**Barrow in Furness (South Cumbria) – Listening to our communities event (31/05/2023)**

**Participants**

Group consisted of 11 members of the public, (including residents, VCFSE organisation representatives and Healthwatch); the Director and Health and Care Integration for South Cumbria (Jane Scattergood), and ICB C&E team members – David Rogers, Lucy Atkinson and Jeremy Scholey

**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 Barrow was the 4th such event to be arranged, with previous events in Blackburn, Blackpool and Preston.

In the session there was an update on the ICB, engagement and priorities from David Rogers and the integration with local authorities, and a focus on local priorities and challenges from Jane Scattergood. This was followed by a Q&A session and then attendees fed back their views and insights in a facilitated discussion.

Attendees were asked to consider three questions; what is working well in NHS services in South Cumbria, 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 South Cumbria area, as well as across Lancashire and South Cumbria. With the conclusion of the listening events in July, we will add insights from East Lancashire and North Lancashire to create a compilation of common insights and experiences for the system. However this brief report is for the South Cumbria 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.

**Dentistry**

**Discussion:**

People struggling to access NHS dentistry.Jane Scattergood informed the group that the Govt. only provides national funding for 60% of dentistry needs and assumes 40% of the population will go private. All dentists are private businesses, and the national dentistry contract is not attractive to many dentists. Commissioning teams are working on getting more NHS dentists and are influencing national policy but it is a challenging situation. Abbey Road Fire Station and Cavendish Street dentists in Barrow now both offer emergency dentistry and follow-up; in the past they didn’t offer the follow-up and you had to go back to your own dentist (if you had one). Brilliant service offered by Abbey Road Fire Station dental practice, although the out of hours service is not as good. An example given from a patient registered with the Mint dental practice (Windermere). Now waited 10 months for oral surgery. 16-18 month wait to go to Kendal; 6 month wait now to go to Millom.

**Key issues**:

* Need for more NHS dentists,
* Availability of NHS dentists,
* Long waiting times for a dentist,
* Quality of emergency dentistry and follow up is mixed,
* Long waiting times for oral surgery

**Action/learning points**:

* It was agreed to have a more detailed conversation about NHS dentistry in the future and develop an action plan for improvement in partnership with primary care commissioners.

**Parkinson’s disease**

**Discussion:**

People with Parkinson’s’ disease must have their own medication, which is tailored to them and taken within a tight time regime. They know their own medication. When you go into hospital, they take your medication away and provide their own, or give it at the wrong time. This isn’t good for people with Parkinson’s. The NHS seems better at listening to patients but falls down on understanding that patients know their own medication regime. Your medication on the ward gets locked in a drawer. You need the staff to open the drawer so you can take the medication when you need to but they try to fit it in with their ward rounds. Staff lock the drawers and keep the keys; only a few of the staff have access to them.

**Key issues:**

Importance of recognising patients self determination and self management of medication (in this case Parkinson’s, but as a general principle.

* NHS needs to shift from a control/parent style of patient care to one that is coproduced, respecting and listening to the patient and carers, the need for more trust (Parkinson’s cited but a general point) in medication where the NHS, particularly secondary (hospital care) tends to take control of people’s medication, rather than working in partnership with them to manage their own medication, health systems are designed more for the staff and the system than for the patient and the service user, needs to be more dignity and respect of individuals in hospital /healthcare settings.

**Action/learning points**:

* To be fed back to the Quality Committee of the ICB, and shared with health professionals

**Hospital care**

**Discussion:**

**Hospital referrals** - referrals for hospital appointments can take too long and patients can be left waiting too long.

Variable and inconsistent hospital care - hospital care is variable, getting good quality care depends on the hospital, and on the service that you are referred to, its not consistent across South Cumbria and within each hospital care is not consistent

***‘Patients in a system’*** - patients in hospital tend to have to fit in to the hospital system, whether that is outpatients, urgent care or investigations. The system isn’t designed for people, rather its designed for staff and the hospital. An example was given where a child who was violently sick with acid reflux was taken to hospital and the parents were told, quite cavalierly, a referral for reflux would take up to 12 months, then sent home.

