Your name:	Christianne Ormston, Patient Public Involvement and Community Development Lead (Newcastle) Jake Turnbull, Patient and Public Engagement & Community Involvement Lead (Gateshead)
Your organisation:	Newcastle and Gateshead Clinical Commissioning Group
Area feedback covers:	Newcastle and Gateshead

Feedback received from: (list groups/ job role)

- #Healthnow Coordinator – Crisis
- Safeguarding Adults Business Manager – Gateshead Council
- Member – Long Term Conditions Group
- HAREF Coordinator – HAREF
- Patient, Public, Carer and Partner Engagement Forum Newcastle attendees (18 VCS organisation representatives and 5 patient representatives)
- Newcastle & Gateshead Joint PPCEF - Introducing ICS Engagement and Communications – meeting attendees
- CEO – Age UK Gateshead
- Project Coordinator – Labriut Health Living Centre
- NGCCG Newcastle Place Colleagues
- Training Wellbeing and Inclusion Services Manager – The Angelou Centre
- Chair – Long Terms Conditions Group
- Prevention, Information and Advice Lead – Newcastle City Council
- CEO – RISE (formerly Tyne and Wear Sport)

What works well

- It's helpful having employees whose role is to work externally with organisations to encourage people to be engaged and there are lots of opportunities to attend and be involved. It's never an easy job to build up interest and I think the team do it well. It's good to have a single point of contact team for this overall and hopefully this will work with the ICS to achieve the same. I'm guessing that they might need more resources.

- I felt that the Long-Term Condition Group has been quite useful in the preparation of leaflets – making sure they were in plain English and taking diversity into account - the making of a video, providing information on how different practices dealt with the Year of Care (very varied) and exploring ways to save on repeat prescriptions and wastage of medications. At the Teams meeting our Chairperson David Hewitson asked if our group would still be useful in the future. I hope it will be.

- Having direct links into the CCG engagement team with named contacts. Our work with Hospital trusts has been more ad-hoc and depended on developing

good contacts with people. As a CCG commissioned service we are given the space and time to build up relationships with CCG staff, and to develop relationships within the NHS. If we were not commissioned this would be harder to do.

- The steering group approach allowed people who represent sectors of the community to have a place at the table and help determine the focus of the CCG network [Patient, Public, Carer and Partner Engagement Forum]. The network itself welcomed all to come and be heard. It was regular and responsive to events in the community.

- Before the pandemic, a group of public representatives accompanied CCG workers on visits to see, understand and comment on CCG provisions, including mental health facilities. This brought in a patient/carer/public perspective.

- Locality working, personal working relationships.

- At Labriut Healthy Living Centre, a project of the Jewish Community Council of Gateshead, we have a long and successful track record working with Public Health and other statutory and non-statutory health groups to address inequalities and break down barriers to improve outcomes for the local community.

- At present we have a clear structure in place despite the pandemic making things difficult on the ground in terms of meeting in person. We as a group of interested patients and the public are regularly kept in the loop through emails and the public engagement and involvement events held online at regular intervals throughout the year. I like to mix with professionals from the wider NHS and other groups and organisations and this did work well when we were meeting regularly in person in Newcastle prior to the pandemic. Being a member of the PPIE [Patient, Public, Carer and Partner Engagement Forum steering group organised by the local CCG was of great value to me. I was one of the few people on the steering group that did not represent a group or organisation of some description. It was important to have the views of the patient, carer, public, which I tried to represent, in the planning of involvement and engagement events in the local area. At present the involvement and engagement team based at the CCG do a good job in the Newcastle and Gateshead areas. They have knowledge of what is going on in the areas important to me and the other attendees at the regular events and they are always willing to listen to both positive feedback, and where negative feedback is provided, they do try to look for a way forward to resolve the issues raised. This is not always easy to do. Where an issue is raised that they think needs further investigation, the involvement and engagement team have been good at indicating that an issue needs further investigation beyond the formal meeting. I have witnessed this approach myself and can report that on the occasion when I was seeking further help, the team were able to put me in touch with the correct people to resolve my issue.

