UK Health Security Agency

Test and Trace Public Advisory Group report

6 May 2022

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Foreword

We publish this report in our new colours, as the UK's first Health Security Agency, UKHSA. Our agency works with partners, such as the NHS and local authorities, to make our nation's health secure, by scanning for hazards, analysing risks and protecting us from threats to our individual and shared health – within communities, across the nation and globally.

We want it to be an organisation which learns all it can from the past, and from recent experience tackling the coronavirus (COVID-19) pandemic, building on the experiences of Public Health England and NHS Test and Trace.

Our new organisation's work will be led by science and data, and its decisions will be made using insight and evidence. That critically includes being guided by the people and communities that we serve, and in particular those most able to benefit from our help. This will be evident in the way we communicate, the services we provide, how we measure our performance, and how we are held to account.

During the pandemic it was clear that information didn't reach all the people who wanted it and that some groups were sceptical of the interventions and support provided. We all saw how waves of infectious disease made existing health inequalities worse, despite innovative, inclusive and rapid improvements by health teams in Government and across the country.

This is why we held UKHSA's first Public Advisory Group in summer 2021 – so that we could listen to what people from the most adversely affected communities had to tell us first-hand, and to use these their insights and lived experiences alongside other sources of evidence on health equity to inform future decision making. We want to make sure that as a new organisation our work and our support becomes ever more inclusive, equitable, respectful and effective, learning from existing evidence but particularly from direct experiences during the COVID-19 pandemic.

Throughout the coming months and years, as we are helping make new policies, designing new services and improving existing support, we will try hard to take the recommendations and expectations of the Group into account, so that we continue to work to meet the needs of the people and communities whose health is least secure.

We are incredibly grateful to each of the 100 people who took part in this Public Advisory Group. Members of the group put aside hours of their time to share their knowledge and insights with us. They were open and honest, and trusted us to treat their experiences with respect. We hope that their recommendations are reflected accurately. We are also grateful to all the representative organisations who have engaged with us on behalf of marginalised communities across the UK right through the pandemic.

We also thank our partners in convening this Public Advisory Group: Ipsos, Imperial College Health Partners and Involve. Our partners put in many months of planning to ensure the recruitment, running and reporting met our mutual expectations. Finally, we extend our thanks to our Independent Advisory Group colleagues. Their relentless challenge and championship ensured we never wavered from our ambitions, and that the quality of the debate, and the value of its outcomes, were better than we could have hoped.

We welcome the expectations and recommendations proposed by the Public Advisory Group. In the coming years, UKHSA has a huge responsibility to design its services around the people whose health is least secure – and this Public Advisory Group has been crucial in setting us on the right path to make sure we do that. Thank you.

Sidonie Kingsmill
Director, Customer, Communications and Innovation
UKHSA Executive Committee

Executive summary

NHS Test and Trace (referred to hereon in as Test and Trace), which from October 2021 onwards formed part of the UK Health Security Agency (UKHSA), is responsible for supporting critical policy decisions with far reaching implications for everyone in England. In order to strengthen that support, and particularly to ensure that policy is informed by the views and insights of some of the communities most disproportionately impacted by COVID-19, Test and Trace established a Public Advisory Group (PAG). The aim was to explore the public's hopes, fears, expectations and values in relation to key policies designed to minimise the spread of COVID-19, alongside the organisation's ongoing programme of audience insights, information gathering and user research. Through this approach, the agency wanted to also understand what might need to be in place to build public trust and demonstrate trustworthiness moving forwards.

This report is a culmination of a deliberative dialogue with the Test and Trace Public Advisory Group, which brought together 100 members of the public from England in 5 virtual workshops in June 2021. Participants were recruited using the industry standard sortition, a random sampling method, to reflect key demographics of England's population. Ethnic minority groups and respondents living in Indices of Multiple Deprivation 1 to 3 areas were over-sampled to ensure a stronger representation of the experiences of these communities given the adverse impact of the virus on these groups.

