

Community Voices

Health Inclusion with Black, Brown,
Asian and Minority Ethnic Communities

May 2021

The Trust for Developing Communities

The Hangleton and Knoll Project

Sussex Interpreting Services

The Racial Harassment Forum



**The Hangleton
& Knoll Project**
Working for a better community

 **sussexinterpretingservices**

Overview

This report describes the work and impact of the Community Voices project that ran from November 2020 to April 2021. The work was jointly funded by Sussex NHS Commissioners as part of a series of Health Inclusion projects and by Brighton and Hove City Council as part of their Third Sector Commission engagement with Black, Asian and minority ethnic communities.

The project took an innovative approach to ensure that the voices of excluded communities could have a direct impact on health and Council policy.

Communities had previously fed back that they found a consultation and focus group approach dissatisfying and disempowering, instead we took a new approach of bringing commissioners to talk directly with members of the community directly affected by the issue. This gave new insight for commissioners and community members felt more empowered.

The project was delivered by a partnership between members of the Community Voices group, the Trust for Developing Communities, the Hangleton and Knoll Project, Sussex Interpreting Services, and the Racial Harassment Forum.

The main recommendation is to continue the development of the Community Voices group. Specifically:

1. Consolidating the Community Voices group
2. Involving people with language needs
3. Investigating specific health topics
4. Building trusted relationships
5. Ensuring impact and change
6. Developing a community research model

These recommendations can all be actioned in the current phase of the project from May to October 21.

Outline of Partnership

The four partners in this project are:

- Trust for Developing Communities (TDC) - Lead Partner
- Hangleton & Knoll Partnership (HKP)
- Racial Harassment Forum (RHF)
- Sussex Interpreting Services (SIS)

Since the on-set of the Covid-19 pandemic, all partners have each provided much needed guidance and support to people from Brighton and Hove's Black, Brown, Asian and other Minority Ethnic communities. Partners are acutely aware of the impact the pandemic is having on vulnerable people within these groups. All possess highly established, well regarded and successful experience of direct work with ethnically diverse communities.

TDC delivers community-led solutions to tackling inequality; supporting communities to build on their strengths, identify issues and deliver solutions locally. TDC has a proud 20-year track record working with the most disadvantaged and excluded people in Brighton and Hove around community development, youth work, community engagement and participatory research/training.

HKP is a community-based organisation working extensively and successfully in one of the City's most culturally and ethnically diverse neighbourhoods. HKP have a track record of working with community groups and young people, enabling increased awareness, confidence, a sense of self-determination, local pride and community cohesion. HKP has created opportunities for residents, contributing towards a greater understanding between groups and the City's support services.

SIS are Brighton and Hove's leading interpretation service. SIS's services include much more than the translating and interpreting of different languages. They work with migrant communities across the city, enabling full access for people with language needs to publicly funded services, to improve health, education and overall quality of life.

RHF recently became a registered charity and have led and pioneered approaches to dealing with Hate Crime matters in Brighton and Hove. They have expanded the membership of the organisation and can claim to have representation in its membership of all the City's BAME Groups; this is a unique achievement. They are responsible for undertaking a benchmarking study that is shaping the City's response and approach to tackling Hate Crime.

The combined expertise of the partnership covers: community engagement, research and consultancy, case working support, organisational development, well-being initiatives and advocacy. Collectively the partnership provides an unrivalled resource that can ensure a comprehensive examination of the issues and provide relevant, realistic solutions to address inequalities in Brighton and Hove.

Communities Covered

The extensive reach of the partnership has enabled us to invite a broad range of members of Brighton and Hove's Black, Brown, Asian and Minority Ethnic communities to participate in the project. We have focussed our outreach with smaller community groups who do not usually engage in citywide or strategic discussions. Our aim is to bring a wide range of views and experiences together for discussions, dialogue and to build connections with commissioners and decision makers.

We have connected this Health Inclusion project with the Brighton and Hove City Council funded Third Sector Commission engagement project. There are many synergies between the work and the combined approach enables us to support engagement around both NHS and Council responsibilities and areas of work.

Background to the project

In the past five years Brighton & Hove City Council and Clinical Commissioning Group have commissioned engagement research and consultation with the City's Black, Brown, Asian and other minority ethnic communities. This engagement has addressed and explored social, health, employment, and planning matters amongst other areas.

In all cases Commissioners have identified matters and subjects that are internally acknowledged as areas where (more) information is required to contribute to policy making and/or the delivery of services. Notwithstanding, the specific findings and recommendations that ultimately emanates from the consultation, there is typically a wider recognition in all these studies that the Commissioners and these communities would benefit greatly for a better understanding of their respective positions and perspectives.

Research as it was undertaken relied on an experienced intermediary e.g. Trust for Developing Communities (TDC), the Hangleton and Knoll Project (HKP) and Sussex Interpreting Services (SIS) to act on behalf of Commissioners to gather information. There are clear and distinct advantages to this approach, not least it provides for confidentiality and anonymity and allows experienced independent facilitators (researchers) to contribute to identifying solutions.

