiful British Sign Language but no knowledge or understanding of English and his feedback on that was that he felt more included.

We have got 2000 hours a year at least of community led health improvements. Three new jobs created for deaf people, as a direct result of our project, external jobs. You might say that's only 3. Anybody in this room can go to Manchester deaf centre on a Thursday afternoon and see the work the job club does that. I was a volunteer myself before I started this project. It is not easy for deaf people. Capable and willing deaf people to get work. More than three hours of training delivered to volunteers that they wouldn't have access to before.

So we asked our volunteers why did you join? Health is not talked about enough we need to know more. I am shocked to find out how in depth diabetes and Alzheimers are. I believe collective action such as this is more important in bringing change and improvements rather than individuals making isolated complaints to service providers. To raise better access to health services without having to justify our needs, being included in all means of communication, making appointments and support doing the Deaf Community to have concerns heard.

Previous involvement from all are volunteers, 90% had never been a member of a group in their GP practice or hospital, 96% never involved with pals, the precursor to Healthwatch.

What difference does it make people? I make sure everybody knows I am partially deaf, I think I manage my deafness more effectively, my wife isn't so sure but I know I have more confidence. Because of this project I am a member of my patient participation group with my GP practice and they provided an interpreter for me at every meeting and this gives me a great opportunity to work closely with my doctors tonne included access for deaf people. Before the project started you seemed to meet deaf people just at bingo and they moaned and moaned and didn't know where to go. This has increased confidence in the deaf community. As a hard of hearing person who has felt isolated for some years now it was fantastic to be able to share experiences and to communicate with those who have a greater amount of hearing loss .

A few fears, what are the fears for the future. That services will stop improving. I want to help people how important and valuable this reject has been to me and also many others. My own job prospects, it is really heart to get a job, deaf awareness companies, don't want to Other to spend money on support. Deaf people are not really worth their time and that's not good for to us feel we're not worth their time. Attitudes need to change. If this project goes then what? Deaf people are at home isolated.

So I hope that has given you an insight into why this project has been so important. Not just in influencing change but of an individual and community level. This is not a new model, it is a model I brought him from social housing into the deaf arena. We acknowledged why people disengaged, we encouraged ownership and gave the right support to the right people at the right time. If people are confident to participate we can get them out of the door and get them involved. We know that there's a huge impact in the mental health and wellbeing of people where there are community led activities and we have heard from some of our volunteers about their own personal journeys. We put deaf people at the centre of health and social care, as do all the partners who work with us.

Thank you very much

{Applause}

I

CHAIR: Congratulations to deaf health champions for what they have achieved so far. The feedback has been very, very good. If we do not complain nobody will learn anything. So deaf people are able to complain R through this service so congratulations. Thank you.

The next speaker is Angela Dawber from Stockport CC G. Angela is the head of strategic development. She's going to talk about good practice in the regions.

Angela Dawber: Good afternoon. I'm Angela. I have worked in the NHS in Stockport for seven years now. Doesn't feel like its been quite seven years, its conrather quickly one of the areas that I look at is equality at interviewer stee the one of the to topics was how can we reduce in equalities faced by the deaf community. We started with the usual data. That's a bit of the problem. In Stockport there are 710 people registered as deaf or hard of hearing. But nationally its one in six so that would quite to 47,000, we do not have a lot of data. Whenever we go to our board and say we any to invest in something the main issue is we need evidence. Why are we doing this? But we find that our health services, you mill know this when you go into a service they ask for your age, they ask your gender, race, religion, our local hospital sends me reports of services on annual basis. I got a breakdown of over 26 different religious beliefs of patients but they couldn't tell me whether any of their patients were deaf or had a disability.

So there are a lot of problems in raising issues that are faced by different communities. We know that there are issues. So rather than trying to go down the route of getting all the data in place, which is a big problem and a bit cost to institutions, we actually reached out to the local community and said, you tell us, what are your need, what are your issues with access. We're quite lucky in Stockport. There are a few active groups so there was deaf health

community is which I now no longer working as a voluntary group but there are still lots of other groups, Crawfort House is a local charity that does work for people with sensory loss. Disability Stockport is a local campaigning group. Our Healthwatch has done a lot as well. They have done a lot of events where they use online tools to get people to come along who wasn't namely hear about more traditional NHS events. They have done useful studies about the use of hearing aids which they quite like called it in the drawer. Given that so many people get a hearing aid do not have the right information, so then do not use it.

We went and spoke to people. We also looked at what information we do have in terms of complaints. We've done a lot of surveys which are online and allow us to speak to different people.

The main issues we've got back you all know and we've heard again this morning. Big issue with interpretation. A lot of this is about staff awareness. People do not know what services there are and they do not know whose going to have to pay for it. If they do know that the CC G will pay for primary care interpretation, they do not always know how to book that. We do send out information guides on a regular basis but the staff turnover issue does make it difficult. When someone new comes in they do not always know how to handle things.

Information was another one which we have already spoken about today. We just are not guard up to give people information in the format they need. That's for lots of different people but there is a significant difference and you see that in the report, if you look on the NHS website all the information is translated into a lot of languages but the number of BSL videos is very, very low.

Staff knowledge, that's a big area. I like to think that staff knowledge rather than staff culture, because I genuinely believe that when people join the NHS its to help people. If they have that knowledge they will make the effort and try to help people, no matter what the adjustment is that they need to do. Its just making sure we get all of our staff training and focus on the impact rather than the one off e learning course when they start in the NHS.

Involvement. There is a big issue with Social Exclusion. We fight on a regular basis to get people in fact in our services. The same people come to every event. They are the people who know how to have their voice heard. That's not always the people with the most needs so we have been looking at that as well as how we tackle that.

What did we do? Started by looking at our interpretation services. We'd had a big issue in Stockport that our the cost of interpretation over a few years had gone from round £20,000 a year up to 80 and the number of people requiring interpretation hadn't really changed at all. So we looked at how are we using our services. Are they the right kinds of services so there was quite a lot of waste in the foreign language interpretation. Which was mainly face to face interpreters which are is very, very costly. So we moved a lot of that over to the phone. That allowed us to stretch our budget for other areas, including sign language.

We revised our contracts and made sure that there is clear clauses in there, so there was some a question earlier on about when you book an interpreter if you have got a contract with one interpretation company what do you do? Our contract says that if they don't have someone to interpret they have to find someone else. So they quite often go to other companies and say none of our staff are available, do you have someone.

We're also looking at on line interpretation. So you will have seen through in the other rooms, some information about interpreter now, we now have a contract with them so that all of our GP practices can offer that Skype service. They have not all taken it up yet. There is bit of people are so busy that what they do is wait until it becomes an issue, it maybe a year in ton someone comes into the practice who actually needs an interpreter at its an emergency appointment. That's when they suddenly realise yes we need to set up this service. We do send the information on a regular basis.

And we now trying to look at getting that into our out of hours GP service and our local hospital, particularly beginning with the emergency department. Because in an emergency you do not want to have the distraught family members having to interpret as well as processing the issues that they are going through and what's happening to hair loved ones. That's our next step in terms of on line interpretation.

