**Burnley (East Lancashire) – Listening to our communities’ event (07/06/2023)**

**Participants**

Group consisted of over 30 members of the public, (including residents, BSL interpreters and deaf community, individuals with both physical and learning disabilities, individuals from the BME community, VCFSE organisation representatives and Healthwatch, Primary Care and PCN/Practice Manager representatives); the Integration Place Leader (East Lancashire) Jackie Moran, and ICB C&E team members – David Rogers, Lucy Atkinson, Jeremy Scholey, Shelley Whittle and Rashda Iqbal

**Background**

Following the formation of Lancashire and South Cumbria ICB, we have been keen to progress the statutory duty to involve the public by developing a programme of listening events covering Lancashire and South Cumbria. This forms part of our process to reach out, listen to and involve our communities. The first of these events within each area are being used to reconnect with patient groups that existed before the ICB was created. The event in Burnley was the fifth such event to be arranged, with previous events in Barrow, Blackburn, Blackpool and Preston.

David Rogers introduced the session and there was a focus on the work of the ICB and the local priorities and challenges from Jackie Moran. This was followed by attendees moving into two breakout sessions, each facilitated by members of the Communications and Engagement Team.

Attendees were invited to talk about their experiences of health services in the area; what was working well, what isn’t working well, and how can we improve those services? Attendees were asked to focus on health services specifically.

**Feedback**

The services or issues listed below are taken from the group as a whole and based on the lived experience of those within each group. Experience of what is working well for members of one group may not necessarily be working well for others. The same applies to what may not be working well. However, some of the points made can be applied more generally across Lancashire and South Cumbria. We are building a powerful bank of insight about what matters to people in the East Lancashire area, as well as across Lancashire and South Cumbria. With the conclusion of the listening events in July, we will add insights from North Lancashire to create a compilation of common insights and experiences for the system. However, this brief report is for the East Lancashire area to contribute towards improvements as well as an ongoing dialogue about what is important to local people.

The following section is broken down into sections according to the topics raised, discussion points, key issues, and finally some action or learning points. The section on action and learning points is purposely left blank at this stage to allow for others to contribute to this report. Firstly, we will share the draft with the group, and then we will share this with key NHS leaders and their teams to see what we can in response to the key issues.

**GP services**

**Discussion:**

**GP appointments** – Trying to book an appointment is still an issue for many patients. You have to call at 8 am in the morning or wait several weeks for a pre-bookable appointment and by then your condition is worse. Even if you are successful, it is usually a few weeks wait. Waiting times are very long. Some GP surgeries say they will ring the patient back over the ‘phone in two weeks’ time. Even if you go down to the GP at 8.30 it’s too late – all the appointments are gone.

Some GP surgeries are using an App to support their appointment systems, but people need to know about this, and this doesn’t help the digitally excluded.

Even with an appointment, getting to see a GP is difficult; often you are directed to a nurse practitioner instead. Once you see a GP often the care is great.

The consensus of the group was that they feel palmed off – not just by the GPs but to other professionals too.

PCN representatives (Practice Managers) attending gave the Practice staff perspective. It can be horrendous. There is a lot of administration, red tape and the ask from patients is relentless. Everyone wants to see their GP – they don’t want to see other health professionals. There is a first contact physiotherapist at the Practice; all you have to do is ask for them, but everyone wants to see the GP.

There also need to be wider conversations about what services and health professionals are available and how they can be accessed. If people don’t know a service is offered, they are unlikely to ask for it. People just perceive primary care as a GP, dentist, pharmacist or optician, not other professionals too.

Dr Naheed explained, things can only improve if communities are working together with their GP to improve them. Patients also need to take responsibility for their health.

**Receptionists** - Receptionists in many practices are not really receptionists anymore; they are working as triage staff. Perhaps they shouldn’t be called receptionists anymore. Patients often don’t feel happy talking about their ailments/problems to the receptionist but may feel differently if they were seen as part of the triage process, rather than as people who often seem to be trying to put people off/blocking access to the GP.

However, some attendees felt receptionists were acting as a block and do not know what is going on. They need to be well informed (Receptionist asked about the hub and spoke service knew nothing about it, even though the service was sat at the same reception counter).

**GP online appointments –** Online diagnosis is not good as you can send a picture/photo of your sick child and you are told its chickenpox, but when you go to the pharmacy you are told it is foot and mouth! So, this online appointment is causing misdiagnosis.