However, whilst this approach did greatly benefit the flow of information between the respective parties and on some level, increased understanding it did little to enhance the relationships between the community and the Commissioners. The approach to research and consult with these communities inadvertently offered no means by which the two parties when appropriate can engage directly with one another.

This project has increased the direct engagement between the communities and Commissioners. The rationale is a response to previous consultations and includes:

- Identifying and implementing feedback systems to participants
- Increasing awareness of divergent cultural sensitivities across the different cultural and ethnic groups
- Opening up opportunities for building trust and confidence between all parties
- Opportunities for consultations and research to be more reflective of/influenced by issues identified and raised in the City's black, brown, Asian and other minority ethnic communities
- Benefits of training and learning to community members

The project is a new experimental approach and the partners, community members and commissioners will all be involved in evaluating the work.

Summary of the work – activity and timescale

Stage One: Preparation

We drafted terms of awareness for the group, promoted and recruited to the group.

‘The purpose of this Community Voices Group is for its members to represent and advocate on behalf of and reflect the views, opinions and perceptions of people in their communities on matters and issues that are important to them. Furthermore, to provide feedback on information and policy plans and decisions of Local Health and Council services.’

- Do you identify as Black, Brown, Asian or from another language, ethnic or migrant community?
- Are you actively involved within your community and would like to do more?
- Do you have good communication skills?
- Would you enjoy working as part of a team?
- Would you like to join a group of people to be a voice for your community?

A partnership of Trust for Developing Communities, Hangleton & Knoll Project, Racial Harassment Forum and Sussex Interpreting Services are recruiting and training volunteers in Brighton and Hove to use their influence, experience and understanding to help their communities make their voice heard and their priorities understood when decisions are being made by public services.

As a Volunteer you will need to:

- Be well connected in your community
- Be able to talk to people in your community about what's important to them
- Bring this information and speak on behalf of the community in online meetings
- Discuss how issues affecting your community could be solved
- Attend online meetings between January and March 2021
- Attend training for the role

Volunteers will receive:

- Free training in community research/ engagement practices and support getting online
- Support and networking opportunities with other members of the group.
- Help with building confidence and skills.
- Recognition of supporting a new way of influencing decisions.
- Out-of-pocket expenses.

For more information and to register your interest please contact Aleya Khatun at HKP via 01273 410858 or aleya.khatun@hkproject.org.uk

This project is funded by Brighton & Hove City Council and Sussex NHS



See Appendix One for full terms of awareness.

Stage Two: Inaugural Community Voices Meeting

We held an introductory meeting with 18 participants. The group agreed terms of awareness and a

‘desire to investigate and learn how they might inform decision makers, in the City Council and NHS, of concerns and problems experienced by members of their community.’

The group wanted to produce tangible outcomes that could be followed through to make change and have impact. SIS linguists represented SIS Service Users at the [Community Voices Group](#)

The issues that arose from the first meeting were

- barriers in communicating needs and accessing healthcare especially for those whose first language is not English,
- GP and Primary Care (telephone) appointment systems
- perceived lack of understanding and cultural sensitivity demonstrated by GP staff
- the complexity of online forms to book appointments
- contact and communication with the City Council
- home-schooling and how parents with language needs could be better supported to help their children who are learning in English.

In a discussion about the vaccine, the group stressed the importance of clear communication about vaccine roll out and welcomed targeted and appropriate outreach work.

The [Hungarian Women’s Group ‘Easier Together’](#) requested a talk about vaccinations to reduce the misinformation and fear around this subject. We provided this in partnership with Public Health.

The group suggested staff training as a solution to the issues they had raised, especially around cultural awareness and sensitivity. Access to interpreting services was also welcomed.

See Appendix Two for full session notes.

Stage Three: First Community Voices and Commissioners Meeting

The Community Voices group met with seven decision makers from the local NHS and City Council. Topics identified with the group and discussed with decisions makers were:

- Access to primary care
- Access to services for people with English as an Additional Language
- City Council communications
- COVID-19 illness (effects & coping).
- Employment and training

- Housing
- Social Care
- Vaccine hesitancy and uptake
- Women's health inequality

Feedback from Community Voices Group members: -

'I am very grateful for this, because (we) need to be able to tell and talk to the Council on things that matter to us.'

'I'm really glad that this has been set up, for a long time I've been looking to be able to speak to the Council on a number of things that are important to my groups that I work for. This is the great way I can do this so thank you.'

'I will tell others to join because this is very good for our communities'.

'I enjoyed the remote meeting on Wednesday. As for sharing our thoughts and experience about the needs of the communities, It's a fantastic idea in general.'

'Yes, this is a very important and good idea. But we have to make sure that something comes out of it and we don't just spend our time talking for nothing to happen.'

Feedback from decision makers: -

'It was very useful to be reminded that however much we share information there are always people who do not receive it and I'll take that to inform comms strategy – more social media, more use of community leaders/influencers, more use of trusted channels like GPs for essential health messages.' **Margaret Ousby BHCC Comms**

'I think there's real potential for this approach and am really pleased we're exploring it.' **Sarah Tighe-Ford BHCC Equalities**

'Yes, I really value meetings such as this to try to understand what are the important questions and the issues people have re COVID19 including about vaccinations.'