The deliberative dialogue with the PAG was designed and delivered by Ipsos, in partnership with Imperial College Health Partners and The Involve Foundation. The delivery consortium worked closely with policy teams across Test and Trace and the Joint Biosecurity Centre to design the format and content of the workshops. To ensure appropriate rigour and to test the robust methodology, the design of the deliberative dialogue was supported by an Independent Advisory Group.

Summary findings

The deliberative dialogue format of the 5 virtual workshops facilitated a genuine conversation that empowered participants to explore the levels of acceptability of different forms of testing – including Lateral Flow Device (LFD) and Polymerase chain reaction (PCR) tests – the self-isolation policy, contact tracing and wastewater testing.

A feature of deliberative dialogue, this one included, is that the interactions between participants change over the course of the sessions, as participants become more familiar with the topic area. Participants had many questions about the virus, how it has been managed so far, about the mechanisms to stop the spread of COVID-19 and how these interact with each other. As participants became increasingly informed about these mechanisms, they recognised the need for the ongoing management of the virus, despite the

vaccination roll-out. They also recognised, however, that many of these interventions rely on widespread awareness and public cooperation, and that certain communities within society, notably those in deprived areas, are disproportionally disadvantaged as a result of limited exposure to those network effects.

During the fifth and final workshop, informed by an analysis of their discussions to that point, participants agreed on a set of overarching principles that they thought could be applied to future policy development by UKHSA. Participants then edited policy-specific expectations, underpinned by the principles, concerning self-isolation, testing, contact tracing and wastewater testing.

The 3 overarching principles established through the Test and Trace Public Advisory Group as ambitions sought by the public for future service development, engagement and coproduction are set out here:

Overarching principles

Communication, proactive transparency and education

Make information about testing, tracing and self-isolation widely available as simple, clear and engaging communications.

Proactively research where people get their news from and invest in the use of multiple media platforms (television programmes, radio, social media) to communicate key messages, accounting for people who do not engage with mainstream media for example Netflix, Spotify, YouTube and TikTok users.

Focus on getting clear and consistent messaging out to the public from trusted people, that is support and enable trusted individuals within communities (GPs and community leaders) to provide information and have national speakers from public health bodies rather than politicians, and also creating some independence of UKHSA from politicians.

Create a sense of shared purpose and community efforts, with positive messaging about measures that are effective – tell the public about the successes, and recognise weariness can be addressed with (realistic) positivity.

Make a UKHSA communications plan that proactively communicates how data is used, stored and shared, and who can use, store and share it, to reassure people that their data is safe. Privacy policies are not enough.

Wherever possible explain to the public how public money is being spent, how those decisions are made and what benefit that spending resulted in.

Give the public a clear, holistic, narrative about the way forward. How do all these measures fit together?

Supporting society to do the right thing

Enable employers to support their employees with testing and isolating through financial support and resources to make changes to their premises and company practices. No business should be out of pocket from employees doing the right thing.

Enable employees to hold employers to account by providing legal support for employees to whistle-blow and ensure consequences for employers who do not support their employees to adopt COVID-19-safe behaviours – testing and isolating, face masks and distancing. This is only justifiable if the first condition is in place.

Keep public data safe and protect public interests; data gathered through testing and tracing should only be used to protect public health. Data should be stored safely, and not be sold or used for purposes other than what it was collected for. This should be regulated and audited.

Take away barriers for the public to do the right thing, like lack of awareness, access or support – only then can the public be held to account for not abiding by the rules and guidance.

Lead by example, get across that tackling COVID-19 is everyone's responsibility, and share learning – the public wants UKHSA to be transparent, and show how mistakes are being learned from.

Equity

Do more to explore what financial, practical and emotional support is really needed for people to self-isolate, especially those who can't isolate as easily as others, and provide support in a timely way with the flexibility to adapt to public needs.

Seriously consider the disproportionate impact of COVID-19 faced by certain communities, and the context of inequality in society, in everything that UKHSA does and make efforts not to deepen inequalities further.