Having online appointments doesn’t help when you need to build rapport. Face to face means you can read people’s body language; you can see more clearly their facial responses or reactions. This can be missed online and doesn’t work at all over ‘phone consultations. For some consultations or some people, only face to face will work.

**GP services** – Miscommunication: a patient was referred for appointment and when they get there realised it wasn’t for the condition they discussed with their GP, so the appointment was a waste of time. Another patient referred for a blood test, but when attending their appointment was asked by the nurse if they knew what the blood test was for (as the patient has a few conditions such as type 2 diabetes and heart problems etc), but they did not know what the blood test was for. This information should be communicated on the referral and is unprofessional (and should also be on the patient record). As the patient didn’t know they had to go home.

Both these experiences highlight miscommunication and wasted time and journeys for both patients.

Other patients have more positive experiences. One said their GP and the care at the GP practice is brilliant. Another patient who has ME has a named GP who is brilliant and really understands the patient. Another was quite pleased with the new phone system installed at Parkside surgery – process is if you ring you get a message to leave your number and someone will ring you back in 20 minutes.

**Continuity of GP care** – Continuity of care is a big issue. If you need to review your progress, but see a different doctor each time, then you have to go through the whole problem and care journey each time and each doctor will review it differently. You expect a review of your care based on your first medical assessment/appointment, but if you see a different GP, you must go through it all again and each GP has a different approach. Lots of locums are used.

Dr Naheed also indicated that most of these problems were because there is no continuity of care, and the GPs are not staying in one practice – they keep moving around and they are not taking responsibility. Continuity of care is vital. If it is the same GP, the GP will know the patient and all the health issues. Every practice has good GPs and good practice, but the challenge is keeping the GPs local. You find once the GPs are qualified, they move out of East Lancs. Good GPs are burnt out.

(Please note there were a range of other GP related issues raised which relate to the deaf community – these form a separate section)

**Key issues**:

* Communication between GP and the specialists needs to be improved so that patients are not having a wasted appointment/journey
* More informed use of allied professionals
* GP appointments remain difficult to access with long waiting times
* Difficulty in recruiting GPs to the area, and keeping them
* GP burnout
* Online appointments are not the solution they are made out to be and should not replace face to face appointments where these are necessary for good diagnosis and care
* Receptionists need to be well informed; should we move away from the traditional receptionist role

**Action/learning points**:

**Pharmacies**

**Discussion points:**

Pharmacies are looking to bring the ‘Community Pharmacy Scheme’ back. Patients can access over the phone, online and via GP surgeries. If appointments have all been booked at the GP surgery, pharmacists can see patients and if they can help, they will, but if it’s something serious then they can refer back to the GP. The pharmacist explained this scheme was piloted in Blackburn with Darwen and it worked brilliantly. This would take the pressure off GPs.

It was generally felt that pharmacies were good in the area, but a query as to why, when prescriptions are given wrongly, pharmacies do not take them back even if the blister-packs are unopened? This is a waste.

**Key issues:**

* Re-introduction of this pharmacy scheme in East Lancashire
* Sensible reduction in expensive waste of medication

**Action/learning point:**

**Hospital care**

**Discussion:**

Staff in hospitals do not always speak English.

Letters are not always sent – they use email or texts but not everyone has email/internet or smart phones.

Referrals take too long.

Trusts do not take complaints seriously. They are so concerned with litigation that their responses are always defensive; they admit to nothing wrong or to anything that can or need to be rectified/put right. The organisation cannot learn from this; things don’t improve as a result.

Communication between GPs and hospitals is appalling.

A lady in the group explained her father was in Blackburn hospital for a blood clot. Patient had to have further tests. The care at Blackburn hospital was good, however communication very poor. Patient and daughter were told on the way to the hospital that patient had pancreatic cancer.

**Decision-making** – Patient had and operation at ELHT to remove wisdom tooth. The operation was successful, but the patient started to have seizures and had high blood pressure but was still discharged and sent home. Patient then went to GP who sent patient back to the hospital due to the seizures. Patient had a locked jaw whilst in hospital but was still discharged regardless of this. After this patient started having mental health problems and developed a stammer and cannot work now (this now overlaps with mental health topic).

Patient wanted to be seen by a mental health psychiatrist and kept requesting this from their GP, who refused as the patient wasn’t in crisis; referral only happened when the patient changed GP. Patient said new GP is fantastic (and will now only see this GP) and patient was finally seen by a psychiatrist, and it was found that patient needed high intense therapy. Patient had to fight a battle to get to that stage.

