UK Health Security Agency

Public Advisory Group
Discussion groups

August 2021

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Background overview

The Public Advisory Group (PAG) was convened in June 2021 to explore the public's concern and expectations about measures used by UKHSA and regional partners to stop the spread of coronavirus (COVID-19).

The aim of the PAG was for members of the public to learn about and discuss issues and policy areas in relation to COVID-19 and set out their expectations. Policy areas discussed were self-isolation and testing, contract tracing and wastewater testing.

The 100 PAG Members reflected key demographics of England's population, with an over-sampling of Black, Asian and Ethnic Minority Groups and respondents living in Indices of Multiple Deprivation 1 to 3 areas to ensure a stronger representation of the experiences of these communities (given the adverse impact of the virus on these groups).

Following on from the previous PAG sessions, it was identified that further sessions should be held with targeted population groups to build on the information already gained.

The aim of the additional sessions was to gather information from key targeted groups who are disproportionately impacted by COVID-19 measures and were not represented in the PAG, to allow them to feed into the expectation set out by the PAG and inform policy decisions.

This information will be presented alongside the reported findings and expectations of the PAG, due to be published in September 2021.

Audience

Representatives from a cross section of organisations who work with the end user target groups were invited to attend series of virtual workshops which took place 16 and 17 August 2021.

Attendees were identified as those who are influential within their communities and able to represent these communities through their knowledge and experience of living and working in them.

Identified communities:

- people living with disability, the elderly housebound population living with health conditions, care home staff
- Roma, Gypsy and Traveller communities, faith groups (to include Afro Caribbean, South Asian, Eastern European)
- homeless and low income/deprived households
- migrant workers, asylum seekers, hidden communities

Methodology

For each workshop it was identified that 10 to 12 participants were required for each session. Invitations were sent via email to over 200 targeted organisations using an established contact list and followed up with telephone calls to encourage participation.

The format of the workshop was designed to encourage a genuine conversation that allowed participants to explore the levels of acceptability and support for different forms of testing within their communities.

The 3 areas for the discussion were:

- self-isolation and testing
- contact tracing
- wastewater testing

Each session followed the same structure:

- introduction and PAG overview
- testing and self-isolation – video presentation and facilitated discussion group
- contact tracing – video presentation and facilitated discussion group
- wastewater testing – video presentation and facilitated discussion group

Each workshop lasted 2 hours and was facilitated by staff from the NHS Test and Trace External Communications team.

Themes that were recurrent in all groups include:

- requirement for improved communications – simplification of message, format of materials, language and accessibility of materials
- non-compliance with rules for financial reasons – the decision to self-isolate is often dependent on an individual's financial situation and for those with poor job security and no financial resources, they are less likely to follow the guidance on self-isolation
- lack of access to support services
- mental health and isolation issues
- COVID-19 fatigue
- digital exclusion
- discrimination
- mistrust of government
- concerns over how any data is used
- a better understanding of individual communities and their specific needs based on faith, culture, ethnicity and so on
- public health messaging review

Date	Monday 16 August 2021,10am to noon
Audience	**Elderly, housebound, those living with disability, care home staff**
Number attended	10
Organisations represented	• RNID • Parkinson's UK • MENCAP • Age UK • Epilepsy Society • Croydon Neighbourhood Association • Age UK Solihull • Warwickshire Community and Voluntary Action group • Independent Age • Scope

Key findings: Self-isolation and testing

Difficulties with self-isolation

It was noted that people with learning disabilities or dementia may find it difficult to understand the guidance around self-isolation and find it difficult to engage with.

People with disabilities, who need to engage in physical exercise are significantly impacted by self-isolation, as not all are able to do this at home, especially if they have no access to a garden or outside space, as a result of which they break isolation.

The challenges for people living with diabetes**,** are focussed around management of their condition including being unable to attend specialist clinics and lack of support staff to assist them.

Problems identified with basic activities such as shopping, accessing food and groceries whilst self-isolating.

More clarity and clear messaging is required about self-isolation and what is, or not, allowed; confusion reported in the interpretation of the rules has caused confusion for some elderly and their carers; similarly with messaging on vaccination, with some elderly groups reporting that they didn't understand if vaccination meant that self-isolation was not required.

Challenges reported from care homes when staff are 'pinged' – this has caused stress and a shortage of staff at times.

Turning off Track and Trace to avoid being ‘pinged’.