Becky Woodiwiss BHCC Public Health

'It was a really good start to what will need to be an ongoing two-way dialogue. I feel like we barely scratched the surface.' **Antonia Bennet Sussex NHS Commissioners**

Stage Four: Topic specific discussion

The topics identified by the group were narrowed down to three: -

1. Vaccine hesitancy and uptake
2. Housing
3. Women's health inequality

In discussion with the commissioners the vaccine topic was prioritised because of the time sensitivity of the discussion.

A Community Voices Group discussed this on 14th April, see Appendix Four for full notes from the meeting.

Our key findings were that the community would like time and evidence-based information to make their own decisions about the vaccine, and that trusted people such as GPs are an ideal way to share messages about vaccine.

The group did not want to meet again to discuss vaccine confidence as this was seen as a personal choice and some preferred not to discuss this as a group.

Consequently, we are moving onto the next topic and, to confirm priorities we are in the process of holding a poll. The group will then meet to discuss the topic and to then invite the appropriate decision makers and commissioners to a joint meeting.

Who we have spoken to

The Community Voices group is reflective of the City's ethnic and cultural diversity. Several different ethnic and cultural groups are represented, including, Indian-sub-continent, South East Asia, West and North Africa, West and East Europe, South America, and the Caribbean.

Recruitment to the group has been through the networks of all four partners and each partner has offered inductions and briefings to participants outside of the main Community Voices meetings.

In time the members of the group will be supported to explore the chosen topics within their own wider networks, thus extending the reach of the group even further. We envisage continuous recruiting to reach all communities in our city.

Key themes and points – engagement

We have:

- **co-produced and co-delivered solutions to inequality** through the Community Voices group. This was a recommendation from our research [The NHS, COVID – 19 and Lockdown: The Black, Asian, Minoritised Ethnic and Refugee Experience in Brighton and Hove](#)
- **developed connections between ethnically diverse community members at a citywide level** by facilitating online sessions to share experiences and concerns that matter to them.
- **established a new group reflecting the ethnic and language diversity of the City** with the potential to connect across these different communities.
- **begun linking community members directly with decision makers** about the services that matter most to them, i.e. vaccine, access to primary care, experiences of those with English as an additional language, women's health, housing.
- **piloted a new community led approach to engagement** which brings ensures agency for community members to influence and inform commissioners and decision makers in both the NHS and the City Council.
- **learnt that personal issues need to be met before wider engagement is possible.** Many groups paused their activities during the lockdowns and are only restarting now.

Key themes and points – NHS specific

We know from our Community Voices group work that:

- **trusted relationships are key to engaging** with statutory services.
- **digital inclusion** support is required for individuals to get online to connect socially and access services.
- **language barriers are significant.** Timely and face to face interpreting is needed so that individuals can access services and understand public health guidelines. There are barriers to digital inclusion for people with language needs especially on-line form filling and access to GPs. An understanding of solutions such as bilingual advocacy is needed.
- **increased awareness of divergent cultural sensitivities across the different cultural and ethnic groups** is needed. We know service standards vary across the NHS, often dependent on the individual member of staff.
- **clear communication with appropriate outreach helps to build vaccine confidence.** Community members need time to make their own decisions and choices. They do not necessarily want to discuss this as a group. Direct contact with a trust clinician such as a GP would be ideal.
- **access to primary care and self-referrals are difficult** because of lack of trusted relationships, shortness of time in appointments, unfamiliar systems and approaches to healthcare, cultural differences, and language barriers.

Recommendations and next steps

Recommendation One – Consolidate Community Voices group

Consolidate the embryonic Community Voices group so members are confident about their roles and the influence they have. Clearly identify change that has occurred and demonstrate the value of the contributions from the group.

Recommendation Two – Involve people with language needs

We are keen to directly bring the voice of people with language needs into the Community Voices group as well as through representative linguists. This has been hampered so far by the need to meet online.

Recommendation Three – Investigate specific health topics

Investigate specific health topics with the group, ensuring topics are identified by the group, discussed, and then explored further with commissioners. This will enable research to be more reflective of and influenced by issues identified and raised in the City's black, brown, Asian and other minority ethnic communities.

Recommendation Four – Build trusted relationships

Build trusted relationships between Community Voice members, decision makers and with commissioners through the project. Embed trust and mutual understanding so that dialogue extends beyond the Community Voices group.

Recommendation Five – Impact and change

Work towards the discussions with commissioners and decision makers having visible impact on healthcare services. Ensure Community Voices members can see change in services because of their contributions and know that their input has made a difference. This would complete the engagement cycle of engage, co-create, action, adjust.

Recommendation Six – Develop community research model

Link Community Voices group to community participation and action research programme supported by Scottish Community Development Centre and Health Education England. Support group members to take on community research style role.

Appendix One – Terms of Awareness

Community Voices Group Terms of Awareness.

1. Introduction

This paper sets out the draft Terms of Reference for the **Community Voices Group** initiated through a project partnership between the Trust for Developing Communities, Hangleton and Knoll Project, Racial Harassment Forum, and Sussex Interpreting Services.

This is a working document. It is expected that as the project evolves, these Terms and References may be amended to ensure Group members views are recognised and the Group functions in an effective and efficient manner.