**Key issues**:

* Communication between teams
* Waiting times
* Not being listened to
* Complaints are not taken seriously and cannot lead to learning
* Discharged when patient still had untreated needs

**Action/learning points**:

**Deaf community access to services and BSL Interpreters**

**Discussions:**

One person in the group has a regular interpreter and prefers this but its not always possible but this doesn’t work as the information may be incorrect. On one occasion this patient turned up for the appointment and realised the interpreter was a best friend. This wasn’t nice for the patient, as there are things about your health you do not want your friends to know. Being sensitive to the needs of patients is key.

**GP/hospital appointment quality and equity** - Members from the deaf community have a serious issue of not being provided with an interpreter for their GP or hospital appointments. They are told they need to arrange and book an interpreter themselves. It is a constant battle to get GP Practices to call/arrange for interpreters for deaf people. They refuse to do it. Riverside GP Practice refused to book an interpreter for three years. Some GPs will send a text, but many deaf people do not read well; even if they can, if the patient can’t make the appointment they can’t text back.

By not sending information in a way that deaf people can access it and making it so difficult for deaf people to contact or interact with the Practices, this has a knock-on effect on appointments. Not knowing there is an appointment; not being able to cancel or rearrange appointments; not being able to understand the information given at appointments – it all has a big impact on the health and wellbeing of deaf people.

Where there is access to an interpreter, some deaf patients would prefer to have the same interpreter as the interpreter knows them and they don’t have to explain everything again, but this doesn’t happen, and this isn’t providing a good service for the deaf patients. BSL is a very visual language and involves a lot of body language so as an interpreter you need to have a good rapport with the deaf person, and they need to trust and be used to you.

**Contacting a GP:**

Ringing for a GP appointment at 8am is not possible for deaf people. With the GPs not willing to book or fund BSL interpreters, this makes getting a GP appointment almost impossible. Arrangements where the GP surgery will ring a patient back is also of no help to deaf patients.

**Barriers in hospital:**

When attending hospital appointments, the professionals refused to take their mask off, even though they knew the patient is deaf. How can things be understood when this is happening? Sometimes an online interpreter is arranged but the screen picture quality is awful, so communication is poor. On other occasions deaf patients are shown a book which has pictures, and the professional communicates with them this way, instead of having an BSL interpreter present. Some of the pictures, are silly and it makes them feel they are categorised as having a learning difficulty and are made to feel stupid. They are not stupid: English is the deaf communities second language; it isn’t their first language.

Not having a BSL interpreter at the appointments is a massive barrier for these patients. Also going to different departments for different health services, is very difficult for deaf people too. Procedures are postponed because there is no interpreter. There are no interpreters in the Emergency Department.

Health professionals think that deaf people “can lip read, she’ll be fine, she can cope”. Nobody should have to just ‘cope’. Often a deaf person will say they are fine when they aren’t. Not all deaf people can lip read, just as not all deaf people use BSL. Some use one and not the other; some deaf people can do both.

There was a member of the deaf community who was refused/not provided with an interpreter. As a result, they couldn’t talk about their condition and this led, eventually, to having a leg amputated – this could have been avoided if an interpreter had been provided at the very beginning and the problem properly identified.

Too much jargon is used in the NHS – deaf people do not know what this means.

**Communication with and information for the deaf and people with other sensory impairments:**

There are a lot of good services out there that nobody knows about. The deaf community, and other communities, are not seeing the leaflet or information about these services. They aren’t produced in BSL, or Braille or in other languages or ways that make them accessible to people. The young access digital information, but many can’t access this and don’t know what is available.

You need to give people information in the format they need. Deaf people are not able to read leaflets or written discharge letters (often only people who have become deaf are able to read English well). If a deaf person is given a letter or information about their care, or what they need to do get better, they can’t read this unless they have an interpreter to support them, but that support isn’t readily available. Deaf people don’t have interpreters on hand to work for them – they can’t afford this anyway.

Knew someone who requested their letters in brail, but they were always normal, written letters. They had to keep going to a third person (didn’t have family) to read it out. These may often contain sensitive information. It is unfair to expect someone to share private and sensitive information just so that they can understand what the health service is telling them. Sometimes by the time these letters were interpreted it the appointment was missed.

Elderly members of the Asian community, who don’t speak or read English, also struggle to read letters and information provided to them, as these are always written in English. There is a delay while they go to other family members to get this translated for them.