Reports of the elderly feeling scared, vulnerable and unsure of what they need to do. Confusion around self-isolation message when many other rules for example face masks, are no longer compulsory in many settings. Specialist nurses noted that there has been a significant decline in disabilities and functioning, and there are general fears about health de-conditioning.

Compliance with isolation

Agreement that if accessible financial, practical and emotional support is available, elderly people are more willing to comply with self-isolation.

Some people in the workforce continue to attend their workplace out of a practical financial need, uncertainty/fear over their job security and personal responsibility, even when advised to isolate. Whilst the importance of self-isolation is not being dismissed, individuals have to consider the personal cost to their livelihood if they choose to self-isolate.

Many elderly people report that the toll on their mental health after previous lockdown periods has left them unwilling and unable to comply with further self-isolation requests which is more acute during the winter months.

Feeling of disenfranchisement and lack of trust in government agencies with regard to how well they have implemented the policies for example poor policing of face mask policies.

People who were identified as having been asked to shield, often don’t understand why and felt that they have not been provided with enough support to make this substantial change to their lives.

Testing

It was acknowledged that information on the spread of COVID-19 that is gained from testing is important, but commented that access to testing remains difficult.

Twice weekly testing for elderly groups who are housebound was regarded as unnecessary and a clearer explanation is needed as to why they are potentially at risk.

Lateral flow tests were reported as not being easy to complete for those with some physical disability or impairment, which results in the test not being carried out.

Information is heavily weighted towards online information, and information in printed form has not been easily available. Some charities reported that they have produced their own versions of the government guidance in a more accessible and easily understandable format for their communities.

Some elderly communities are digitally excluded and cannot go online for support. Requirement for dedicated telephone support.

Suggestion that more work should be done working in partnership with advocacy groups and charities with regard to the most effective way to talk to vulnerable communities.

Key findings: Contact tracing

It was highlighted that for those with learning disabilities, there is a range of different support that is needed, as they often experience problems with communication and understanding contact tracing.

Communication around contact tracing should be expanded into easy read print and video format to explain clearly what contract tracing is and how it is used; information packs to be provided for carers; foreign language materials required; consider those who use BSL as first language; making information available in places where it can be accessed for free – for example Libraries, Community Centres.

Information needs to be presented in a shorter format – bite sized chunks – to aid understanding and sharing of key messages.

Requirement for clear messaging about contact tracing – how the data is used and why, and assurances on the security of this.

General fear in elderly community about giving personal details which can lead to an increased sense of vulnerability.

Within some elderly communities there is a higher level of digital exclusion, which makes accessing and using the NHS App difficult on a mobile phone.

If we are relying on people to make their own risk assessments, they need simple scientific messaging to understand the risks and why they are required to follow certain rules such as ‘take your vaccine’ or ‘you have to self-isolate’.

The elderly community has heard the message about the impact of COVID-19 on the NHS and as a result some continue to delay accessing treatment they require yet are aware that this could have a serious impact on their overall health.

Key findings: Wastewater testing

Overall awareness of Wastewater Testing was generally low in the elderly and housebound community.

There was an acknowledgment that this could work as an effective tool in helping stop the spread of COVID-19 and delivers some cost benefits.

Question raised as to whether WWT could be used as part of a suite of wider Public Health messages.

Elderly communities' welcome tools that help protect their community and welcome the non-invasive element of WWT.

The messaging needs to be clear and understandable demonstrating the benefits of WWT, how it works in practice, and explaining how is the information that is gathered is used.

A genuine fear that simple messaging could be misinterpreted. For example "We are carrying out wastewater testing", is heard as "Don't drink the water" (which in an elderly population could lead to further health problems).

Fear that WWT could lead to discrimination and possible incidents of hate crime in some already marginalised communities if COVID-19 found in their area.

Small scale lockdowns driven by wastewater findings might make people think a particular street or neighbourhood is engaging in high-risk activities or poor compliance with COVID-19 regulations – this needs careful management and messaging.

Date	Monday 16 August 2021, 1 to 3pm
Audience	**Faith Groups, and Roma, Gypsy and Traveller Communities**
Number attended	10
• Organisations represented	• National Federation of Gypsy Liaison Groups • Volunteer Interfaith Partnership, Bradford • Gypsy Traveller Organisation • ROMA Support Group • GTDT • Yorkshire Travellers Trust • Sikh Community Church • Traveller Movement • Seventh Day Adventist Church • Jewish Volunteering Network

Key findings: Self-isolation and testing

Faith groups

There has been a reasonable amount of compliance in faith communities surrounding testing and self-isolation, however some are hesitant about vaccinations such as the AstraZeneca vaccine and potential health risks.