We set out quick easy guide on how to book interpretation. We have posters up in practice. How long they will stay there because you will know your practice notice board is covered in millions of leaflets about everything and anything. So we do sent that out quite regularly. Also information about ensuring staff know how touse hearing loops. One of the issues we did find in the CC G is we had ea thing own hearing loops fitted at reception but the reception staff never switched it on and because day didn't know how to use it at they scared they would be asked. So they kept it switched off. We have shown everybody how to use it. Switch it on. Tell them to turn to it t there you have done it. That's worked now but a lot is when things are different and you have never done it before staff are don't want to get it wrong so they quite often shy away from anything that is difficult but a lot of this work that we have done here in Stockport really is not difficult. Its very basic access to services.

Information, we took we asked some of the local deaf community what were the main issues for them in terms of health. We translated the standard NHS leaflets into condensed it down into a conversation and then I just sat and finmd an interpreter who was signing that information at we added on subtitles. Very easy. Very cheap. The cost of an in tufter at we used our comms team camera. That was it. We now have sixteen videos in sign language about how to make a complaint. Different health issues like diabetes, flu vaccination we're asking people to tell us what else they want to information about so we can make sure there is more information there.

We also looked at some easy read booklets because let's face it, NHS jargon is a different language. I have only been in the NHS for seven years and I do not have a clinical background, so I relied heavily on my degree in translation, I

speak five languages and I'm still struggling with the NHS language. But we have made some easy read booklets which go over basic health information in signs and symbols to make it more accessible for more people.

Staff training. We have done quite a lot of deaf awareness training and we have upped that a lot with the deaf health champions. So we've done we did some open courses an event that we held. We have done training for our own staff in the clinical commissioning group and for GP staff. We've the deaf health champions came out I trained at the GP master classes. Then they very kindly went out to 10 out of of the GP practices at gave them not only the training but by bringing a deaf individual with them they were able to say, look, in this specific practice this is the issue. This is what you need to resolve. Because like I said, people want to help but you do not know what you do not know.

We've also given training on how to use interpretation and we use patients stories at the start of all are board meetings where we film a waytioned explaining something that has gone really, well, something that's a problem, something that's a gap so that we can see how it impacts on an individual and it really turns around the conversation from being about numbers on a spread sheet, so what percentage of people were treated in the four hour target, to how that feels when you are the person who is stuck in A and E and you are worried.

Public involvement have been a big thing too. We health a deaf health event at the local hospital in may last year wheker we had 20 information stalls from local health services, social care sfrs and community groups and I do recognise quite a few faces round here who came to that. We also as part of that we had professional sign language interpreters there. We ran deaf health hraining and health checks for hypertension as well as awareness sessions on cancer, alcohol and breasts awareness which fur all signed so that we could help bridge that gap where people don't get the information in the format they need it.

We also run quite a lot of equality events and we try to put as much as we can on line for people who prefer to use that method. So we now have one of our patients satisfaction surveys on line which has embedded videos. So for every question there is video of somebody signing the question and signing the answer options so we an can get a wider feedback from more people

And we've found out this morning that we may have someone to join the local patient Panel for the local commissioning group. We got agreement to pay for interpretation for all to the panel meetings. Hopefully we can get one or more people people to come along and give us more information

In terms of next steps. Its very nice to be asked to come along I give a presentation about best practice, but I feel a bit of a fraud because this is not best practice, this is basic standard to allow everyone access to services which they should have already. I do feel there is a lot more L we need to do. So what I would like is for any of views from anyone, what more can we do? Even if its more of the same, more events, more surveys, more involving more be in the meetings, and more information in different formats. Is there anything new that wnee can do? Because realistically everything I have said to date although it is best practice to the NHS, it should be standard practice.

Okay. That's all. Thank you. (applause).

CLAIRE JOHNSON: Thank you, Angela.

Did coto the event last year, there were lots of different things and different deaf organisations there, it was a great day. Thank you.

Your presentation shows really good and simple examples of what people can do to improve services. Now I am going to introduce Matthew James who works for NHS England and will be talking about how to improve the quality of interpreting and translation services .

MATTHEW JAMES: I need somebody to voice over for me, my signing is not so good so I want everybody to bear with me. My name is Matthew James , I have been working with the NHS for the last ten years during which time there have been lots of changes, my role has changed and most have been good I have been learning about a lot of different things, about the system and politics and practice. And now I am actually back working on placement with NHS England, which has been for quite a while. I don't work for them, but generally they are my client, the organisation I work for.

The project I am working on ..... Is this on the slide. Before I start, I have to say that from what I have heard today, there has been really interest, a number of really important things happening which if you combine them, I don't think we have been in this position before. NHS England has started O talk about deaf people's needs more than ever before. Healthwatch, we know there's 152 of them, Healthwatches around the country and if you look at all of those a lot of them have done reports 22 of them have created reports about deaf people's access and there's five more coming that we know about. That is really significant.

The Sick Of It report has made a huge difference. The House of Commons has had a debate as well add all of these things has had an effect. Last week in Scotland they launched their video relay service a video interpreting service. I am not sure if everybody has heard about this? It is the first in the UK. It happened in other countries a similar service, but this will actually solve a lot of our issues, to have something similar in the future. So the DeafHealth Champions project, I have met the team and had a conversation with them and I think wow, you have to remember deaf social work as a profession, people have disappeared. It feels like the role of DeafHealth Champions is going to be the way forward.

Deaf people need the support and empowerment within the NHS there's going to be very little change until complaints have made, until there are complaints, that will make change happen. What I have heard about Stockport CCG. Wow I have worked with CCGs myself and Stockport, that has been really good to hear what's happening there is none other CCG I have heard about doing something similar with deaf people.



To look at my specific project ..... I seem to have lost my logo, I actually work for the North of England commissioning support unit, which supports the different CCGs and we're developing the support in the NHS to deliver this project for them. I have two delivery partners I am working with, one of which this social research unit at Manchester university and the other is called Education Partnership, so SORD for Manchester university on the deaf side, in primary care and education partnerships are looking at problems of spoken language interpreting within primary care. I am mainly focusing here, talking about the deaf side .

To look at the big picture, commissioners, I have to say, I really ought to be careful what I say because I am speaking at the moment on behalf of NHS England and I don't want to get into any trouble. But we have to be clear that NHS England and CCGs have a responsibility to deal with health inequalities. Interpreting and translation service for deaf people and others in the protected characteristics groups, by looking at this it can help reduce health inequalities. So health providers, GPs, they have a duty to make reasonable adjustments and this includes and involves having quality interpreting, the Commissioners and the providers both have shared responsibility. One to reduce health inequality and the other in relation to reasonable adjustments and they need to work together. So the project is looking at supporting both commissioners and providers.