**BSL contract:**

It used to be part of the BSL contract that the interpreter service issued information to the deaf community. Since the interpreter contract defaulted to the current provider (Co-Sign – based in Blackpool), this has not been happening. People in the deaf community in this area won’t use Co-Sign. They never come in person, always try to do it online. The deaf community here don’t know them and prefer to use the local BSL interpreter service, but this comes at a cost because they are no longer the official BSL providers for the NHS in East Lancashire.

**Patient records:**

GPs and hospitals need to have a way to flag that a patient has certain requirements on their patient records. Visually impaired; deaf; frail; someone with autism; something that tells you they may require information or a service in a different way to others. Should be simple to do. Why can’t this be done?

**Positive steps:**

One male in this group said he had a very good experience with his GP and other health services and cannot fault them.

PCN/Practice Managers: Why don’t the practice managers invite someone from the deaf community, from advocacy or other services, as guest speakers, so that they can hear and learn directly from these groups. (The PCN leads at the meeting welcomed this and said they want to reach out to and invite groups in so that they can provide a more holistic, integrated service).

**Key issues**:

* Communication between patients from the deaf community lacks equality and equity by not having a BSL interpreter present at the appointments
* Professionals not taking face mask off when talking to deaf patients
* Information needs to be provided in the correct format for the deaf and others with sensory impairments or risks missed appointments, poor diagnosis and poor care/treatment – miscommunication can be catastrophic
* Lack of training, understanding and empathy amongst health professionals – it isn’t good enough that deaf people may be able to ‘cope’
* Systems (telephony/waiting rooms etc. for access to GPs, in hospitals etc.) do not support communicating and delivering care to people with sensory impairments
* Continuity of BSL interpreters where possible and to check if the interpreters have any relationship with the patient i.e. friend or relative
* Communication and the way sensitive information is relayed to patients needs to be professional and show empathy
* There should be appropriate flags on patient records
* Jargon and acronyms meaningless to deaf people and others
* Existing NHS BSL interpreter contract is not fully supportive or supported
* Local PCN leads to reach out to deaf and other community representatives

**Additional information (letter given by deaf patient at the listening event)**

1. Last march – was the last time I had been to see the GP – he retired
2. Every time I go to see the GP I am told at reception to book an interpreter and then phone back – it is the GP responsibility to book – I cannot ring as I am profoundly deaf
3. Last September 2022, saw 4 different GPs for an eye issue. They don’t understand that I cannot understand without an interpreter present nor can I ring for an interpreter due to being profoundly deaf – receptionist was not helpful; I refused to see GP without interpreter.
4. Frustration with lack of communication with face masks on and refusal to take off.
5. Last September 2022 – GP referral to hospital for cataract surgery. Appointment through, went for ophthalmology appt in three different rooms – difficult to navigate, went again February 2023, told that the appointment for surgery will be next January
6. Face masks used instead of shields – can lip read slightly better.
7. Interpreter service at GP isn’t good enough, they don’t respond
8. Push deaf out of the way – disgusting attitude by those who can hear.

**Action/learning points**:

**Mental health**

**Discussions:**

Patient was referred to the mental health crisis team and wanted to be seen by a mental health psychiatrist and kept requesting this from GP, which didn’t happen until patient changed GP.

Patients with mental health issues are referred to Mindsmatter which is a telephone service. A lot of these patients are suicidal, and pathways need to already be in place to deal with these calls, but this isn’t the case.

Having no mental health beds at Burnley General Hospital is unacceptable. Patients being referred to a telephone service is not acceptable.

Systems are failing patients. Those making decisions are blaming the social workers but it’s not their fault, its those higher up who are not acting on what they are being told.

There are long waiting times for mental health counselling appointments – these are at least 9 months. People will be in crisis by then.

Emergency department is a massive problem for people with mental health problems. They have one gear they use, and they don’t move from this gear/mode. Even if there is only one patient waiting, why is it still taking four hours to be diagnosed?

**Key issues:**

* No mental health beds in Burnley
* Suicide risk – services not there
* Pathways in place in the Mindsmatter team when they come across suicidal or more serious patients, so that these patients access the right service quickly.
* Counselling appointments waiting 9 months plus
* System doesn’t work from lived experiences, it is trial and error
* No dignity in Emergency Department for mental health patients

**Action/learning points**:

**Health Passport**

**Discussions:**

One member of the group talked about how the ‘health passport’ has really helped when attending appointments and explained how all your medical conditions, your medications, details of your doctor and all your health triggers and traumas are on there. The rest of the group had not heard about the health passport and said this is brilliant as it would stop patients re-living their trauma and experience again and again every time, they were seen by someone new and having to explain everything from scratch again.