- In general terms, in our experience, local NHS systems are very sporadic and

ad-hoc in the way we as a VCSE stakeholder are connected into conversations. The key area of strength in our experience lies with individuals within the local systems, as opposed to a wider strategic approach to engagement. Certain individuals have the vision to take a holistic approach to draw upon the strengths of local organisations and their insight and understanding of the many complex health and social issues faced by people, who invariably then draw upon health and social care resources to survive. With that said, in areas such as how the environment links to health and wellbeing, there has been very limited engagement from anyone in local NHS systems with us as a member of the VCSE sector (the notable exception being those involved with the Sunderland and South Tyneside NHS Trust strategy).

Key themes identified:

- **Direct connections into NGCCG** - Having named and public facing Engagement Leads that the public and community organisations can easily access allows for personal and good working relationships. Communication between NGCCG and stakeholders is generally good.

- **Meaningful involvement** - Patients, the public and communities who attend NGCCG groups/forums feel that their voice is heard by the Engagement Team; they listen, provide feedback and try to resolve issues that are brought to them.

- **NGCCG involvement forums**
- The Patient, Public, Carer and Partner Engagement Forum (PPCEF) works well; it provides a regular formal space for people to learn about CCG activities and get involved in projects. It connects CCG staff with the general public and VCSE sector.
    - The PPCEF until recently had a Steering Group made up of local organisations and individuals. They provided insight around what people were interested in finding out about from the CCG and therefore helped set relevant agendas for the meetings.
- NGCCG's Long Term Conditions Group is an opportunity for the public to get involved in CCG activities and for the CCG to hear from patients. The group has been involved in various activities such as providing accessible patient information and exploring ways to reduce wastage of medication.

What could work better

- I represent a group of people with lived experience of homelessness who contribute to the health of people in Newcastle and Tyneside through peer-to-peer research into health inequality, and activities that are aimed at not only identifying where inequalities are, but coming up with ways to deal with them and improve them. Homelessness is not really about housing, the housing issue is generally an expression of another issue, mostly unsolved complex trauma which permeates throughout life, and then shows up in homelessness, in drug and alcohol use, in poverty etc. We don't think that the people we work with have complex needs, they have needs that because the system is not designed with them in mind, end up being complex because of design. A bit like the social model of disability, if your system doesn't fit, it's not the disability, it's the system. So we have a group of people who not only represent their views, but views of other service users through their research, and their involvement as volunteers in providing advocacy support to people currently homeless. I think it would help if the ICS involvement engaged with the Inclusion Health Groups through a specific forum, because these groups tend to be the ones that fall outside the system and who, with good healthcare design, could progress from their situation into more productive and fulfilling lives. Our group is pretty well informed, and we don't just consult with them, we mostly co-produce what we do, so they are driving the work. They can help you work out how better health systems could be and could work as they are the end users. We would like to engage with the ICS and have some scope to look at the way we work and the work we do so that we're more aligned with what you're trying to achieve. Where there are groups like this, the ICS has an opportunity as they don't have to create them from scratch. The HealthNow project can support the ICS work.

- I think the pandemic has made community involvement very difficult at the present time. Patients used to get information from leaflets and posters in surgeries, hospital waiting rooms and once upon a time – community centres. Recently, for obvious reasons, that has not been the case. There are people who seek out information but those that don't, also need to be reached. I think some televised public information films about forthcoming changes could be useful or slots on local TV and radio.

- Better links and involvement with Hospital Trusts, especially following place-based working. How do we best work with the Trusts? The Involvement forums can often feel presentation heavy and would be useful for more engagement opportunities in these. Haref attends two Hospital Trust stakeholder meetings, but these are often Trust driven in terms of the agenda. CCG focus group work streams stopped due to COVID. These used to be helpful to make sure conversations were being had with different community groups about health service changes.

- I always wished to see consultation and engagement earlier and later in the change process—particularly in planning and reviewing. It seems to me that we need to observe the "10 commandments of engagement" enshrined in the

new ICS guidance in engagement. Secondly, I think we have made insufficient use of the patient voice from PPGs and PCNs. All locals belong to a practice and, in many cases, also a PCN. We can reach and listen to so many more people, so much more evenly spread throughout the larger community in terms of age, ethnicity, location and social class by using this already existing tool more effectively.