We know that there's lots of issues with interpreting services. There are examples, and generally there has to be change. Some of you will be familiar with some of these comments, these words, these statements up here. Some of them are problems that need to be solved. We need a quality interpreting service. If you think about all of these different situations. People want to bring family and friends in some cases this might be right, in others not. Rightly or wrongly there still people who choose to use family and friends. There are lots of grievances but few official complaints. We need to do something about the grievances we hear of.

The time it takes to book an interpreter, that's a big problem. Deaf people go to their GP and want an appointment tomorrow. The GP will say 'sorry I have got to book an interpreter I didn't know you needed to see someone and at might take 3, four or 5 days. So the deaf person has to wait for a letter to confirm when they can see the doctor with an interpreter. There's issues with choice of interpreter. These are all things to be resolved. The project I am involved with is looking overall at those three points. The quality standards framework -- I will come to that in more detail later. That is really the link to the healthcare interpreting. What makes a good interpreting service within healthcare settings? This will then build into a service specification for healthcare which will be used to deliver different models, ways of delivering interpreting services. It might be personal but also video relays and looking in a region at a regional service.

Today, what I want to focus on is looking at the specific themes within these areas. I just pulled out five different themes; I am sure I will find more. Awareness of interpreting services at primary care level, it is not consistent. That's why access isn't consistent. That's why contracts are so variable around Britain. The interpreters - I will come to that a bit more later. We couldn't manage without them in relation to having interpreting services. How often do deaf people see their GP with an interpreter? How many assignments, how many jobs can one interpreter do in a day?

That's important because it varies and will impact on how services are .... back to the first one, awareness. The thought - we heard about deaf awareness training which needs to be repeated and repeated but we forget also that - I know that within the NHS, there's some deaf awareness training that happens but it's not mandatory. Disability and diversity training is mandatory and that happens more frequently. I want to ask you as the audience one question: if you are in a lift, you have got into this lift, there's a person next to you in the lift and they say, "Oh what is it I should know about deaf awareness". you have 20 seconds while you are in that lift - what is the one thing? What does deaf mean? You have 20 seconds to come up with something.

The next slide is actually a picture of something which I think symbolises in my view the needs of deaf people and their communication. What do you think it is. What do you think the next image is going to be? No? I had a cream egg at home, I was going to bring it with me , I forgot to pick it up, it was going to be the prize. There's a picture on the next one. It is used quite regularly by Dr Kitson who sadly passed away last year. You used to use it in some of his training sessions with students and it worked well. Okay? Nobody has any idea? That's it. Everything to do with the deaf person, to do with their communication, needs to be visual - signing. Sign language is visual. If you think about the deaf person and their eye, that means everything to them. Forget the ears. It may just help people remember the basis of deaf awareness.

I have looked at a lot of data recently and I believe to be reasonable to argue that big D, deaf people belong to the largest mono lingual group in the UK. We know Polish is the second most common spoken language in the UK, but there's a lot of Polish people who have some degree of speech in English. Deaf people, the numbers might be similar. So when we talk about policies and funding, don't forget that deaf people who are signers are representing a large group, the largest monolingual group.

So I want to move on to talk about interpreting. I think there's something around 700 interpreters in the UK, we're going to visualise ten of them. Sometimes we imagine they are all visible to work in healthcare settings. I have spoken to a lot of interpreters, I am talking about I don't think all will be interested in working in healthcare. Two work part-time. So don't want to work weekends, don't want to work out of hours. Another two will say, no I have got regular bookings, I am working in education or other settings so they are not interested. Another two say healthcare, it is just not my game, I am not interested.

Maybe they have some emotional or past experience and don't want to be working in that, not in their comfort zone. So we may be end up with 40%, four out of ten, available and happy to work in healthcare settings. That means not all of our group of interpreter are available, just a finite source. That pool of interpreters is not growing fast. So we have to use them, we have to use that 40 or 50%, we have to support them and use them in the best possible way. A lot of interpreters who work in healthcare at the moment are booked through agencies because there are bigger contracts around which means that ..... . Thinking about one interpreter, possibly could go to three different assignments in a day, 3 would be booked for a two or three hour slot through an agency. The agency might make

three bookings for that one person. It might be three hours each. So it means the interpreter is booked for the day. It might be that each assignment is only short so there's a lot of potential waste.

What if the interpreter is not restricted to the time restraints but if they are employed as part of a house team. They could then cover four, five or six bookings throughout the day. I know interpreters who have worked in localities, going to different assignments, and they have the capacity to do more than three they might be booked for through the agency.

What about video relay? Using video relay, in Britain it is new, in Scotland it happened in Sweden and America, Australia, it has been used widely for a long time. So in one day one interpreter could potentially do short interpreting assignments, this number. So many many more if they were working on a video service. I want to hold on to that because I want to think about the use of interpreters, video relaying interpreting in the future. The accessible information standards, there are more deaf people who are going to say I want to have an interpreter in this setting, I think there would be a risk of not having enough interpreters to cover the work and I think using a video relay might be part of the answer.

How many times do people see their GP on an annual basis. Average is 5.4. Deaf people it maybe the same or it maybe variable how many deaf people tell us use an interpreter when they go to see their GP? We don't know that statistic because the information isn't there, it is not available. It could be 5%, it could be 10, it could be variable in different areas. That's a concern which we have to be prepared for a big increase in interpreting demand in the future.

The quality standards, we're developing these. We want to discuss them with focus groups. There's one focus group that's going to follow on the Conference later, so the information will be based on the research and the evidence also coming from GPs. When it's developed it will help Commissioners commission better services, because what we would be able to show is what a model of a good interpretation service would look like, the benefits of different approaches, how to monitor the standards, contract management with interpreter contracts. I could give an example of ten potential standards but I won't go into all of this. The codes of conduct. Sometimes that's not enough.

Awareness and promotion of the service. The question about when it is suitable to have face to face. Some deaf people may say no I only want face to face interpreting. Sometimes that will be specifically needed. But what happens if it is a really short check up consultation. A person may never have used video relay service before. We would like them to try. Can that be a reasonable adjustment?

Thinking about response time and booking confirmation, it is not good for a deaf person to have to wait for an appointment. If the system is different, the response time could be immediate, the confirm what's happening. We need to develop interpreters in the context of working in healthcare in the future.

Complaints. The complaints system. The system is not fit for purpose at the moment. The accessible information standards will have an impact on that.

{Applause}

CLAIRE JOHNSON: Very interesting to see different issues with the interpreters. Thank you for your time. We're going to have a break now. Keep to it ten or 15 minutes because we want to finish the sessions on time. If you could be back within ten or 15 minutes. Thank you. ....

CLAIRE JOHNSON: Thank you. An excellent presentation and how audiology services can improve their services and the examples you have given today are solutions that can be achieved so well done you! I am now going to introduce Shelagh Whiteside, our volunteer deaf health champion.

SHELAGH WHITESIDE: Hello everybody. Can you hear me up there. I am Shelagh Whiteside, I have been a volunteer , I started off with my lovely boss Tony Kay, there you are. Started off running a group. We got the room and a taxi service picks me up and takes me back home, an interpreter was booked. I am in my 4th year with that so thank you Tony for that. Before I go further I want to tell you a bit about where I am now.