**Key issues**:

* Everyone should hold a health passport

**Lancashire:** <https://www.lancsteachinghospitals.nhs.uk/media/.resources/619e28d5df1d49.95281303.pdf>

**East Lancashire:** <https://elht.nhs.uk/application/files/6015/7658/2571/Hospital_Passport_Template.pdf>

**Action/learning points**:

**Dentistry:**

An attendee who is a dentist indicated that the NHS dental contract isn’t attractive to dentists; it isn’t easy to work with. Dentists are leaving the NHS contract in droves. There is no retendering of a dental contract once a practice withdraws from it. This makes it ever harder to find an NHS dentist.

People have neglected their teeth throughout COVID. Post-COVID children’s teeth are extremely poor. They are lots of extractions, lot of abscesses. We are doing referring after referral (to hospitals) but there are no appointments. This is exacerbated by the problem of having no school nurses available, very limited or even no education on oral health.

If the Govt open up NHS dentist contracts again they will be swamped. There are too many people needing dental care. Our capacity has shrunk and we can’t take on the patients who want NHS care. We need to catch children early to educate and guide them about good dental care – not sucking thumbs, brushing their teeth regularly; have fluoride enamel treatment. In areas of deprivation, we see lots of issues starting early.

It was highlighted that there was no crossover between dentists, GPs and pharmacists, which could be mutually beneficial for themselves and their patients.

**Key issues:**

* NHS dental contract is not attractive to dentists
* Fewer and fewer dental practices are signing up to or maintaining NHS contracts
* Need to start good dental hygiene and practices early, but little or no service in schools to support this
* Dentists, GPs and pharmacists should have a space where they can talk to/liaise with each other

**Action/learning points:**

**VCSFE, community support groups and other services**

**Discussions:**

The voluntary sector is a huge player in prevention and the provision of care. How will the NHS work with the VCFSE and how will it fund it?

Faith groups deal with many people from all sectors of life, but they don’t know who their community representative is in the NHS. VCFSE groups need to work with GP practices to address the issues we face. It would be beneficial if the NHS funded a Community Engagement worker for Churches Together to help them work with communities and connect with GPs and the health service.

We need good VCFSE representation at Place level.

Over the years there has been a great deal of investment in supporting people in areas of deprivation, but it doesn’t last. Money goes in, starts to make a difference and then the funding ends. Within a short time, we are back where we were at the beginning or worse off. Deprivation has a big impact on health but there appears to be an acceptance that is has always been like that and it won’t change. Unless the underlying issues such as poverty are addressed these issues won’t go away.

There is a scattergun approach to sorting things out. You are trying to do everything, but there need to be priorities – you can’t do everything at the same time. You need to focus on a smaller number of things, get them right, and move on.

Social care is the poor relation to the NHS and has been grossly underfunded and under resourced for years. It is in a very poor state.

**Key issues:**

* The funding of VCFSE groups within the area
* Need good VCFSE representation at Place level
* Scattergun approach to delivery and short-term funding
* Social care the poor relation to health

**Action/learning points:**

**Support Groups**

**Discussions:**

Patient with ME is setting up a support group for people ME in the Stoops estate. It was felt local support groups for people with long-term conditions are needed. If they already exist, people need to know about them.

In this area the ADHD/ASD service was decommissioned and was unavailable. Now it has been reinstated but it can only undertake assessments; it doesn’t offer support for autistic people and their families.

Mum of daughter who has autism stated there is no help or support for parent carers and respite. When she asks her GP, she is told her social worker should help her with that. She said she has been waiting 10 years for respite care. Dr Naheed explained GPs could refer to services who provide respite care.

**Key issues:**

* Identifying and recognising what support, services and networks exist and creating one place where people can get this information easily and quickly
* Need local support groups for people with various long-term conditions
* ADHD/ASD service is restricted to assessments only
* Need for information and clarity

**Action/learning points:**

**Feedback on presentation**

**O**nly one person from the deaf community can access the survey online, most of the group wouldn’t know how to access and complete the survey digitally. Most people want to speak to someone.

The presentation was too complex to understand as it had too much jargon. Communication needs to be clear, plain and simple.