2. Purpose.

The purpose of this **Community Voices Group** is for its members to represent and advocate on behalf of and reflect the views, opinions and perceptions of people in their communities on matters and issues that are important to them. Furthermore, to provide feedback on information and policy plans and decisions of Local Heath and Council services.

3. Membership

Membership of the Community Voices Group is through the invitation of the project partners, Trust for Developing Communities, Hangleton and Knoll Project, Racial Harassment Forum, and Sussex Interpreting Services. All members of the Group will represent and likely to be from a Black, Asian, other culturally or ethnically diverse community in Brighton & Hove.

4. Meetings

NB: Until Central Government announce it is safe to do so, there will be no physical meetings of the Community Representatives Group. All meetings will take place virtually using a Zoom© or Microsoft Teams© type function.

1. It is planned that there will be two induction meetings for the Groups' members Thereafter, the group will meet to address issues and concerns raised within the Group and their communities.
2. It is expected that the group are likely to meet between 3-4 times per quarter. However this will to be dependent on the issues discussed and the outcomes sought.
3. It is expected that at least one of the meetings quarter will involve a representative, or person speaking on behalf of the local Health or Council service.
4. All meetings will be no longer than two hours in duration.
5. Meetings may be recorded.

5. Role & Responsibilities

Agreement to be part of the Community Voices Group will come with commitment and responsibilities. These include an understanding that members agree to

1. Attend induction, information sessions and training that will support Group members in their roles as effective Community Representatives.
2. Attend scheduled meetings to discuss and raise issues relevant to the Group and communities they represent.
3. Consult with members of their own community to identify and explore issues of importance to their communities.
4. Consult with partner organisations on how best to explore views and opinions of the Group collectively. In addition, how the Group can best communicate to relevant authorities.
5. Attend meetings with representatives from local Health and Council statutory services to discuss issues and concerns relevant to their communities.
6. Support the production of reports on matters discussed and raised within the group.
7. Contribute constructively to discussions amongst the Group members, project partners and local service providers.
8. Where relevant expenses will be paid to cover cost of the Group's members. attendance at meetings.
9. Take part in an evaluation of this project.

The above is not an exhaustive list. If necessary, additions may be added to Roles & Responsibilities.

Appendix Two - Notes from Inaugural Meeting

COMMUNITY VOICES GROUP: Meeting Summary.

27th January 6-7.30 pm Zoom.

Introduction:

Wednesday 27th January a group of people from different ethnically and culturally diverse backgrounds met via Zoom. The Group was brought together through a partnership between four Brighton & Hove Community & Voluntary organisations, namely Trust for Developing Communities, The Racial Harassment Forum, Hangleton & Knoll Project and Sussex Interpreting Services. The purpose of the gathering was to start piloting a process as an alternative approach to local government consultation.

Rather than have an approach where third sector organisations conduct research or consultations on behalf of the local authority and NHS commissioners on subjects they have identified; a different approach would be adopted. This was one where the residents from communities highlight and identify issues and areas of concern. Thereafter, these issues and concerns would be presented to appropriate staff within Brighton & Hove City Council or Sussex NHS to explore and discuss solutions to address the issues and concerns raised.

This particular approach would be undertaken by bringing together a broad cross section of people from the the City's ethnically and culturally diverse communities.

In the first of these sessions there were 18 people in attendance, including the two facilitators. Overall, the group was reflective of the City's ethnic and cultural diversity. Several different ethnic and cultural groups were represented, including, Indian-sub-continent, South East Asia, West and North Africa, West and East Europe, South America and the Caribbean.

Amongst the attendees there was consensus on the reasons for attending the session. Most mentioned a desire to investigate and learning how they might gain opportunities to inform decision makers, in the City council and NHS, of concerns and problems experienced by members of their community.

The majority of the attendees to varying levels had experience of community and or advocacy work in their communities. This included roles and positions such as, community interpreting, community Champions, Project Coordinating for community specialist groups, membership of local Patients' Support Groups, culturally specific Friendship Groups, membership of gender specific groups and interest in mental health services.

In addition, there were people who had lived in the city for decades as well as others who have been resident for a few years only. However, despite the length of time living in Brighton & Hove all reflected a keen interest in contributing to efforts that could see improvements of services to the city's culturally and ethnically diverse communities.

An early point made within the group was the hope that this process would change from the previous type of consultation engagement. It was hoped that it would produce tangible outcomes that could be followed through to achieve the objectives they were set. There was a suggestion that past consultation and some initiatives although well intended had perhaps not met the expectations when it came to either follow up or implementation.

Background:

When asked for general perceptions of the City Council, not surprisingly there were a range of views expressed and examples of experiences given. They included a perception that it was difficult to generalise, because experience (good or bad) was largely dictated by the person speaking on behalf of the council. Naturally in some cases this could be a largely satisfying and positive experience. However, the same issue dealt with by a different Council staff member could elicit a negative, unproductive or frustrating outcome.

Also mentioned was a perception that lack of visible diversity within the Council's staff was a factor in its perceived inability to respond adequately to needs expressed within diverse communities.