**Centralisation of services** – while the group recognised that for some specialisms this may be important, the group highlighted the difficulty of having services in for example Preston or even in some cases Lancaster. To access these services people need to build in travel time, fund parking and essentially consider a visit to a health service in Preston as a day out of their work or daily lives. For many people this is not only inconvenient but also time consuming and costly.

**Decision-making** – along with the discussion about centralisation of services or their location outside of South Cumbria, there was an additional concern about decisions made centrally that have little bearing on the lived experience of people in Barrow or South Cumbria. Decision making from the centre has a poor history of implementation and effectiveness, and participants were keen that the decisions about health service and health care should be made as locally as possible. Local people involved in the decision making process was regarded as an essential aspect of decision-making or services and health care developments would not be meaningful or relevant.

**Seeing the whole person not just a condition or a body part** - There was a recognition that historically the GP (“Your GP”) would be the coordinator of a patients care, so that they would be considering the whole person rather than the specialist who would be interested in one of your health conditions, or the problem with a specific part of the body. People felt that the health services as a whole needs to adopt a more wholistic approach to patient care so that patients are not just a cancer case, an ENT case, or a symptom. Understanding the patient, and their circumstances needs to be as important as understanding and treating the symptom or the condition.

**Key issues**:

* Ease/difficulty, time taken and cost of travel and transport are important factors for patients
* Long referral waiting times
* Variable and inconsistent hospital care
* Caution about centralisation of hospital services
* Concern about decisions made out of the area that impact on people in the area
* Considering hospital care systems and processes that put people at the heart and making it easier for people to be seen and treated
* Thinking, engaging with and treating patients as whole people not a symptom or case

**Action/learning points**:

* To be fed back to the New Hospital Programme and integrated into the five year forward view feedback report, shared with the Quality Committee and the Patient Involvement and Engagement Advisory Committee, and the Provider Collaborative Communication and Engagement Group

**Self care**

**Discussion:**

There was a good network of first responders in Barrow and South Cumbria , it was a good system and people were well trained. St John’s Ambulance and other trained first aiders and responders are not so prominent now and in some cases seem to have disappeared. Training has lapsed during and after COVID the first aid, first responder network doesn’t seem to exist. In Barrow and other parts of the South Cumbria area, the first responder and first aider network are very important given the isolation and rurality, as well as the distances to urgent care and other services. The fire service are good at first aid training. Things taught in school years ago, such as first aid, child care and other practical things, are not taught now. What happened to health coaches and health coaching ? This used to be well developed and it could be done in schools to equip and empower children and young people. Parkinson’s UK used to have a group in Kendal and in Penrith. During and after COVID these folded. Can you do something to help set groups up again? People with Parkinson’s are reluctant to find out more about it. They need support and encouragement. Lots of charities only operate from Carlisle or Penrith – there is nothing local. Deaf community what we are doing with the deaf community is bringing in people who can give health education (on prostate cancer for example). We need more of this for people in the deaf community – more awareness and education so that community are better informed and more able to understand and access services. Some good networks exist, for example asylum seeker support links in the NHS and this group appear to be supported. However there are pockets of good community support and networks but this is very mixed and variable. The good practice and pockets of community support need to be shared and spread across South Cumbria.

**Key issues**:

* Lack of first responders, community first aiders, and availability of first aid training for the community
* Value of health coaching for children and young people, as well as the wider community
* The value of community networks, the impact of the loss of support groups and the importance of establishing links with groups and networks in the community for the NHS
* Better, accessible information in the community about services and support is needed.

**Action/learning points**:

* Investigate what happened to the first responders, community first aiders and availability of first aid training and consider next steps
* Investigate health coaching and consider next steps
* Gain a detailed understanding of local community networks and groups and build a list of this
* Consider community information about services and support available

**GP services**

**Discussion:**

**GP services** – GPs and GP practices can be absolutely brilliant (examples given of good practices), or it can be a mixed. There is considerable variation of the quality of GP practices. GP care is not consistent across the area.

**GP appointment availability** - is mixed, with some GPs offering appointments within one week while others almost a month waiting for patients.