I had three children, Tracey, David, Tina. In 1975, I got into a car, we had a car crash. Tracey was on my knee, she was aged 4. She saved my life. So you can imagine how hard that was to live with. I had to get on with things. In 1987, Tina went out with her friend, just after Christmas and she was crossing over the road with her friend. She saw her car coming, pushed her friend out of the way and she was killed aged 14. So I was devastated. I was a mess. I started smoking pot taking pills, drinking alcohol, anything to feel normal, not to get high or anything but to feel normal. Turned into a recluse. .

I am going to cut a long story short to where I am now. I was in the house all the time, terrible depression I have had since I was 17. Experience has taught me how to deal with depression but I was stuck. I had stopped the drink and the pills, I had stopped all the negative things I was doing but I didn't know how to move forward. I had already been with Tony Kay at Aintree Hospital for a few years, but it wasn't enough, it was a once a month meeting and wanted more. I saw a group on Facebook. I went along to an induction day.

My depression was bad that day , I paced back and forth at the front door trying to push myself to take the step to get out. Anyway , I did , I arrived at the deaf centre, and from that moment I never looked back. That's because of DeafHealth Champions. I never looked back. I have been with them 16 deaf awareness training in hospital environments, doctors surgerys, tax offices. I have also done - just let me check a minute .... cook and taste, that was a massive help to me because I had gone from having a big family and cooking for a big family to an empty nest, because David went into the Air Force just after Tina was killed so I had no family at home, I was on my own. I was

still cooking big meals and eating it, I put loads of weight on. So cook and taste taught me how to reset myself and start cooking healthily and eating properly. I have Hodgkins Lymphoma as well. I had a stroke in 2006, so all of the illnesses I have had has shown me all the barriers deaf people face in the medical community.

So what Deaf Health Champions enabled me to do was to go to Clatterbridge and give a talk on my views as a deaf patient. That was very well received. I hope changes have been made because of that. Deaf Health Champions also liaise with Sheila wish heart and we all went to a few hospitals to show them how to make changes on the ward and one of them was a stroke ward that I was on. I said to tell them how to improve their services because I was a patient there. Where I am now with DeafHealth Champions, I feel normal. I do have down days but I know it will come up again. It won't be like that for ever because I have a support network in the background.

The Care Quality Commission - Andrew isn't it - he also helped. That was very inspiring. My future plans. I want to set up a tinnitus - Tony inspired me to do this - a tinnitus Support Group for BSL users, because I have noticed there's no support for BSL users who have tinnitus, they are all hearing and hard of hearing but not deaf people. We started it last year, Janice and I. We had a trial run and it was okay. There was a debate---- hopefully we'll get funding for that and it will get bigger and bigger.

As well as helping to make the deaf Health service work better for deaf people I am revitalised, I have more friends, and a better social life. It has given me my life back and long may it continue. Thank you.

{Applause}

CLAIRE JOHNSON: Your strength is amazing, thank you very much for sharing your story with us today, it has made a massive impact .

CHAIR: Hello everyone. Can I have your attention please? Okay I'd like to begin again. I want to ensure that all of you do take the time to fill out the feedback form that can be found in your blue folder and the smaller feedback form is on the conference centre itself. I do hope you take the time to complete it before a leave today.

The next presenter is Tony Kay, Head of Audiology Services, Aintree University Hospital NHS Foundation Trust, he will speak to the good practice within his region in the area of audiology.

TONY KAY: Can you hear me okay? Thank you my name I Tony I'm an audiologist. I feel like a minority myself because I'm the only audiologist in the audience. If there are others come up the front I help support me also from Liverpool because, we have got some arrival in the football. As you are aware the great bill Shank set there are two great football teams in Liverpool. Liverpool and the second one is, Liverpool reserves. He was great at putting down Everton.

Much of the work I'm presenting today about what we've done about improving deaf awareness is the work of my colleague Jennifer. We had a colleague with Jo Slater who I can't see at the moment, a few weeks ago, Jo invited us

to come along I present about what we've done about improving deaf awareness. Jennifer straightaway said yes, and looked at the diary and said I'm in Tenerife that week. Whilst I was at train station at 8 degrees this morning she's got 25 degrees in Tenerife.

I would like to thank you Jo and all the workers that deaf health champions for putting together a great package today. I'm sure you will take away loads of food or thought about improving and helping empower ourselves to improve deaf awareness amongst the services that we use.

Aintree hospital in Liverpool, its a large university hospital, it's called inry because I right near the Grand National ground which is coming up shortly. We supply services to the 30,000 services in the meet catchment area and about one and a half million regionally. That's the elective care centre where the audiology and ENT services are held. It's a brand new purpose built centre that opened in 2010. So we're in its fifth year. Its very much state of the art.

I'm very proud to be the leader of the team that have got the first accreditation of the UK accreditation service improving the quality of audiology services. Part of that looked critically at the patient experience and interviewed many, many patients. It was quite a proud moment to get that accreditation. If you want to know more, you do a web search and you will see what its all about. Our mission statement is to be the centre of choice for hearing, balance and tinnitus services the actual trust mission statement is getting it right for repatient every time. I do not think that we get 100 per cent right for every patient every time but that's what we're were kind towards

I was pleased see that some of my colleagues from NHS England were on the guest list because I that put this quote from an NHS England document. That gives you some confidence that there are people out in the field that read the policy documents. I thought it was a great quote from a patient about person centered care. I will read it out it means professionals seeing me as a whole person. Not simply focusing on a list of conditions to be treated. It means designing my health care and support in partnership with me, to help me managing my own life at live the life I want.

That's very, very powerful. I think that quotation about patient centered care, fits in beautifully with the deaf health champions partnership aims ppt engagement and empowerment, improving access to services at increasing positive patient experience and at the heart of that is obviously good communication and that's what we're trying to improve at all levels.

As I mentioned before much of the work I present is work that my colleague Jennifer has lead with expert patients like Shelagh who will speak are me, we can't do this work without the input from our expert patients that use the services.

What Jennifer and the team did was design questionnaires that were used to audit levels of deaf awareness in both in patient areas and out patient areas. There were two slightly different questionnaires because challenges on wards are different to challenges in an out patient department.

These questionnaires, these audit questionnaires were distributed and collected by volunteers that work at Aintree. And we gave out hundred in patient questionnaires and a hundred out patient questionnaires to staff. We got about 50 per cent return rate on each sample. We audited a few months later to make sure we catch as many people that we can.

What we found, and its very interesting, we have about 4,000 staff in the trust and we only gave out a 200 questionnaires, the base line audit showed us that 50 per cent of staff admitted that they were unsure how to communicate with a deaf or hard of hearing person. We also found out from the audit of staff that deal with patients on the ward that 35 per cent didn't know how to change a hearing aid battery. So if a hearing aid user came in and their health was compromised and they couldn't change the battery we have a third of staff actually caring for the patients didn't know how to change the battery and two thirds didn't know how to do a simple hearing aid check.