Prioritise reaching people who don't have the internet or access to a computer/mobile phone, so that they receive the same level of information and support as the people who are online.

Proactively reach out to the public with tailored messaging – especially those who are fearful over data use – and tell them the facts about data use and security, honestly and clearly (about contact tracing and wastewater testing in particular). Be clear what guarantees are in place for example data will not be shared with the Home Office.

Do further work to make ‘fit to travel’ PCR tests more affordable, and understand what will make testing more accessible to more people generally through understanding different audiences and communities (for example language barriers, mistrust in the Government), so that efforts are better tailored to what the public really needs and finds engaging.

As a national body, empower and support local leadership to enable and support their communities to isolate, test and trace (including local councils and community leaders).

Policy-specific expectations

These are the summary expectations voiced by participants in the Public Advisory Group, in response to the specific topics covered during the process. The expectations reflect the Group’s perceptions of the evidence at the time of the sessions. The full detail and context of these expectations is outlined over the rest of the report.

Self-isolation

The Public Advisory Group suggests it is reasonable to expect the public to self-isolate when people are told that they need to, if the following conditions are met

Provide more financial and practical support which is easy to access and in a simplified format and is given immediately and automatically, to all who are told to self-isolate.

Ensure that no-one is disadvantaged for doing the right thing. Support should be available regardless of personal circumstances for example employed, self-employed, unemployed. Reassurance about no wider repercussions if they give their details.

Provide a dedicated telephone / text / online help service (which will make it accessible to all people).

Provide more emotional and mental health support, following exploration of what is needed across the population (the importance of preventing, rather than reacting to, mental health or emotional problems).

Improve the process for monitoring people who are self-isolating and at the same time assess if there are any further actions required to support them.

Give the public legal protection from being penalised at work. Help employers and hold them to account.

Provide more clarity to the public on when we need to self-isolate, how long for and in what circumstances. Help the public to understand the risks and why it’s important to self-isolate.

Provide regular free PCR tests while isolating so isolation can end as soon as possible.

Testing

The Public Advisory Group suggests it is reasonable to expect the public to engage more with testing, if the following conditions are met

Provide more adequate, timely financial, practical and mental health support, which is easy to access, to all who are told to self-isolate, so that all those who – but especially to those who need it and/or who are disproportionately impacted – are identified and have access to support. No-one should be disadvantaged or suffer a financial loss for doing the right thing. Communicate directly and clearly to those who need support (including where and how).

Make it clear we will be living with the virus going forward and we will need to adapt our lives to accommodate it. Provide accessible, compelling, precise and validated evidence to the public about what they need to do and why it matters for all forms of testing (PCR, LFD, and include wastewater testing in why it matters) that reinforces the narrative that whilst vaccines are important, they are only one tool to get us out of the pandemic.

Communicate with the public through people they trust, using a range of channels with support from local leaders (including religious leaders) to engage their communities and keep them informed.

Enable the public to engage with timely testing by providing easy, free, safe, contactless (that is does not require having to travel to access PCR tests) access to PCR testing in all circumstances.

Build and publicise a compelling reason for the public, including people travelling to the UK from abroad, to do regular LFD testing. This should include reassurances and visible/tangible development of LFD tests to improve the accuracy of these tests. Including holding testing labs accountable to audits and agreed standards, as well as publishing results.

Reduce the need to do routine testing (LFD twice weekly) by working with the wastewater testing mechanism alongside others, on a local level and making the public aware of this. Don’t ask people to self-isolate if it isn’t necessary.

Contact tracing

The Public Advisory Group suggests it is reasonable to expect the public to engage more with contact tracing, if the following conditions are met

Communicate with the public in a clear and simple way how contact tracing has been improved (if you can prove it) and how it is now working and why we should do it and how important it is. And implement some specific changes:

- for example, revise the app so the instructions are clear especially regarding people who have to self-isolate when not displaying symptoms
- train staff to be consistent

Don't rely too much on technology to ensure the system works (for example some don't have smart phones).