**GP appointments** - The time with a GP is too short for some people, especially those with multiple conditions. It can take so long to see a doctor that by the time you see them you may have several things to discuss rather than just the one you had when you tried to get an appointment. Examples were cited of GPs who are very good at dealing with all patient issues at one appointment while other GPs will only consider and talk about one issue or health concern during the appointment.

**GP quality** – Most people were supportive and positive about their GP, they felt listened to and appreciated the expertise of GPs, once they were able to have an appointment with the GP.

**Continuity of GP care** – Never see the same doctor. There is no continuity. Seeing the same doctor can be really helpful if you have a sick child under treatment or for other cases where treatment takes place over a period of time. Different doctors prescribe different medication or have a different opinion, or say something isn’t a problem when another thinks it is. Not seeing the same GP leads to poor continuity of care. For people with long term conditions, continuity of care is important and not seeing the same GP means that patients have to keep explaining their situation to different individuals, even though there is a medical record. People recognise that GP services are under considerable pressure and that “you have to grab what you can” (ie see any GP) was preferable to not being able to see a GP however reassurance about continuity of care is needed.

**Care Homes and GP** – when a person becomes a resident in a care home they often have to change GP and lose the continuity of care that they previously had. This can be an issue and needs careful managing by the care home, GP and carers. An example was cited of a person who went into a care home who was forced to change their doctor after being with them for 30 years. This experience which was considered to be typical was traumatic for the care home resident.

**GP phone access** – getting through to a GP can be very good, or very difficult, there is a reliance on GP phone appointments which can be useful, but for hearing impaired and deaf people, as well as older people, this can be a challenge. Choice of type of appointment (ie face to face or phone) needs to be available and clearer.

**GP prescribing** – changes to medication need to be done in partnership with the patient not just done unilaterally. The consequences of medication changes can be far reaching. The change could be from a branded drug to a generic drug and this can result in real challenges to obtain the prescription as it might not be available locally, and may need travel to another pharmacy. The change can lead to a change to the habit of taking the medication for example, because the packaging and the information with it will be different. It can be anxiety inducing. When there are changes in medication, this can be really difficult for patients. No support is offered to nurture patients in changing to new medication and understanding a new medication regime (from GP or pharmacists). Do GPs and pharmacists still do medication reviews ? This was successful and people wondered if this could be reintroduced as this may be one way to support changes to medication.

**Repeat prescriptions** - it appears that there is a considerable backlog for repeat prescriptions – many people call 111, the out of hours GP service, or turn up to urgent care for prescriptions when they run out over the weekend, and this has an impact on the demand for urgent care services. It was agreed that if collectively, health and the community could work on this it might create more continuity for people’s repeat prescriptions as well as lessen demand on urgent care. People on repeat prescriptions need to have a better system of reminders to forewarn and prepare them to reorder more medication when they need to. Repeat prescriptions are an example of where digital technology is proving more complicated than the old paper based system, An example was given that through the NHS app repeat prescriptions take longer than doing it via the old paper prescriptions, which only took 2 days. Now it takes a week. Individuals can now only order repeat prescriptions within 5 days (of the medication running out). If an individual goes too early the pharmacists reject the repeat prescription but this is not clear on the app or anywhere. As a consequence a patient may turn up to collect repeat medication and find out it was rejected. Repeat prescriptions are only for 28 days. People live and work in months. An example was given of a person who is on medication for life but the individual had to really press to get 2 months of medication. Pharmacists don’t fall within the (BSL) interpreter contract for the NHS. Most will not pay for an interpreter. It’s a real struggle for the deaf community.