- Reach out to a wider audience, concise emails. A named person to talk to, constant changing staff prevents understanding and working relationships

- The Jewish community has its own specific cultural needs which can raise barriers in accessing health and social care provision and in particular engagement initiatives which can give them the title of a 'hard to reach group.' The Jewish community generally do not access mainstream media and social media platforms. This will mean they do not see or hear advertising campaigns that are carried out in newspapers, magazine, tv or on the radio etc.

- Primary care - Need everyone to know engagement is their responsibility. Need to take the engagement further than to just the services affected (i.e. If you're asking people about GP access – need to do this in other settings, not just GP practices, ask in A&E, your local pool etc).PCN's should be engaging with Community, we don't know if/how this is being done?

- We would be interested in being more involved using our already established collaborative working group on health inequalities. Need to move from equality of service to equity of service; use of special interest organisations and engaging with workstreams to support people with multiple complex needs and minoritised experiences.

- The lack of diversity is worrying. Simply asking the groups and individuals who do attend, why a diverse mix of attendees is not attending, is not good enough. I feel that rather than asking why underrepresented groups don't attend our meeting and events and engage with emails and surveys. We should be going out to where these groups live, work and pray and reach out to them in that way.

- There doesn't appear to be a clear plan around engagement with the VCSE sector. At present there are so many different NHS engagement and consultation groups that this presents a significant challenge to know where voluntary sector partners can make the biggest impact. This therefore needs to be streamlined and modified to enable local VCSE organisations to have their voice effectively heard. As an example, we, just one VCSE organisation, are involved directly with public health teams, PCNs, GP practices, Foundation Trusts and hospitals directly in some cases, and hence that naturally leads to some resource wastage….including from the initial stage of trying to better understand the landscape itself! We have good involvement and connection with many health partners, but it is very sporadic, and I guess ideally for us we'd want a way of communicating and getting messages out to

multiple health partners, or ways to engage with a more co-ordinated system. Improvements in the way that VCSE groups can be connected to the right local NHS staff, who have the skills and competencies to listen and use this insight to connect to local system priorities, which look to address wider social and economic outcomes, would be a good start. Also useful would be clarity on NHS department roles and responsibilities, especially given the significantly changing NHS landscape. This knowledge would help VCSE organisations to connect to relevant NHS system leads and enable our connectivity to be improved.

Key themes identified:

- **Better use of existing local knowledge and structures**
- NHS involvement partners could be better at utilising already established VCSE groups (particularly Inclusion Health Groups) in their involvement work. They could work directly with groups as well as through forums.
- Current NHS structures should be better used, particularly Patient Participation Groups.

- **Improved communication**
- Streamline and make it easier to understand how to get involved at a Place level - a single point of access informing people of the structures and opportunities available across community, primary, secondary and acute sectors.
- Share information so that people know everyone who works in involvement and engagement is, as well as what their role is.

- **Increased diversity** – To increase the diversity of groups and individuals getting involved in activities suggestions included ‘advertising’ opportunities more widely for example on local radio/TV. However it must also be noted that particular groups will not see information posted on social media or online. The NHS should also go to organisations/communities and should not expect them to come to them.

- **More opportunities to get involved in Hospital Trusts** – enable VCSE organisations to get involved rather than just sharing information around Trust priorities.

- **Regular opportunities** - Have a standard regular process where VCSE organisations can get involved, so involvement isn’t so sporadic.

- **Involvement at every stage** - Involvement and engagement should be planned into projects earlier and later.

What does 'Place' mean
• Is engagement wider than just health – should we have a Newcastle system engagement team – delivering variety of messages from NHS, LA, VCS etc (helping to develop relationships that are two way and supportive of both communities and organisations). Coordinated approach to delivering messages across the ICS.
Key themes identified:
• Place is bigger than health and the ICS needs to have good working relationships with other statutory bodies and organisations within the different areas of 'Place'.

Concerns at working to larger geography / connecting into regional conversations

- I think it's difficult with any organisation at such scale as the ICS to hear different voices. There are inevitably priorities that preclude work with groups like people experiencing homelessness. Engagement needs to happen before the decisions are made, not during or after, being round the table at the start is key to making anything work. I think this can get lost in a large organisation with multiple aims. Often we work with people who are 'not popular', we work with offenders, drug users etc, and instead of thinking about these are people who we need to bring into the conversation, they can get excluded – there's not much 'popularity' in some groups as they have little sympathy with the general population. But these are the people that most need our help!