Some will not participate in self isolation because of the financial risks to their families through loss of earnings due to self-isolation.

It was highlighted that there is a need to have a more holistic approach, considering all socio-economic impacts, and recognising that people will require different support; such an approach would also help in addressing the blame culture associated with COVID-19 and encourage people to work together as a whole community.

It was noted that during self-isolation in the faith communities, there was great support around delivering food to people, reaching out to those struggling with mental health issues and providing support for spiritual needs as well.

Messaging association with testing needs to be positive and demonstrate that it is acceptable to tested and taken care of, as this is part of a pathway to recovery in the pandemic overall.

Faith groups would like clearer evidence to show that testing works.

Gypsy, Roma and Traveller communities

Clearer messaging and translated into required language is needed about self-isolation, what it means and why it is important. Examples of GRT children who had been asked to self-isolate from school but the message was misinterpreted into “the teacher is sick” or “it’s a free day today”.

Information was not targeted towards some of these communities, with little translated material available and the channels for distribution were not easily accessible.

Close knit communities that will self-isolate but do require support for day-to-day practicalities such as shopping; some communities however have concerns about asking others, such as voluntary services, for help.

Some groups reported obtaining information about COVID-19 from their countries of origin due to language translation problems.

Financial support whilst on offer, was inaccessible to many GRT communities – not passing the residency test and a high incidence of cash in hand/part time work, meant they were ineligible for grants and so some continued to work.

Within some of the GRT communities, accepting financial support through benefits is not always culturally acceptable, hence people continue to work rather than self-isolate.

Self-isolation was reported as having a large impact on mental health especially in the male population.

Problems with traveller communities and house-boat dwellers being forced to move on from their sites.

Confusion over why there is a need to test – vaccination has made people feel safe and mixed messaging has caused some communities to feel unsure about what they need to do. Obtaining a test and administering it was identified as problematic.

Key findings: Contact tracing

It was noted that in some faith communities, people are starting to disregard the fact that COVID-19 is still a danger as restrictions have eased and many are now double vaccinated. A feeling that this has taken away from the urgency to continue to contact trace.

There is a mistrust in how personal data is used if an individual registers their test results. Needs to be more positive messaging about contact tracing and its aims to protect and support all of society.

It was suggested that a local point of contact, a trusted voice, within a specified community working in partnership with the local authority would be beneficial in sharing messages in a positive and beneficial way around COVID-19. Also using younger members of a community to assist older members in explaining the issues.

Financial pressure of needing to work causes some to delete the app.

Concerns about how data is shared, concerns that this is shared with the Home Office and leads to deportation fears.

Digital exclusion identified as a problem especially with more elderly communities.

Need to re-establish confidence in the app – that it works and helps stop the spread of the virus.

Communication needs to be clear and in a format that works best for the community – not just digital, but printed materials and visual guidance and foreign language support.

Distrust in government and perception in some GRT communities was that contact tracing is an exercise in control, finding out where they live, how long they have been at a camp and so on.

Reports that the contact tracing call felt intrusive and like an interrogation, rather than giving advice on the need to self-isolate.

A fear of one individual asked to self-isolate, then resulting in a large number of other people to self-isolate – this puts some people off engaging with contact tracing.

Giving information to government agencies is always treated with suspicion.

Within the GRT community, there is a feeling that trust has been diminished over years through government policies which are perceived to punish and destroy their way of life. In engaging with these communities, it is important to consider the wider context in which they live and their historic interactions with public services and government.

Practical issues reported in some communities which include frequently changing mobile phone numbers, not answering unknown calls, not responding to voicemails.

Date	Tuesday 17 August 2021, 10am to noon
Audience	**Homeless, low income and deprived households**
Number attended	11
Organisations represented	• Porchlight • Crisis • Norwich Food Bank • YMCA • National Housing Federation • Oxfordshire Homeless Trust • Big Issue • Glass Door • Mungo's • Sanctuary Housing • Single Homeless Project

Key findings: Self-isolation and testing

It was noted that in places such as hostels for the homeless, self-isolation was difficult as people living in close proximity with shared bathrooms and kitchen facilities.