Communicate with the public through people they trust, using an accessible range of channels with support for local leaders to engage their communities and keep them informed.

Communicate that there are clear rules being implemented around data use, storage, sharing and destruction for all tracing data.

And support / provide guidance to venues to implement in a more effective and standardised way rather than using pieces of paper and then make them more responsible for ensuring people do it right.

Do further work to consider who should have access to what data, and what should and shouldn't be mandatory and for how long – always keep data sharing and mandatory measures and length of time as minimal as possible and only for 21 days, and for the sole purpose of protecting public health during current and future pandemics. Whatever you decide, tell the public clearly and be transparent about it.

Provide better and more focused financial, practical and mental health support, which is easy to access, to all who are required to self-isolate, and especially to those who need it and/or are disproportionately impacted – no-one should be disadvantaged for doing the right thing. Make sure the advice and support keeps up with changes.

Wastewater testing

The Public Advisory Group suggests it is reasonable to expect the public to accept the carrying out of wastewater testing, if the following conditions are met

Ensure that data gleaned from wastewater testing cannot be used by private organisations, non-public health related government departments or state services for profiling communities and discriminatory practices – wastewater testing data should only be used for pre-approved public health purposes and should be tightly regulated (including legislation) with oversight from senior public health professionals. Offer protection in the form of consequences for anybody that uses wastewater testing data for discriminatory practices, as well as regulation to stop private organisations from accessing wastewater testing data.

Create a strategic communications plan that proactively educates and informs the public about wastewater testing and frames it as part of a suite of measures we will use in the future to live with the virus.

Explore whether to make wastewater testing data publicly available on a wider area scale. Whatever you decide, tell the public clearly and with great care.

Make PCR surge testing the first step in response to wastewater testing identifying high-prevalence of COVID-19 in an area and lockdown should be a last resort – where COVID-19 is found in wastewater (clarification) people who test negative with a PCR test shouldn't be forced to isolate, nor businesses closed, unless necessary.

If the purpose of what is a great public health tool is expanded beyond COVID-19, then there needs to be a proper dialogue with the public about conditions of use. Ensure regulations and legislation are in place to ensure the public have protection from discriminatory practices or data breaches before it is implemented.

Structure of report

The structure of this report follows participants' journey over the course of the 5 virtual workshops. It sets out the principles and expectations formed and, importantly, captures the detailed reasoning and nuance behind these recommendations: the discussion and debate between participants, and the trade-offs which supported a civic-minded view to be reached on behalf of the public in England.

Public Advisory Group report – UKHSA's response

Response from the Director of People and Places Policy, the Director of Community and Local Services and senior leaders across UKHSA – February 2022

Test and Trace is hugely grateful to the 100 people who took part in our Public Advisory Group (PAG) sessions during summer 2021 for giving us their time, knowledge, reflections and advice to help us learn how we can improve our response to COVID-19, and prepare and act better in a similar situation if it arises in future.

We are also very grateful for the huge amount of time and energy our organising consortium put in to make this a success, and for the challenge and encouragement provided throughout by our independent advisory group. In addition, we welcome the additional recommendations provided directly to Test and Trace by over 40 representatives from organisations that support marginalised groups, which appears alongside the publication of this report.

What Test and Trace do with the advice the PAG has given us

Many of us attended the sessions as observers. Since we received a draft copy of the PAG report in early August, policy and delivery teams across Test and Trace have met to reflect on the report's advice, and it has been circulated to the organisation's leadership team.

Once the report is published, it will be widely presented and shared with policy and delivery teams in the new UK Health Security Agency, and we will be recommending staff involved in policy, service design and operations teams read it and learn from it as we develop future policy and services for citizens and communities.

There are many important recommendations and insights in the report, and we cannot respond to all here. We want to highlight a few immediate actions and responses which teams across UKHSA have taken since the Public Advisory Group, and are continuing to work on. They have resulted from a wide range of research we have carried out to improve equitable access to services, including the Public Advisory Group.