- Maybe I'm a bit cynical but it strikes me as a possible money saving exercise. The CCG seemed to be working quite well and felt 'closer to home' than what is on the cards now.

- Concerned about making sure Haref has a voice when we don't cover regionally. Who should we be speaking to in the ICS? Who are the best links? How will commissioning work in the future?

- Our ICS is so huge that I do fear that the local will drown the regional! When this happens it is easier for the local communities to be treated all alike and it is all the more important from strong local networks to thrive and be supported to be heard.

- Loss of locality prevents person based one to one working. Regional work loses locality relevance when addressing need. For example, Bridges ward in Gateshead how will that be recognised when set alongside the North East, Teesside and Cumbria?

- Heard all this before in terms of involvement and engagement, will this actually happen? I'm not convinced it will be different.

- Will patients be at the heart of work in practical terms? There needs to be a way of groups being able to share their work and experiences.

- Concerned that transition to ICS format means that individual voices might get lost, and that ICS will only hear from select organisations.

- The ICS needs to develop consistent measures across the region and ensure there is a regional perspective on tertiary services.

- A lot of engagement issues are strictly local and although high priority locally, not necessarily common to other areas.

- I was at an event, not related to this particular engagement and involvement theme, but still to do with an NHS regional organisation the other week. It was really well organised locally and was designed to have a national impact.

I know the organisers and they are all very professional and easy to work with. When I entered the building I was challenged by a regular participant who I know. They asked what I was doing at the event, in a manner that indicated that they thought my views would be of no relevance to the subject to be discussed. I made sure that they understood clearly and in no uncertain terms of the validity of my attendance. I've been doing this kind of PPI work for years and experiences like this just encourage me to continue getting involved! But I do worry that a less confident participant might have just left, before the organisers even had a chance to welcome them to the event. This was a one-off experience for me, but I do worry about others receiving a less than warm welcome. Perhaps if someone had greeted us as we arrived this may not have occurred. I will be feeding this back to the organisers, having just received a feedback link. I'm a very active person in the region and beyond when it comes to not only engagement and involvement, but also innovation, governance and advocacy. I am aware of a number of organisations that are supposed to be professional, and I would expect would be welcoming and open to someone like me, being less than open and friendly. I give up a lot of time to try and make things work better for everyone and it's sometimes surprising where the hostility comes from. I can usually find a way in to most places with my persistence and tenacity, but some regional conversations seem to be a closed shop and they have no intention of opening up anytime soon. So all I can do is keep raising my queries and concerns and hope at some point the small minority of problematic groups and organisations change. It's always better having me as a critical friend engaged with someone inside of the organisation than a loose cannon on social media! I'm certainly not planning on going away! Someone needs to undertake a review of what involvement and engagement work is taking place in all the CCG's that will disappear into this NENC ICS. I've had a look online just out of interest and found some good and not so good stuff published online from some of the CCGs covered by the ICS footprint. I think we almost need a central NENC ICS level review of all the online and paper based/PDF type documents relating to patient, public, carer engagement and involvement work that is being done. The purpose of this could be in identifying best practice across the ICS area, archiving/deleting old and out of date information and managing expectations as to what will be available to people in each of the CCG areas relating to engagement and involvement in the new NENC ICS environment. Might be an idea to ask some active engagement/involvement citizens to feed into/help with this work. It could be almost run as some kind of Priority Setting exercise.

- Given the size and scale of the NENC ICS, we are concerned about connecting into both local and regional conversations as we are very time and resource poor, so when we do connect regionally, we need to ensure that our time is efficiently utilised to maximise our influence, whilst making the right connections. Past experience highlights that we are not always engaged in the right forums, and there is arguably already too much pressure on the voluntary sector to attend multiple engagement meetings/forums and conferences and the call to actions are not always clear. It would also be helpful to have a coherent plan, as mentioned above, about these engagement streams/opportunities, and potentially how it may be broadly

themed, in order to find the right channels through which to connect relevant to our size/areas of interest/geography/capacity. Perhaps a document that clearly maps out the local system and points of engagement would be useful.

Key themes identified:

- **Local voice lost**
- There are concerns that individual voices and voices of different communities within the local setting may not be heard in favour of regional priorities.
- Worried VCS/individual patient voices will be shut out of regional conversations as they cannot speak for the whole region, just certain 'Places'.