The view that the Council were inconsistent with their support and engagement with diverse communities was also expressed. This was a reference to initial positive support (including funding) for communities. However, an example was given where eventually the Council appeared less engaged or willing to support a group, despite the view that the original reason they were involved still remained. Many referred to the Council ceasing to fund a community group they had previously supported.

Also, mentioned were periods when it was considered the Council were very proactive in the community for a while. Then, it seemed like no activity or presence at all. Some within the group felt the services delivered by the council are often reactive and that situations have to get to a level of need or be desperate before the council are active in addressing a problem.

However, the areas where there was wide agreement by the attendees focused on contact and communication with the City Council. There was broad agreement that the methods for contacting the Council were considered to be ineffective. First not speaking to a live person was associated with a detached, remote service. It was felt this system does not take into consideration people less familiar with these systems who may struggle to understand instruction systems and options. In addition, if a caller does not get to speak to a person, but leaves a message to call back, the perception is they never receive a call back. This, it was pointed out was contrary to the pledge given on the Council's website, of a return call within a given period.

The impact of the comments made above is a perception that communicating with the City Council is difficult and at times a frustrating process. Furthermore, seeking to rectify

or address problems with contact and communication were also difficult, because many were not aware there was an official complaints procedure. There was little chance of a matter being taken to a more senior level as Council staff could often deny that opportunity to request to speak to anyone else.

Another issue raised concerned home-schooling and how parents with language needs could be better supported to help their children who are learning in English.

On the NHS, it was acknowledged that the principles of the NHS and many areas of its service were excellent. When compared to other health care systems across the world, the NHS was seen as one to be proud of.

However, there was also broad acknowledgement that, for those whose first language is not English they could face some significant barriers in communicating their needs and therefore accessing the healthcare they required. Often a significant factor in this issue was the GP/Primary Care appointment systems. Whilst it was recognised different GP Surgeries had their respective systems and levels of effectiveness, it was also a strongly held view that overall the telephone call systems for making GP appointments disadvantaged people whose first language was not English and particularly those without basic levels of competence in English.

These problems for some had been substantially increased with the conditions and restrictions for seeing a GP during the COVID-19 pandemic and local lockdown restrictions. Examples were given where appointments were denied, because the caller failed in expressing their needs or urgency to the GP receptionist. Or the receptionist failed to provide a response that acknowledged the caller's urgency, importance or level of concern. There was also an example of an in-surgery incident where a patient was asked in the waiting area (with many other patients present) to explain their reason and need for an appointment. Struggling to feel at ease and make themselves understood, the person whose first language was not English, was left feeling humiliated.

There was an acceptance that measures needed to be taken to ensure the best use of GPs restricted time during the pandemic. However, the perceived lack of understanding and cultural sensitivity demonstrated by GP staff was causing discouragement, hardship and suffering amongst some people in diverse communities.

Solutions to these problems were not considered difficult to identify and implement. In the first instance it involved training staff. Cultural awareness and sensitivity training was mentioned. Also making resources available to pay for interpreting services was another solution.

Most people who have a need for professional interpreting services simply do not have the means to pay for them. Whilst provision like those offered by Sussex Interpreting Services provide an invaluable service, financial resources to ensure it is available to all who need it were considered not to be in place. Thus, it was concluded, many will be forced to go without this much needed support.

The principle of the ability to self-refer oneself for specialist's health services like physiotherapy was welcomed as a positive initiative. However, the nature and extent of the online form to book an appointment was seen as complex and requiring much information. Again, for those whose first language was not English, there was doubt that they could complete the referral form effectively without guidance and support.

Vaccine and Communication:

Awareness of the vaccine rollout was universal amongst attendees. Virtually all receiving news about it from national TV and radio media sources. However, there were mixed experiences on the question of receiving information on the vaccine rollout locally. National news from central government had been seen as good in setting out intentions and expectations for the vaccine rollout. However, it was mentioned that the Government COVID-19 related website was advising members of the public not to contact the NHS. Therefore, there was uncertainty on how the local process of call up for the vaccine would take place.

Amongst the attendees were members of SIS community interpreters. They welcomed the fact that SIS had made arrangements for them to receive the vaccination because of their frontline staff status.

There was also a perception amongst some in the group that they (and others they knew) had not received the local follow up on the vaccine they had expected. Comparison with other areas was made, in which vulnerable people and their carers in other parts of the country had received information on when they would be vaccinated. By contrast some in similar circumstances in Brighton said they had heard nothing. Amongst some who were expecting to be contacted about their vaccination, there were feelings of anxiety and concern that the system may not work effectively for them.

The perception that some people amongst the Black and Asian communities are reluctant to take the vaccine was mentioned. Those who raised this point felt this situation could be addressed with targeted and appropriate outreach work. Relevant workers could meet with communities to build trust and reassurance in the vaccines. It was felt without this type of engagement, vaccinating people from certain communities could provide highly problematic. The solution of community outreach engagement would also address the misnomer that these communities are hard to reach.

There was a direct request for the Hungarian Women's Group to receive a talk about the vaccination jabs to reduce the misinformation and fear around this subject.

A consistent message on vaccinations, one that reflected the positive services and expectations people in other parts of the country were having was suggested. Guidance and advice should be centralised. It was felt it should not be for other third sector bodies and organisations to provide official advice on local vaccination processes.