One thing that we found particularly useful between two audits was booking BSL interpreters in out patient departments, the first audit 55 per cent knew how to do it at the second audit 83 per cent knew how to do it. That was a good improvement, that was because the policy was implemented it went to every member of staff. We saw a good increase in that audit.

What happened to date with deaf awareness at Aintree the first thing was set up a multi disciplinary deaf awareness project steering group with patients on board like Shelagh. We had ward staff, out patient staff, audiologist, and we had a sample of other clinical areas involved in trying to shape what we're doing. Round about this time as a separate sort of policy there was interpretation translation folders in every out patient and in patient areas. Bright so they can be seen and if anybody from Sefton Healthwatch is in the audience visits in try ask where the pink folders are and alternative information about translation, interpretation services in there. We included communication tactics. This was a leaflet that were designed by the project steering group to help staff become aware how to communicate with someone who is deaf or hard of hearing.

We introduced the work that we have done BSL user alerts on the patient electronic notes so when the patient name is clicked on an alert comes up to book an BSL interpreter. Simple but effective.

We designed some shared decision making tools in easy and showing differences of picture of hearing aid colours and the benefits of using one hearing aid, two hearing aid, what it meant if you do not choose, and if you do not use any hearing aid and use assistive listening devices.

Jenny and the team designed an e learning package I was delighted to find out in January, I must update the information, 971 staff had used the non mandatory e learning package. 90 per cent passed. To improve their level of deaf awareness. We opened up a hearing aid maintenance class to all staff so that HCA on the ward, nurses, health care scientists would book in to a hearing aid maintenance class to see how to change a battery and do simple hearing aid checks. That will stop any dlain patients who have a simple problem with their hearing aid when it breaks down out of hours. My policy with any breakdown of hearing aids on the wards, the answer to the telephone call was bring the hearing aid streait way. We realise how difficult it is for the patient and for us if communication breaks down.

Jenny and the team have also done many deaf awareness presentations at nurse forums. To again help at the out patient and in patient episodes. Out of this group a cochlear implant user group was developed chaired by Shelagh who will talk about her see pt's experience. She's done an awful lot before this about improving deaf awareness at the University hospital

What we found as well during the project is nobody in the Trust knew where all the loop systems were in all the clinics. We weren't sure whether there were loop systems in all the clinics. We wo not sure if they were working. As part of this exercise we have found out where they all are. We have got funding to make sure day there is loop system in any every area. We have a system in place where the loop systems are checked on a weekly basis by a volunteer using a hearing aid and a tele coil and there will be a process I place how they report at the estates department will get that loop system fixed on a 24 hour turn around. Not only do we have loop systems where they are needed and they will. Checked regularly.

Jennifer and I presented at it was called a Dragon's den innovative funding bid. We set aside two £150,000 to improve quality of care. We put together a package to phrent to the board, that was a bit like Dragon's den zero you go in with you communication device and all things, you have 15 minutes to pitch, they are awe lined up in front of you and hi have a you have O make sure your finance is right. We had 15 minutes to pitch, fief tee minutes for questions and answers. The aim of the bid is to get the communication device, the head phones and the personal amplifier funding for every ward across A and E across medical assessment you unit and for us to give training for that. We did get the funding. We've now purchased the devices. We managed to get a very, very good price for that. Now we're going through a package to get them out to the warts. Whilst I accept this is not a quick fix to anyone who uses BSL, for somebody who present to A&E without hearing aid, we've had a couple of cases mentioned this morning, at least we have got means of communicating with someone with a moderate to severe hearing ring loss. I'm pleased that the work that Jennifer at her colleagues and Shelagh have been doing with deaf awareness got first prize in a competition called safe in our hands which was funded by a university in Liverpool. I got first prize in 2012, it came runner up in the team awards last year at the safety and quality category. I hurt last week, I put Jennifer forward for a chief. Scientific officers award and she's been shortly stakeholders as a finallyst and we get to hear on Monday where this project is going to be part of the chief scientific officers award 2015. That shows how



much has emphasis has been put on the doing the work but show case the work. The more we go out I tell people about what we too with deaf aware ness it may get another light bulb going on with colleagues.

I won't go through all this. Thats the timeline since 2012. What we've done with deaf awareness to date. My last snide because I know that we're running short it off time to make sure we finish on time is our aim is to constantly in prove deaf awareness and working across the whole trust, with wards, assessments units, and partnership with patients, the next stage is going to be set up a patient forum, and get patients involved and maybe healthwatch Sefton can give us names of patients who want to be involved in the forum. We want to make sure we get it right for every patient every time. Thats the end of the presentation. (applause).

So if you are ready for the final session today, we have a question and answer session. I would like to ask the presenters from this afternoon to make your way to the front please. . Before we start I would like to ask can we have both deaf participants and hearing participants if they would like to ask questions to come to the front. If you would like to make your way to the front to ask a question, that would be great.

Are we ready to start? Make your way forward, please.

## **Q & A Session 2**

AUDIENCE: Looking at today's presentation you have received a lot of information about improvement, access, we spoke about BSL, and so on. Sorry is everything okay? Everything okay .... ....? We talked about BSL, the loop, the hearing-aids and so on. So what I can see is a picture and it's a triangle. At the core what I think has been forgotten, at the base we're for getting things like second language users, people coming into the country, because they are even more vulnerable so my concern is yes we're talking about BSL and talking about interpreters but how do we assist those out the vulnerable groups? I work in the area of mental health and I have had deaf people that don't use BSL but would use international signs and also for those that are Muslim. Muslim women can't speak with a man, there are so many other issues that need to be considered and I would like those issues to be raised because like I said we have got the triangle but we have got the big picture stuff of yourself at the top but what about at the bottom? For me, I think 30% of sign language users, 70%, we have the ethnic languages, those coming into the country, so there are out the barriers and limitations that need to be highlighted. I just wanted it to be raised.

Angela Dawber: I know for the services we use for interpretation, you can request female interpreter. There are some people who can help us with international sign language but obviously that creates a massive big issue because it is numbers, we heard this morning and this afternoon how difficult it is to get an interpreter because there are so few, the numbers who can do international sign language are even smaller. Things like video relay and interpretation is coming into its own because we can use video relay interpreting 24/7. At the moment limited on the signing because there are limited hours it works because it is BSL. If it was widened to include ASL and out the international sign languages that could be something we could expand further

JO SLATER: I think I would like to add that we do have a number of volunteers who have refugee status in this country and it is a really valid point you are making and I think we need to go back to the volunteers and gather the information from them as to how they access. Anybody after who wants to ask me about the Lithuanian deaf couple I help who have been trafficked in by the Russian Mafia where the Russian uncle interpreted for them, those people found Manchester deaf centre and very quickly could communicate with people using British Sign Language. So I am not saying it is always about BSL. What I am saying is that as a project you are raising brilliant points, we need to go back to those people registered with us from different countries and different first languages and ask that question.