Problems of self-isolation compounded where individuals have drug and alcohol dependency, meaning they would leave isolation to buy drugs and alcohol.

Mental health problems reported due to self-isolation, through lack of interaction with others and little stimulation during isolation period.

The 'Everyone In' campaign highlighted a fear within the homeless community about COVID-19 and many chose to remain in housing as they received support enabling them to continue to communicate with friends and relatives, and provided easy access to services, including self-testing.

Some within homeless community don't fully understand the severity of COVID-19 or even believe it is real.

It was highlighted that ensuring that the homeless community has somewhere to go is the biggest challenge, especially during the winter months. There is a continuing challenge associated with some homeless people who might have tested positive, continuing to sleep rough.

In terms of those who have been able to move into accommodation, the delivery models to help support such as food deliveries is reported as being effective although there are challenges for people adjusting to living inside after periods of living rough on the streets.

Messaging for the homeless community needs to be clearer and delivered in a way that it is easily understood, printed materials more effective and not a reliance on digital communications. Some of the messaging around COVID-19 has been perceived as complicated and confusing and for those with literacy problems difficult to understand.

Recommendation that using a peer approach to engage with the homeless community works – using contacts who have been homeless in the past and experienced the reality of this community. Such people could positively assist in providing reassurance around testing, self-isolation and contact tracing.

The decision to self-isolate is often dependent on an individual's financial situation. For those with poor job security and no financial resources, they are less likely to follow the guidance on self-isolation.

For people with high support needs, they cannot afford to be isolated for a period of 10 days if they need to travel to access the services they are dependent upon.

More clarity is needed on what support is available to each group and how they access this help. Information needs to be available in an easily accessible format.

Self-testing was thought to be difficult for those living with no fixed address and clearer advice needed on what symptoms to look out for, and the importance of testing.

Key findings: Contact tracing

Digital exclusion with the homeless community – lack of mobile/smart phones which makes contract tracing difficult to carry out. Noted that digital exclusion is not just about access to the physical resource, it is also the skills, training and capacity to use, download and navigate the online tools.

A feeling that contract tracing within the homeless community was extremely difficult if reliant on technology.

Reliance within the homeless community on outreach workers to collect data and built-up trust in the communities.

Members of homeless community who have moved into fixed accommodation expressed nervousness about opening letters and answering the phone, based on distrust and previously experienced trauma.

Lack of trust as well as a fear of being tracked in these communities; many people don't want to be found, and providing personal details is a challenge for these people.

It was noted that over the last year house prices and rent has increased, resulting in a rise in the numbers of homeless people, so the challenges surrounding contact tracing, testing and self-isolation have been amplified in these communities.

There is a demand for support services to work together collaboratively to support the homeless sector, although lack of funding was acknowledged as a barrier to delivering a joined up offering in some areas.

For those in unstable employment or informal work, they do not engage with contract tracing for fear of not being able to work.

Trust in government is very low amongst the homeless community many of whom feel failed and because of difficulties engaging with local authorities to get the services they require.

For these communities, Test and Trace needs to be part of a wider discussion about their health and wellbeing rather than just approached from a Test and Trace perspective.

Key findings: Wastewater testing

Lack of familiarity with wastewater testing overall.

The potential benefits of WWT were acknowledged, and if it reduces the need for individual testing this was felt to be positive.

Issues were identified about the potential discrimination against a particular community where COVID-19 has been identified, due to the granular level of testing with the possible accusation that one community has caused COVID-19, leading to a stigmatisation and negative connotations towards that community from others.

If WWT could be used to implement prevention strategies without this being public information it would be more welcomed.

A need for clear communication and messaging around WWT – what it is, how it works and how it benefits everyone. Communication must reduce any risk of stigmatisation and discrimination for any one community.

For rough sleepers (on the street) and transient populations, WWT was felt to be irrelevant due to the nature of their lifestyle – lack of access to bathroom facilities, moving accommodation frequently.

WWT was welcomed if it could be used as one tool in the fight to improve public health.