February 2021

Appendix Three –

First Community Voices and Commissioners Meeting

Community Voices Group: 2nd Meeting:

Wednesday 3rd February

Following the 1st meeting of the Community Voices Group (CVG) on 27th February this second session (Wednesday 3rd February) involved members of the Community Voices Group and representative from Brighton & Hove City Council (BHCC) and NHS Sussex.

In this session CVG members would raise some of the points discussed in the first session in order that appropriate representatives from Brighton & Hove City Council or NHS Sussex would respond specifically to the issue raised.

It should be noted, that this first sessions with representatives from BHCC and NHS Sussex was not expected to result in direct action to address the problems and matters raised. The objective of this sessions was to use it as an initial stage in a process of increasing awareness and understanding of issues faced by ethnically diverse communities. Thereafter (in follow up sessions) all parties would jointly work up and agree solutions on how these issues can be best addressed.

The following BHCC and NHS Sussex departments and areas were present at this 2nd session

- Public Health: Heath & Adult Social Care (BHCC)
- Sussex NHS Commissioners
- Communities, Equality & Third Sector Team
- Patient & Public Involvement Team
- Marketing & Communication (BHCC)

The CVG members questions asked of the representatives focused on the following areas

1. The difficulties experienced in making GP and other health service appointments, particularly those whose first language is not English
2. Reactions and experiences of information being sent out on Covid-19 particularly the information on the vaccination roll out.
3. The difficulties and experiences of making contact and attempting to communicate with the Council

Additional questions asked by the group were

- What had work well and not so well in relation to local management of the COVID-19 pandemic, including the recent vaccination roll out.
- A recent national study had highlighted higher negative outcomes for ethnically diverse children affected by COVID-19; was there any work being done locally to explore how these research findings might be reflected in the local population.

The representatives from the BHCC and NHS Sussex listened to the questions. Once all questions were asked, representatives answered those questions relevant to their area of work.

In general, representatives from the City Council and NHS responded directly and proactively to the questions raised. Where they were able, they gave direct guidance and advice to address the problems raised by members of the group. Further, in those areas where they were unable to provide answers to the issues raised, they gave suggestions as to where solutions could be found. In addition, they also gave assurances that issues requiring a change in policy or approach would be looked into. Some of the Community Voices Group members who asked specific questions were also given contact details of people within the council or NHS services who might be able to assist with the specific question or query. Lastly, the representatives also provided information on steps being taken to ensure the communication of services was being improved.

1. The difficulties experienced by patients whose first language was not English was acknowledged. Reference was made to some of the existing services that offered translation of NHS information. However, it was recognised these problems would require some intervention that could include staff training, increased awareness of the services that currently exists to assist patients whose first language is not English. Also identify what else could be done to support those who struggle to receive the health service they require.
2. It was noted that since the first Community Voices Group meeting, information and awareness on the vaccination and its roll out had improved. However, there remained some uncertainty for some regarding where they would get information and ultimately the vaccine from. An NHS representative provided background information on the process involved in the vaccination roll out. Further, why in some instances the information may have seemed not clear. However it was considered that in principle the roll out of the vaccine was progressing well, although there was acknowledgement that it would require continued effort to ensure continued success of the vaccine roll out.
3. The difficulty in experiences in contacting relevant departments in the City Council was acknowledged by those relevant representatives. They responded by stating the communications team were working on a number of new initiatives that it was hoped would address the issues raised. Further, it was stated that the marketing and communications team were engaged in producing information that would improve the information flow from the City council. However it was also acknowledged that the examples given of problems currently been faced require a specific approach and this would be looked into further.

Other matters raised including the issue with ethnically diverse children and the long-term impacts of COVID-19 were acknowledged by the relevant NHS representative with an assurance that they would look into this issue and assess the extent it might apply to the local population.

Overall, there appeared to be broad satisfaction from the Community Voices Group members to the responses given by the City Council and NHS Sussex representatives. Although it was not the case that solutions were found and issues addressed for all matters addressed, the session clearly demonstrated how this process of interaction between the community and statutory service providers could work effectively in identifying and meeting needs.

A comment and suggestion made by both parties to the session indicated that more focused themes for discussion with a smaller number of people involved may facilitate a more effective approach to raising issues and finding solutions. For example, a range of different themes and subjects will be identified. Group members can decide which of the subjects they would like to be part of. An example of the difference subjects or themes would be the following.

- Housing (Council and Social housing)
- Housing (Private tenancies)
- Translation & interpretation needs and support
- Health & wellbeing needs
- Education (Children)
- Access to education and training (Adults)
- Access to health and social care
- Implications and impact of Brexit
- Vaccination roll out

Therefore, in the next session this idea of smaller more focused groups will be explored. Please feel free to bring your suggestion to the areas you would like to discuss with the City Council and NHS Sussex

Appendix Four – Vaccine Confidence Meeting

Community Voice's Group: Commissioners' Report

1. Meeting Wednesday 14th April 2021.

This paper is a summary report of the Community Voices Group (CVG) session that took place on Wednesday 14th April 2021. This was the 3rd subject-based meeting since the group first met in January 2021. This session was distinguished from the previous meetings because rather than members of the group identifying and agreeing which subject and themes to cover, the subject under discussion for this session had been requested by the commissioners of this initiative (i.e., Brighton & Hove City Council and NHS Sussex). However, it is worth noting that the subject of vaccination, mainly focusing on where and how one could get it was spontaneously raised in a previous session of this group and we had hoped to build on this interest.