AUDIENCE: My name is Christopher Reid and I work within the CCG for the local authority. I have two questions. Before I raise those questions I have a comment. Looking at this morning, looking at the issues, the problems, the access to services, all of this is nothing new. These are issue we have seen 20 years ago and we're saying them again today and it is quite depressing. To me, it shows that there's a big problem. One of the problems with numbers of deaf people is small, it is not big enough a number to be raised as an issue. But looking at the two positives from today. Technology maybe the may forward. We speak about deaf awareness training with GPs and I am sure that may not work because it requires repetitive training. GPs don't have the time. Their time is meant to be with patients and they have to focus their attention on that. Then to think about deaf awareness repeatedly I am sure that would be effective but I think technology will be of use to a deaf person in the GP surgery her they can click on a button on a computer and make that link to interpreting services. I think that would be the better way forward.

Now, the two questions. I would like to ask the Panel: what work are you doing with the the local authorities to improve access? The reason I ask that is because we have from April this year, we had the new framework that looks at the importance of working with and changing the local legislation as we know, and it is about encouraging and working with the local authority in conjunction with them and we may know it is the better care and better and effective use of money so access to interpreters is a problem in health and it is also in the others. It is not J just a health problem. What engagement are you doing with the local authority, is the first question. The second is: offering health checks for deaf people. That's something that is already offered for people with learning disabilities so GPs have to offer every single patient who has a learning disability a health check. Why can't something like that happen for deaf patients? Have I made myself clear? I hope so.

MATTHEW JAMES: The comment really about technology and also about better care. So thinking about the CCGs the clinical commissioning groups and the local authorities are trying to work together, or have tried to work together in the past. But now because there's the new NHS 5 year forward plan, which the Department of Health is driving for the future, in that we can see---- sorry this 5 year forward view we can see quite robust plans of CCGs and local authorities working together more closely. There are also two areas of prevention. Prevention of diabetes and other health conditions, other long-term conditions, to actually stop people from going into hospital so keeping them closer to home. I think that there's a big opportunity for looking at deaf. But my concern the CCGs - sorry, ..... I think the local authorities maybe two or three ..... I am sorry (interpreter coughing)

NEW SPEAKER: I am going to apologise on behalf of the interpreter. We need a robust champion ship driver getting patients and interpreters, health and social services, because different arrangements need to be made and also service specifications. Now, there are obviously financial implications but there's a lot to be said about this issue. Funding will be one way forward. There was a programme for release recently called vanguard and that's talks about rapid entry around England but we do need collaborative working, we do need to keep raising awareness. Looking at the diabetic programme that will be national. There are a lot of deaf people who had diabetes but deaf people are not in that programme yet.

AUDIENCE: When will the recommendations from the Sick Of It report be implemented, because won't that act as a way forward for working with local authorities? The public health is going under local authority and this today should be part of their agenda. Is the report weak in that it doesn't talk about working with local authorities?

GILES WILMORE: Sorry I was going to answer the previous question. I agree about technology. What I was going to say, picking up what Matthew is just saying, I think there's an emphasis, certainly I see in NHS England with the review and greater collaboration to work more closely between the NHS and local authorities, the Vanguard s programme is another example of that. What I was going to particularly mention was work that we're doing around personalised commissioning, to promote the person centred care, that the needs of individual are taken into account when care is commissioned on their behalf and this manifests itself in some cases as a personal budget, for people with high or on going care needs, it doesn't have to be a personal budget, working with 9 different parts of the country, developing the on September of personal commission so an individual would have a personal care and support plan that would articulate all their care and support needs in this case ways they need to access information and support services, and expectation that this fits with the plan. That is definitely the future because any individuals needs are always going to be different and I was talking earlier on about the programme, the accessible information standard which is about information and communication, and that doesn't address people health per se, it is the combination of that alongside out the more person centred approach that we think will get towards the challenge that you rightly articulate

ANGELA DAWBER: Just - I can only speak from my CCG in my locality but in Stockport we have been working very closely with our local authority and we have won one of the vanguard funding places, about 200 CCGs applied for it and it is funding to develop a new model of working to integrate health and social care services and we are one of the 29 areas that won the funding. What we're looking at is developing an integrated system where health and social care work together to develop the needs of the patients where a rather than the patient having to go to different places and link them up. This is a perfect opportunity to embed the recommendation and training is vital because people with multiple conditions who will be using this service a lot maybe from the Deaf Community and a lot will be from the older population, there's a lot of people with hearing loss that will be involved in these services so these recommendations come at a great time for us to make sure these standards are in the new contract. Also, we're doing, I think the accessible information standard will help enforce that that any new service will have to have these accessible standards and we have already, some of the expert patient groups, back to the prevention side, we have run specific expert patient programmes only in BSL. We found we did initially started just having signers at expert

patient courses, but they didn't always quite translate because you are working between the two different groups, the hearing group and the non-hearing group so we have specifically run groups on diabetes in BSL in Stockport

CLAIRE JOHNSON: The second question asked by Christer was access to the health check similar to that offered to those with learning disability

MATTHEW JAMES: Personally, I think it is up to the individual. Some deaf people may avoid going to the GP for years and years because they are not confident about having communication support there and they might have a big need for a health check there, blood pressure, glucose levels etc, because they have never been for health checks around the age of 40 so they should do. We need the health champions to increase awareness, that's going to be the best situation rather than to get - increasing people's confidence and empowerment, because I think lack of awareness is what is stopping people from actually accessing this. I had a health check recently, I am fine. Because I know about that. I think we need the health champions from that point of view.

CLAIRE JOHNSON: Next question. .

AUDIENCE: Good afternoon everyone. Two points. One for NHS England and the other is talking about the future vision, 2020. You know, have problems been resolved by then?

Before I start, my name is Clinad (?) I am from Leeds. There are no conflicts between Leeds and my County and the others, but I am a Leeds supporter, and there's a Liverpool supporter on the Panel. I will to that point soon about that league but at another time.

I was interested in the presentation from audiology services. I have experience of audiology, some have good, better awareness than other wards but when you do go, make the appointment, you are sitting inside the waiting room. There's a TV screen there but it doesn't have subtitles. Do they have deaf awareness in audiology, if they don't have subtitles? I make it known, I say to reception but then I am left waiting. You can see them panic. They don't know how to get the subtitles. I told them simply this is how it is done. Whether or not that applies to all audiology services the I don't know but it is something to be considered.