Date	Tuesday 17 August 2021, 1 to 3pm
Audience	**Migrant Workers, asylum seekers and hidden communities**
Number Attended	11
Organisations represented	• Doctors of the World • Women's Support Project Glasgow • UK High Commission for Refugees • UK Community Foundations • IOM UK • Great Yarmouth Borough Council • North East NHS Ambulance Service • GYROS • Migrant help UK • Good Things Foundation • UNHCR

Key findings: Self-isolation and testing

Financial pressure to provide for families and dependents, is a major reason for some individuals not to comply with self-isolation. Low paid or zero hours contract employment, make it impossible for some people to stop working for 10 days. A supportive environment needs to be provided that allows people to comply with self-isolation rules.

Migrant women working in low paid jobs that were lost during the pandemic, reported facing an increased pressure to return to paid work in order to support their families.

Many women working in the sex industry have avoided self-testing so they can continue to work and avoid self-isolation.

Unsecure accommodation, informal housing and a lack of stability in the lives of some in this community, means that some people do not have the physical space to self-isolate if required. Providing temporary support to allow them to self-isolate safely would assist in compliance.

Refugee communities reported a lack of access to information in the correct language or accessible format, leading to a lack of understanding about what they are required to do.

Support in providing medicine collection and shopping support does allow greater compliance with self-isolation.

A lack of trust in mainstream healthcare by people who have previously felt excluded from this, has resulted in a lack of engagement now with the rules they now need to follow.

Communication needs to be clear and available in multiple languages and format. Messages need to be broken down by theme with clear guidance on what a person needs to do. Within hidden communities it is very important to be clear that any data is not shared with the Home Office.

Communication channels should include using message sharing via community champions, and proactively reaching out to places where these hidden communities/ migrant workers are based. Face to face sessions on farms and in factories.

Reported a poor uptake of Lateral flow testing amongst these communities and if an employer does not require it, there is no incentive to participate. If employers encouraged this, levels of testing and compliance could be improved.

Communication around the need for twice weekly testing and why it is necessary, was not felt to be very clear; and some communities expressed difficulty in accessing tests.

There is concern over where some communities look for information, with reports that the use of social media sites is high even though the messaging is not necessarily accurate.

The fear of testing and the possible loss income through a requirement to self-isolation is high across all communities.

Feeling within some of these communities that “Covid isn’t that bad” and the government is scaremongering. Improved communications needed to explain the severity of COVID-19 would help.

Key findings: Contact tracing

Language difficulties have acted as a barrier to understanding and accessing appropriate help and support.

Mistrust and fear of providing data to authorities and how this will be used, stored and who it is shared with; sharing personal details causes significant anxiety for people with insecure migrant status.

For many of these communities, a lack of trust in government (possibly based on historical personal experience in another country) means that there is a reluctance to provide personal details that can identify them as individuals.

Amongst young migrant workers, who live alone with no dependent family to support, the risk from COVID-19 is perceived to be low.

Communication needs to be clear, accessible and appropriate to the group and delivered in a timely manner; sharing information via charities and organisations that work with distinct

communities is well received as is using a ‘trusted voice’ from within a specific community. Translated materials in print not just digital communications required.

Cultural norms mean that within some refugee and asylum communities, communication can only be directed through male family members. In some communities there will be an identified woman who is regarded as the link between the community and necessary authorities.

Digital poverty and digital exclusion is high in many refugee, asylum and hidden communities.

Key findings: Wastewater testing

Low awareness of WWT overall.

Accepted that there were positives to doing this – cost benefits, less intrusive personally than self-testing and a good way of testing particular geographic regions.

As a form of testing, WWT felt to be less reliant on an individual’s personal data as this would be carried out on a geographic basis across multiple households.

Reservations expressed about potential for discrimination of a community where COVID-19 is identified and how this might lead to tensions amongst different communities within geographic boundaries.

There needs to be clear, understandable and accessible communication to avoid any confusion and messages being misunderstood, for example “we’re testing the wastewater” which is understood as “don’t drink the water”. Reinforce the message that this is not an activity targeting one particular community.

Work closely in sharing messages with community ambassadors who understand the cultures and beliefs of a particular community; messages need to be accurate but also culturally appropriate.

There is an opportunity through WWT messaging to reinforce public health messages and signpost to support for those affected.

About the UK Health Security Agency

UKHSA is responsible for protecting every member of every community from the impact of infectious diseases, chemical, biological, radiological, and nuclear incidents, and other health threats. We provide intellectual, scientific, and operational leadership at national and local level, as well as on the global stage, to make the nation health secure.

UKHSA is an executive agency, sponsored by the Department of Health and Social Care.

For queries relating to this document, please contact: enquiries@ukhsa.gov.uk

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