This session addressed the subject of **COVID-19 vaccination hesitancy** amongst black, Asian, and other ethnically diverse communities' national statistics (which are said to reflect local data) indicates people from ethnically diverse backgrounds are significantly less likely to have the vaccine when compared to people defined as 'White British'. Moreover, the figures are said to be low for some specific ethnic/racial groups. This session was asked to explore factors contributing to comparative low uptake and what solutions could be employed to significantly improve vaccination levels amongst these communities.

Attendance of CVG members for this session was very low. Five people attended. Eighteen people attended the first session. Although it is typical to expect a degree drop off, this number was far lower than we would normally anticipate.

No assessment has yet been undertaken to explore what might be behind the reasons for the low attendance. However, the partners to this project will be addressing this situation in forthcoming meetings and examining why despite initial interest, members did not attend. It has not escaped the attention of the partners that the comparatively low vaccination levels amongst these communities have been reflected in the low attendance on the subject. However, there is no evidence yet of a link in those two facts. Possible reasons why numbers in attendance were low, include fasting due to Ramadan, Easter holiday period, attendance at other meetings, less interest amongst member and of course forgetfulness. Also, several people gave their apologies. There is awareness amongst the group that they are not expected/required to attend all meetings. Lastly, some feel enough work on vaccine hesitancy it is already being undertaken amongst people in their communities.

Notwithstanding the low numbers, the racial and ethnic groups who contributed to these discussions were

- South East Asia
- Middle East*
- Eastern-European
- South American
- Caribbean*
- African*

*These contributions were made in two separate sessions on this subject with people from these communities.

It is relevant to note the relatively small sample involved in this session. Whilst there is no question on the authenticity and validity of the responses given, the relatively small sample does not allow for the broadness of opinion/views one might consider ideal.

2. Findings:

2.2. Vaccination satisfied

Firstly, those people who have decided to have the vaccination typically reflect a belief that it is the sensible course of action to take. Virtually all who had the vaccine said their decision/assessment centred on the belief that COVID-19 posed a significant risk to their health/life and avoiding contracting it was a health priority. Therefore, amongst this group the levels of persuasion to get them to take the vaccine was low. This is reflected in the fact that many proactively sought out information on when and where they could get the vaccine. Many in this group are elderly. But the sample was too small to determine whether age is a factor for whether these respondents had or would take the vaccine. Some having had the vaccine said they were/would encourage others to take. Again, they felt 'the benefits outweighs' the negatives.

Nevertheless, it was noted that even amongst those who had the vaccine some concerns were expressed regarding vaccine side effects (including deaths), limited clinical trials, conflicting efficacy data, experimental nature, and the extent the vaccine would be effective on people of colour. However, most of those who expressed vaccination doubts but had had the vaccination felt the vaccination was 'the lesser of two evils' when compared to COVID-19. Interestingly, most of those who have had the vaccine are members of other wider groups who also positive about having the vaccine. This suggests the possibility of positive collective mutual endorsement for the vaccine that might also be encouraging others to take the vaccine.

2.3. Non vaccination reasons

Perhaps not surprisingly there is not one single narrative that appears to influence people who so far have decided not to have the vaccination. However, what is becoming clear it is unlikely to be lack of information (where to get the vaccine) and lack of opportunity (convenient options) that

represent the main reasons a substantial proportion of people from black, Asian, and other ethnically diverse backgrounds are choosing not to currently have the vaccine.

To identify solutions or actions that would increase the levels of vaccination uptake amongst ethnically and culturally diverse communities it is important to understand the range of factors that are likely to be influencing individual and collective thinking. Significantly, in several circumstances there are multiple factors that converge to present evidence that cast doubt on the trustworthiness of the information on the vaccine.

Alternative information. A common perception is that alternative information sources are more trusted than official sources. This is often because these sources are recommended by or have been referred from a trustworthy friend or family member. Therefore, there is existing familiarity with a source, be it from the person recommending it or it being a source where information has been sourced in the past. Often, the source is not UK based, but might originate in a country of origin or the United States.

Mistrust of the services. This is typically due to perception or experience of previously being treated poorly or unfairly. An example given included NHS staff not acknowledging their errors. Or in some case where people have had past concerns and NHS staff being dismissive of these concerns. Some communities believe NHS staff adopt a '*we know best*' approach that disenfranchises and creates perceptions that, because of their ethnicity, they are not listened to.

Historical social inequality. Some communities believe they have historically (in the recent and distant past) been subjected to systemic and institutional inequality. This has created or caused them to be cautious and, in some cases, suspicious of most institutions, including central, local government and even medical services. Interestingly, this sense of inequality does not have to have occurred within the UK. The example of mass polio vaccination and sterilisation of black women in Africa was cited as an example of Western disregard for the health rights of black people generally.