Looking at the NHS England, a friend of mine living in the south went to their GP a few years ago with some kind of health problem. There was communication breakdown, there was poor communication, the doctor misunderstood, wrong medication. Unfortunately my friend died last year at the age of 40. But it stems back to the problems and difficulties of communication where as if it had not been in place he would be in a better place. I think there's an importance in the change of policy in terms of decision making. It needs to be a priority. The decision making should role out all over England. Please make a note of it. Please you know, let us influence that point that has been raised. I am raising this point because I am sure that experience is going to be shared by others. Looking at the future, 225, what is going to change. We talked about this, it is an old story and I do agree with that but if we had a finishing line, it seems like we're just about to get there and we go right back to the start again and it is the same old thing

happening. We still talk about needing interpreters and the growing numbers of mental health issues, depression, loneliness, being at home, but if we are looking at the future of other people, I believe that a way of resolving the problem, depending what you think, and this is based on personal experience, I believe we need a BSL Act. Some of you may think well why? You know, we had communication tools, that maybe the answer. We don't want tools. We want a language. The Welsh language has been officially recognised. Gaelic, BSL is not a foreign language, it is a language of the country, it is here, it is present. Because if we had that BSL - if we had the BSL language, the BSL Act, it means deaf children become bilingual, all children can become bilingual that's a better future, less communication problems, less isolation, because communication starts from school age. If you start at primary, with the BSL Act it would make it easier because it is an enforced law so you can't just forget. You can't have staff just forgetting. Basically what I am saying is the BSL Act is the way forward to influence the future. Here ends the show.

CLAIRE JOHNSON: We have got a very long queue and we have only got 10 minutes so if you can keep the questions and the points brief.

TONY KAY: I was going to quickly respond .... I was just going to quickly respond to your comments about the subtitles and I share your frustration. I was delighted to see on the deaf health champions stand a photograph of my clinic. Who took it? Janice took the photograph. It was a lot of you said we did and we engaged with all of our service users, not just our deaf service users, but foreign language etc. I was delighted to see a lot of 'you said, we did' about moving the seating arrangements around and having the subtitles. It is about engagement, if you speak to audiology departments hopefully next time you go in they will have subtitles on

GILES WILMORE: I will try and be brief. I was really sorry to hear about your friend, that's an awful experience. I am not claiming what I was talking about earlier about the accessible information will solve all life's problem. If people have accessible information and are communicated with in a format they can understand and be clearly understood they will be in a much stronger position to get involved in what we call shared decision making to have dialogue of equals with commissioners and out the health professionals and make sure their concerns, fears, questions etc are properly understood so I think it is important in that respect and as I said in my previous response, it is a fundamental building block to adopt a person centred approach I travelled over P nines from West Yorkshire today I am a Bradford city fan , I hope you will cheer for us in the FA cup

NEW SPEAKER: About NHS England, there are three things happening simultaneously and three steps forward. As Giles said the acceptable information standards are going through and a programme looking at the quality of interpreting service to do my presentation this afternoon and the third thing is something I am working on with the patient experience team, which is looking at how the complaints procedure can be more accessible for deaf people through NHS England website. So hopefully in the future the technology will be a big answer and a big help but technology means that we can access interpreters and I should say that in Scotland what they have launched there, BSL Connect, and it is soon going to be that every deaf person in Scotland will have basically an interpreter in their pocket in one of these little devices. I have got one, I can click. I will just show you in two seconds. There's an app on the phone here. You press a button, there we are. There's several different logos. There's one there for Scotland. I

click on that. It says connect Scotland, it is ringing, it is live. Wait for it ..... . There we are. There's an interpreter! Okay. It is as quick as that. 30 seconds, and that's it, you have access to an interpreter if you are in Scotland. That's available in Scotland. In England, not yet. Thank you very much to the interpreter on the screen

CLAIRE JOHNSON: Isn't that amazing thank you for showing us that and let's hope England can achieve that at some point in the future.

AUDIENCE: My name is Aleks I am a doctor, psychiatrist, working in Northampton, at the deaf services in St Andrews. I am hearing but I prefer to sign because I communicate with so many deaf people. So hello everyone. Today has been a fantastic day. Thank you, thank you, thank you for making it so interesting. Now I am wearing two hats. One as a psychiatrist. And secondly as a child of deaf parents. There's fantastic work being done all over the place and really interesting but where do you make the links to all of this? You know, research are old. When I was a child of 6 I was asked the problems of deaf people. Going to the doctor. I would have to explain this. I thought they would go, I don't know. My son. I was there six years old. I am six and I am interpreting for my father. It is gobsmacking. That story is not new. How do we make this better? It is not just about research. It is about doing something.

CLAIRE JOHNSON: I have to agree with you, that story is still happening today. We should be stopping children from interpreting, they should not be interpreting at a young age and I am sure all the Panel would agree with that. Thank you. Next question? .

AUDIENCE: I don't want to give you my life story. Or should I give you my life story. I am .... University of Manchester research team. I have a meant to make based on the theme of accessible information standards. Today is the first opportunity that we have got this information about what is accessible information standard that is going to be done from the NHS England perspective. The Deaf Community perspective maybe different because if I am signing, I will say the NHS England have done an accessible information standard. Will it say that the information will be accessible in my language? If it is talking about my information, it becomes accessible to NHS England to give me accessible communication. Can we see what's happening here? I want to ask accessible information standards - do you mean that my personal patient records with you become accessible to you for you to understand what my accessible communication requirements are? It is not just about all healthcare information is accessible in BSL. Is there going to be consideration regarding accessible information standards? Is it fit for purpose? What is required

GILES WILMORE: If I understand the question rightly, are you asking for all the information in your personal health record to be translated into a different format? Is that what you are asking? No? Okay. Sorry I have misunderstood the question

AUDIENCE: The title of this initiating going out in 2015, says 'accessible information standards'. From your presentation today you have explained what it actually means. It is about I have my personal records with NHS England so that staff will be aware of my communication requirements. But the actual term it's self 'accessible

information standards' what it means to me is that you will provide an all of the health related information, it will be provided in BSL so the Deaf Community will assume all I have to do is press a button and I will all that information in BSL. That's not what you mean today because it is about I become accessible to you, NHS England. I am asking is the term 'accessible information standard' appropriate

GILES WILMORE: I think what I mean is somewhere between the two different positions you described. So firstly it is not for NHS England to use, NHS England is leading the work as looking to set the standard but it would be for healthcare providers and social care providers, hospitals, doctors, Social Services etc to use for people delivering health and care services to you. The emphasis on recording communication and information means that you have as an individual, a .... it maybe BSL or different formats but the onus is on them to provided information in those formats. That's not just support in communication in consultations but record and letters and other sources of information. It is not going to happen ever night, every bit of information in a different format but if you have expressed a need for communication in a different format whether spoken face the face meetings or written, it will income the format you can understand so your interactions with the Health service are accessible, so I guess that's what we're talking about. .

AUDIENCE: Thank you for that

GILES WILMORE: You are welcome. .