**Key issues**:

* Generally a positive experience of GPs and primary care however getting through on the phone to book an appointment, appointment waiting times, appointment duration and continuity of care are key issues mirrored regionally and nationally
* Prescribing, particularly changes to medication needs to be done in partnership with patients not done “to” patients
* The value of medication reviews was highlighted
* Repeat prescribing currently doesn’t support people with long term conditions and on long term repeat medication, needs to be more support to ensure continuity of repeat medication and to reduce impact on urgent care and out of hours services

**Action/learning points**:

* Feedback findings to the primary care leads and commissioning team for consideration and comment
* Share findings with the Primary Care Networks for consideration and comment
* Focus some work on improving the repeat medication challenges faced by patients and impacting on urgent and out of hours services

**Pharmacies**

**Discussion points:**

Local pharmacies have given support on various issues, there was particular recognition for support during covid, but local pharmacy opening hours are not always helpful to working people. There are new regulations for pharmacies to provide additional services, but will they have access to records? Recognition that locally pharmacies have supported self-care, and health awareness such as carer awareness,

**Key issues:**

* Pharmacy opening times
* New services provided by pharmacists along with:
* Are health records integrated between GPs and pharmacists for better care ?

**Action:**

* Share these findings with the primary care commissioning team for consideration and comment.

**HRT availability**

**Discussion points:**

A lot more women are using HRT, but there has been a shortage. It is difficult to get any. This can be very scary for women, and no information has been provided about how to manage without it, and no alternatives are being offered, even though there may be some available. GPs don’t offer this. They don’t inform or work with the patient on this. There is a real lack of information about why there is a shortage, what the reason for the delay is and how people can cope in the meantime. Menopause cafes and support networks are important, but these are not consistently available.

**Key issues:**

* HRT supply information and lack of communication with patients about alternatives, self care and future provision

**Action:**

* Lancashire and South Cumbria ICB engagement team are working with the Chief Nurse and her team to develop two patient stories which will be used along with this insight to improve our commissioning and management of the HRT supply and alternatives, and around self care for the menopause

**Power of community networks and assets**

**Discussion Points:**

Recognition that through Better Care Together and the ICC (Integrated Community Care) networks, there is a lot going on in working together in the community. This NHS here is getting good at letting people do what they do best; allowing people to shine. However, what is notable is that the continuity of support is missing. In Millom we have a month of working with the ICC. Used to work with Whitehaven, but this has stopped. Now need to work with Barrow. We have what we call ‘Guided Self-Care’. A place where people can come together. We are helping other areas with how to set-up peer groups – connecting people. There is a warm space network in Kendal. We are building communities – go from warm space to warm space, connecting with people. Patients know themselves where to go for the warm spots. There is a willingness to work together.

**Key issues:**

* Recognition of the community assets, groups and networks and the importance of the NHS and partners working with the community to unleash the power of the community.

**Action:**

* Gain a detailed understanding of local community networks and groups and build a list of this
* Consider community information about services and support available

**Community support and signposting to it**

**Discussion points:**

It is difficult to find out what support groups and networks exist. There doesn’t seem to be one place where you can go to identify this support and these networks. It all depends on who you know, and some areas are well supported with good information and communication, but mostly it is very poor. You have to work hard to find the networks and groups that are available for communities, including NHS and health care. Is there some sort of local directory with everything in it ? Outreach and pop-ups in communities have a place, but it is important to have up to date information about self help, support and services in one place that is easy to access. Peer support networks also have a place and there are some good examples of peer support networks in health for conditions, but again it is a mixed picture. There is a dearth of good information and you have to hunt to find it.

**Key issues:**

* Identifying and recognising what support, services and networks exist and creating one place where people can get this information easily and quickly

**Action:**

* Gain a detailed understanding of local community networks and groups and build a list of this
* Consider community information about services and support available

**Further engagement**

**Discussion points:**

This is a good start, need to continue and build on this event, needs more promotion, getting people to come to an event is harder than going to where they are – suggestion is for ICB to visit different groups, networks and communities to continue the conversation, the group were happy to continue to meet, recognition of the important of GP practice PPGs and other patient networks and group. Why are young people not at this session? Where was this advertised? If we’d been given more time we could have got more people here. We can’t just do this digitally. We could have used a poster to share with those who are digitally excluded.

**Key issues:**

* Importance of the ICB engagement and other staff, including staff based in South Cumbria, meeting people in their communities, regularly, and engaging and listening regularly

**Action:**

* Gain a detailed understanding of local community networks and groups and build a list of this
* ICB Engagement staff working with Jane Scattergood, and community leaders and groups to develop a schedule of relationship building, visits, engagement and listening regularly in each part of South Cumbria.