A vivid example was given at the beginning of the session when one respondent at the session shared on her smart phone an extract from two separate sessions in which people purporting to be experts were presenting information claiming the vaccination was a plot/ruse to limit reproduction levels of racial groups. These included claims that the worldwide vaccination programme was being controlled by a group of global industrialist and pharma companies that included Bills Gates. Naturally, this was one of the more extreme reasons given why the vaccine was not being taken. Notwithstanding the specifics of this claim/belief, it does highlight an important factor. This being that official UK NHS information is competing with other sources and whilst most people consider it outlandish many others believe it is as equally credible. Further, even those who do not fully believe the conspiracy theories claims of a shadowy group of globalism seeking to control world, there is still mistrust of information.

One respondent said having the conversation in their community on why the vaccine should be taken, was currently very challenging and in some instances not possible. This was because feelings were so strong, many simply were refusing to have the conversation, because of some of the reasons expressed above. Further, in these communities those who were openly advocating having the vaccine, risked some degree of ostracization from those opposed to the vaccine. Amongst the views held were the sense that they were being forced into this action and of having the power to make one's own decision taken away from them. And instead, not being given an opportunity to wait and take their time in coming to a decision. Some felt these feelings could cause them to strongly resist efforts to persuade them to have the vaccine. The notion of being treated as a guinea pig was also mentioned.

The following as an extract from research conducted by a member of this project team.

2.4. Barriers:

'Myths/conspiracy: infertility, Halal, vegan belief, alter DNA, inject microchip, tracking, health complications, underlying health issues, BME, diminished level of education.'

'Vaccine Hesitancy: approved too quickly.'

'Astra Zeneca – banned in certain countries including Ireland (4th country to ban), Norway reported four cases of blood clotting). WHO said no clear links in the vaccination population, but countries are banning for precaution. The news highlighted that France and Italy have stopped the vaccine and 37 cases of blood clotting were identified and an investigation is being made.'

'On a personal level my aunty passed away days after taking the Astra Zeneca vaccine. She had side effects: temperature, vomiting and diarrhoea. She collapsed on Friday with failing blood circulation, her brain was starved of oxygen and caused swelling of the brain causing permanent damage. She was on a life support machine and then the machine was turned off yesterday. She was fine before taking the vaccine. Now my other family members who have appointments for vaccines are no longer willing to take the vaccine. This is the Bengali community and like other BAME communities now this will be the case, over 90% will refuse to take the vaccine.'

'What type of vaccine to take according to personal circumstance/underlying health conditions? There is fear of taking vaccine with underlying health conditions.'

3. Conclusions

Existing information is not providing the levels of reassurance and trust some people from black, Asian, and ethnically diverse communities are seeking. Importantly, many of the official information sources are not specially addressing some of the (outlandish and extreme) claims on why the vaccine should not be taken. Many believe they are not hearing enough from official UK

sources that addresses acknowledged and wider concerns such as side-effects, efficacy, and death rates.

Amongst those who have had the vaccine, there is a strong belief that action can be taken to increase the levels of uptake. They believe this is also true to a lesser extent amongst those currently resisting having the vaccine. However, the following actions may have a positive effect on the vaccination levels:

- Working with acknowledged community leaders such as religious leaders, community or association chairs and leaders, local businesspeople to support and endorse the vaccine. Using trusted channels, creating a 'messenger' effect, and building trust.
- Recruiting well regarded community representatives or community engagement workers who have built good relationships with communities as vaccine advocates.
- Light touch/persuasive approach to information dissemination (i.e., not doom-laden narrative of the folly of not getting the vaccine).
- Correct sources of information backed up by scientific research. Proven experiments by scientists and conversations to dispel scare mongering/fake news misinformation and political element. Fear of not knowing the unknown.
- Information that counters and speaks directly to the concerns raised (even the outlandish beliefs)
- Continual and consistent messaging
- Fear of vaccine greater than fear of COVID-19
- Rebuilding trust in the NHS. Amongst some in these communities, trust in some areas of the medical profession has been lost.
- Hard copy of 'Yellow card' to note side effects (in other languages)
- Opened discussion, creating dialogue, allowing communities to come forward, open invitations, taking away the pressure and being forced is causing resistance. There is a need to 'not push'.
- Data based, evidence with regular updates.
- Eliminate the fear of discrimination in ethnically and culturally diverse communities who choose not to be vaccinated.

- Counter misinformation with GP support. This is likely to be seen as the most trusted information source. Tailor messages to individuals such as addressing patient's fears about side effects, muscle pain and fatigue so they do not worry that the vaccine gave them the disease.
- Consider who is delivering the messages about the vaccine. Information needs to be well researched, accessible and evidence based. Ideally it would be shared by someone 'like us', or an authority figure. People want information from a familiar face, local GP's, or known community staff members.

The vaccine hesitancy has possibility highlighted a further consequence of health and social inequalities amongst ethnically and culturally diverse communities. It is worth considering if these inequalities did not exist, there would be this degree of hesitancy. Regardless of its source, addressing vaccine hesitancy and reducing/eliminating some of the factors that are governing it will require an on-going effort.

End

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