- **Early engagement** – There are concerns that with such a large geographical area early engagement will not happen.

- **Stretched VCSE resources** – VCSE organisation are concerned that they do not have the resources to influence at both a local and regional level. It is therefore important to have clear information about involvement channels/structures so that organisations do not waste their limited resources attending the wrong meetings/meeting the wrong people.

How would we know that involvement across the ICS / ICB was working well?/What would good look like?

- Co-production - co-production involves seeing people as assets and building on their capabilities to identify problems and find solutions themselves, rather than seeing them as problems to be fixed. Co-production is a shift in the balance of power from professionals to local people and communities, placing service users on the same level as the service provider, sharing power, and drawing on the knowledge and resources of both parties to develop solutions and improve services. The aim is to engage a public that are able to participate in (as a key part of) decisions and actions to tackle the social determinants of health inequalities. Co-production is grounded in an asset-based approach to health.

- As part of the consultation, you ask what good would look like. It is imperative that ICSs engage with the regional Safeguarding Adult Boards / Safeguarding Children Partnership's to ensure that there is alignment with respect to how the ICS and our statutory Boards / partnerships safeguard our most vulnerable residents. This would involve the ICS receiving our Strategic Plans and Annual Reports and learning from our statutory safeguarding reviews when there is system wide learning as to how our health and social care partners work together.

- Good involvement may be groups within Practices – questionnaires – more online conferences and I'm sure a multitude of other things.

- Ensuring we don't get invited to lots of replicated meeting to cover all the place-based working. Ensuring the public and groups we work with know how they have a voice with the NHS. How do we explain simply to people what their involvement needs to be? Make sure the feedback loop is there, people need to know what happened when they did have their say.

- I would like to see at least 2 PPI members on each ICB, with parity of esteem, to bring the public voice into planning, monitoring and review of services. I would like PPI present on the quality assurance groups. I think it is immensely important that independent public voices join these with lived experience in order to bring perspective and a wider public view into play.

- Even at a CCG level we forget it's about people and place and should try incorporate that where possible. Recognition that the voluntary sector do not have the capacity for lengthy zoom meetings and their resources are substantially less than the statutory sector. Possibly consider a dedicated ICS portal with a log in that allows interaction and geographic based info.

- Therefore, any engagement and involvement strategies would need to include an element of how to reach the Jewish community in Gateshead. We have a long-standing track record of working with public bodies and the NHS in creating strategies to engage the local Jewish community. E.g. advertising in the community advertiser, specific events etc. We would be happy to engage and discuss this in more detail as and when needed, but it is important to include in any plans an alternative option to the mainstream plan in order to engage the hard-to-reach groups.

- Citizen panel – needs to be representative of our local population (Newcastle is very different to other Place/ICP/ICS footprints). Engage with people via various formats website, etc (not just digital – we need options for all, open and accessible). Linking into community groups – community grass roots organisations not the bigger ones like haref/Involve – need to engage wider. Public – how to encourage local population to join in, need to consider inequalities and how to engage with our hard-to-reach communities

- Patients will be at the heart of work in practical terms. There needs to be a way of groups being able to share their work and experiences.

- I've attached a couple of documents regarding what I think good looks like. One is a historic document, and one relates to the NENC ICS - Digital Strategy of which I'm interested and have had some good experiences working with some of those involved already. NOT WORKING IN SILOS - I reached out the other week to a whole range of health and care services for a little help and advice. Despite them all knowing who I am and knowing that I'll go on to tell everyone who will listen about my unsatisfactory experience, I got no real help what so ever from any of them! This must change. I'm not really impressed with the northeastandnorthcumbriaics.nhs.uk website as it currently stands. At first glance it looks like lots is going on, but investigate a bit further it lacks details relevant to the people it is supposed to be serving -

the patients! Plenty of details on the NHS staff side, but I consider that the staff are a means to an end. The care of patients should be at the heart of this website. The patient is the end point here, everything else is just process and practice. For an important regional organisation like this not to even have a clear address, phone number or email contact point is really bad. I've studied who is involved at a senior level in this organisation and I'm yet to be convinced that this is anything other than a career improvement stepping stone for a number of individuals. It might be that I'm wrong, I do hope so! Until we actually see these people in action, and they start take actions that actually make a difference to people's lives on the ground I can't be sure that this NENC ICS is going to make any difference. The lack of real engagement and involvement in patients, public and carers, who should have been involved in the heart of this organisation from the start and not as an afterthought, is a real cause for concern. I'm not the only person who feels this. I make a point of speaking to a wide range of people and at present most don't even know the North East and North Cumbria ICS exists, never mind what power it will hold over the day-to-day health and social care of so many people.