AUDIENCE: Hi everyone. I have two points. One is from me myself. My name is Helen and I am an interpreter. I would like to ask a question of Matthew. You spoke about out of hours interpreting let's say at three o'clock in the morning on a weekend. Within my area, the answer is yes, we have out of hours emergency service but what does it mean? It is literally saying either interpreters are willing to be on a list, that's it. At three o'clock in the morning a phone call is made. No answer, no answer, no answer. Oh dear. The theory is saying there's out of hours but in reality it is rubbish. What about scrutiny, what about monitoring, is there actual provision? The second point is about flexibility. Let's say somebody comes to me and I need to be there at half past two or three o'clock. The agents say they phone out, send out text messages or emails. I can't do it at half past two. Can you see the point I am making here? That's with Matthew, those two points. For the CCG, thank you for your presentation, it was wonderful. My colleague works in SORD. She said it was a shame, what a pity that CCG do not share the information so that it could be shared nationally. Why is it that one CCG does all the work and all the others are clueless so they end up with duplication of work and effort. Why is that? So is there a system where you could share and disseminate information and good practice. So those are the two points. Thank you

MATTHEW JAMES: Just a quick response then. The out of hours query I have not been involved in any understanding about this but yes, that's certainly needs to be checked out. If someone is saying there's a service it need to be managed properly. The police have a similar networks of people, whether it works well I don't know but I have made a note, it is something to follow up on. Flexibility about timings and bookings, that's really critical because I know that there's often a lack of direct communication between the GP and the agency and the deaf person and things are

going round in a circle to say we have an appointment at half two, the interpreter can do that, can you do this time, three o'clock, can the deaf patient do that? The process of going through this, agencies and sometimes agencies are sub contracted to sign interpreters, it can become a mess. There needs to be a clearly managed service for interpreting and that will solve those issues. The CCGs. I have to say, really there has been lots of change from, so much change from when the PCTs devolved responsibility to CCG;s. In some areas interpreting services were handed over and other areas they weren't and they were passed to area teams to be managed by CCGs and there's a lot of inequality around the country, what we call, there's something called a commissioning Assembly, which is representatives of CCGs and I am passing on information through that to make they can better look at a collaborative way of looking at a regional basis of services. That's work in progress

ANGELA DAWBER: When I made those information leaflets in sign language, I brought in our local Healthwatch, colleagues at the Council and I offered all the videos to the Greater Manchester CCGs, but I didn't get any feedback from them. On a positive note, I have spoken to some people at University of Manchester and they have said the students in the audiology team are very happy to make more and I could source permissions to do the technical explanations I know absolutely nothing about. I am happy to share them. If your colleagues want to put them on their website too great and I would be happy to do more if people are interested.

JO SLATER: A quick point to say when we talk about good practice being disseminated, that's part of the DeafHealth Champions, promoting good practice across the regions and we hope to continue and we hope volunteering initiatives are mean steam so deaf people are influencing. .

AUDIENCE: Sarah. With the introduction of the new Care Act coming into force next month there's going to be greater responsibility on local authorities and those providing regulated care and support services in terms of looking at holistic support for service users and particularly in the use of advocates and I would love to see increase in the provision of deaf advocates, particularly in medical and health appointments, because you have the communication support, you have BSL interpreters for that but you need advocates for supporting your rights making choices and decisions. I would love to see that. That would increase the skill set of deaf people and also the support towards their service users. My actual question is for anybody on the Panel, or Matthew in particular, I understand that there's going to be a framework introduced for capping the costs of BSL interpreters are interpreters in general and that could see a great decline in the amount of interpreters available for deaf people. So, how will NHS England be looking at funding around that provision and access to interpreters if there's going to be greatly reduced because interpreters can afford to use interpreting as their single income, particularly for specialists services that have literally no funding for interpreter access and deaf people are left to figure out the issues on their own because nobody will pay for interpreters for them.

MATTHEW JAMES: I am happy to respond to that. I have met with the crown commissioning service so - sorry the crown commercial service in Liverpool who are involved in the draft framework being talked about. The next draft will be released sometime soon. In that next draft framework , I believe they are going to say that all interpreters should be qualified, registered with NRCPD, there has been a big debate in the past about this. I don't think that



there's a risk of a shortage of interpreters being prepared to work. My view is that the framework has still got potentially one problem that might be challenged. There are five different lots on the framework, there's something called lot 4 which is focusing on face to face interpreting and relay interpreting. I have a problem with that. I have been talking to them about this. I think it should be national with just three preferred suppliers registered there to cover the whole of England, that's what they are recommending. I think they would struggle to deliver that within every region of the country every region will be fighting over the number of interpreters to go through the three preferred agencies. I think what would be better is if lot 4 was made regional so each regional could have three preferred suppliers to match specialised needs within that region. That's my response to that one. I think there will be a balance of demand - supply and demand.

CLAIRE JOHNSON: The final question.

AUDIENCE: I am going to keep it short because we need to finish off. I had considered whether .... this is my experience. I am team leader of SignHealth in London give supported a lot of people with mental health, any issues to do with depression and so on in supporting them it goes to psychologists, assessment, the procedures of diagnosis. With all the funding you can't have a deaf service like as you know Springfield hospital where they have specialist provision where they could assess mental health and make that diagnosis. Now, some clients can't be referred to spring filled because of funding so will be referred to a local mental health unit. A lot of discussion has been made on the need for interpreters and booking of interpreters, but what we need to look at it diagnosing deaf people with mental health issues because often psychologists have no clue or understanding of what it feels like for a deaf person, they have no clue of why they have depression. I can see and empathise myself as a deaf person but they can't see what do you mean by this or that. The assessment is never a success. But the point I want to raise is that we need professionals to be involved and know how to assess and diagnose appropriately, that they have an understanding of deaf identity, deaf culture, deaf views because we have to say no this is what they meant but it is not being understood. That means the assessment has failed and they are unable to provided the service and I think that's the biggest problem I have seen. So that's it.

CLAIRE JOHNSON: Okay. Thank you. Oh there's one more. .

AUDIENCE: I just wanted to say I work at the John Denmark unit and for people with mental health problems as well as deafness, there are three regional units. There's the one in Prestwich, John Denmark unit the one in Birmingham, the Denmark unit and the one in London, now Springfield hospital. These are all tertiary services which means you need to come via, a secondary service, so if you know people, that would be the route to take. .

AUDIENCE: In the old days in my time you could go straight to the psychiatrist, now you have to go to the GP first, they would make that referrals and that's where the problem lies because they can turn round and say no. That's where the problem lies. .

AUDIENCE: You need to go to the GP and get a referral to the local mental health services and then come to the tertiary service, if you have problems accessing that is an issue. But I see people, I still work there.

CLAIRE JOHNSON: We have to draw this to a close because I can see people putting on their coats and getting ready to leave. Today has been amazing. The wealth of experience that has been shared to all our presenters, thank you very much for your presentations and your efforts. There are solutions that had been offered today that you can utilise within your own local areas. I want special thanks to the deaf health champions, staff and volunteers for all of their hard work today. Thank you so much

JO SLATER: thank you for Sam Davis and .... and SignHealth for putting all the work in and supporting me and Roger Hewitt has been phenomenal. Claire for stepping in in her own time, she is a busy professional woman, running her own charity and growing a baby right now. Tony and Sheila are doing the graveyard shift that nobody wants to do, thank you for that and for those who stayed until the end, we appreciate it, thank you. And one more Amanda, thank you to Amanda, she is actually a deaf person a professional photographer and you will see the pictures on our website. And a sign language interpreter