- Providing clarity on how the voluntary sector can influence strategy and service development, not forgetting the importance of place, i.e. we need to understand where our time is best served and where we can deliver the greatest impact. Regular updates and information about any work that is being carried out in this area.

Key themes identified:

- **Co-production** – this should be built in when services are being re-designed or changed.

- **No duplication** - Ensure there is no replicated meetings/duplicated work between the different localities to enable VCSE to target their resources and engage meaningfully.

- **PPI representation** - There should be patient and public representation from all localities on different boards and panels within the ICS.

- **Accessible involvement** - Have various ways to get involved, so all communities are reached and are able to get involved in a way which is accessible for them.

- **Clear structures –** ensure VCSE organisations and individuals understand the new engagement structure and how to get involved.

- **Individual level** - Have a process in place whereby all community groups/organisations a chance to have their say and be involved; do not just rely on bigger organisations to feedback.

- **Joined up working** - between different health care services.

Any other comments

- I would like to highlight the positive work of Safeguarding Adult Boards and Safeguarding Children Partnership's across the region. These longstanding statutory partnerships have excellent engagement from a wide variety of stakeholders including the public sector and community / voluntary sectors. We have good health and social care engagement from Local Authority, CCG, Foundation Trusts and Healthwatch. Our Safeguarding Adult Board also has approximately 200 Safeguarding Adult Champions from across Gateshead, representing all sectors. Safeguarding Boards / Partnerships must statutorily set out priorities for how we intend to safeguard our most vulnerable, which includes an increasingly important prevention agenda. We also undertake statutory safeguarding reviews following the death or serious injury of an individual as a result of abuse and neglect. These reviews involve family members and are a vital mechanism for us to understand how our systems have worked well, and where we need to make improvements.

- People want to know how long telephone appointments are likely to go on for. For some things they are just fine and for other things they seem nonsensical. For example – tomorrow I apparently have a telephone conversation with an ophthalmologist set up. As far as I can see – or not see - this is going to be a waste of both our times. Eyes cannot be checked over the phone. Face to face consultations and meetings is something our group has discussed online – so this isn't just a personal gripe. It was mentioned that Health watch would have representation at regional level. How will this feed back to more local groups?
  Just a thought.... one of the most stressful things for a patient – is waiting for test results. Obviously, everyone understands the NHS is struggling under a huge backlog of cases just now and NHS staff have been under the most immense pressure for the last couple of years. Being given a provisional timetable for when appointments and follow ups could ease stress somewhat.

- Thanks for asking us all to contribute. It seems we have been answering questions like these fir 1 1/2 years now. It would be great to see if and how any of our suggestions are taken on board. When you say you want to make the most of past success in engagement, it looks as though may be more of the same—which was a good starting out but needs to go much further. Some smaller ICS are so much more developed and mature in their PPI (Portsmouth, some London ICSs and so on). Before July, we need to see something tangible! Again, thanks. If I can provide any support at all, please do contact me.

- One issue we've been trying to tackle is the integration of different care pathways e.g. eye health and mental health. We have been working at an ICS to establish specialist pathways for people losing their sight to receive appropriate support services for their emotional wellbeing. On the flipside, we want to make sure people with mental health problems are screened for undiagnosed/untreated eye conditions.

- Hello all - I am chair of a cancer patient group Northern Cancer Voices and we have been working to the ICS model to set up 4 area patient groups for the new NENC areas. Working with the health professionals we are really encouraged over the last few months at the engagement we are being involved in. Our structure going forward is to embed and keep that engagement with the new ICBs. The open dialogue and engagement is reassuring. thank you, Julie, for the presentation.

Key themes identified:

- There is already great work done by organisations and groups in Newcastle and Gateshead that can be used to inform the ICS.

Case study title:	
When did project take place?	
A little bit about the project:	
Why is this a good case study:	