Some of the actions UKHSA has taken that the PAG has helped us achieve

1. Extending the scheme to help people out of financial hardship

The PAG report was one of several sources of evidence that helped us show that people believe that financial support helps make it possible to self-isolate.

We agreed with the PAG's observation that no one should be disadvantaged by doing the right thing. Throughout the pandemic we worked with local authorities to ensure the Test and Trace Support Payments reach the people that need them. We helped local councils pay government grants to self-isolating people who might have faced financial hardship through Test and Trace Support Payments. We also continued to fund local authorities to help them extend practical, social and emotional support for people self-isolating, as well as funding the medicines delivery service, so that people who self-isolated could have prescription medicines delivered to them free of charge.

The PAG report reminds us that we should work closely with councils and community organisations to make sure everyone is aware of the support available and make it as easy as possible for people on low incomes to apply for and receive hardship payments.

2. Doing more to make sure we are reducing public health inequality

In the People and Place Policy team, and the Community and Local Services team, as well as other policy and service delivery teams who reflected on the draft report, the insights around inclusion and reducing health inequality were welcomed as a valuable source of evidence. The PAG participants echoed insights from our ongoing collaborations with (amongst others) local authorities, health protection teams, ethnic minority clinical networks, community champions, and faith groups.

As part of the Public Advisory Group process, we convened 40 representatives from organisations which represent marginalised groups to capture their views alongside the 100 members of the PAG itself. We have published their response alongside this report. We also made all our webinars we hold with community leaders public so that everyone who needs the information has access to it.

As a result of evidence including the PAG, we formed a new Equity and Inclusion Performance Evaluation working group – which has been monitoring how well we are reducing health inequality and making recommendations. The team reports directly to our Health Equity Board, which incorporates senior leaders from across UKHSA.

3. Making sure employers do the right thing for their staff

Like PAG members, we also heard about concerns over illegal behaviour by employers to their staff. There is already a special COVID-19 phone line – 119 – which anyone can use for

advice, or to ‘whistleblow’ if they think their employer is asking them to do something wrong (for instance, if an employer is threatening to fire someone if they take time off to self-isolate or recover from COVID-19). Many councils also have dedicated phone lines. Although UKHSA is not responsible for employee relations, we continued to engage with teams across Government to ensure the regulations for employers were well known and communicated.

4. Improving our contact tracing services to make them clearer

Many of us at UKHSA have been personally affected by COVID-19, and so we know as well as anyone how complicated the guidance can be when you need to know what to do. We cannot avoid all of that complexity – the way COVID-19 affects each individual, family, community and locality is different – but we can always work to improve it.

During autumn 2021, as a result of the examples and insights provided by PAG, the COVID-19 contact tracing service design team reviewed the guidance given face-to-face, on the phone, and on the NHS COVID-19 app to specifically ensure nobody was told to self-isolate unnecessarily, to clarify the guidance about when an infected person and their contacts could leave or avoid self-isolation, and to make the reasoning clearer for asking someone to participate in contact tracing and self-isolation. In early 2022, we set up a working group across all our communications channels to make sure the rapid changes to regulations were shared clearly and consistently. We also continued to make sure all the information in the NHS COVID-19 app was available in multiple languages so that as many people as possible would receive up-to-date information.

5. Making sensitive but positive progress with wastewater testing

We were excited that PAG members were supportive of wastewater testing, and were reassured that we are working towards the right goal of making sure more people understand what it is and making sure it would be visible and trusted if it is used in future. While some of PAG’s recommendations will require further exploration – for instance setting regulation on it – we incorporated some of PAG’s recommendations into the subsequent trials of wastewater analysis with adult social care homes, including ensuring people knew what information was being captured and how it was being used.

6. Ensuring our communications reach the most important audiences

We really welcomed the feedback on our efforts to engage with the public throughout the pandemic. Very few other events in our lifetimes will have so much airtime on TV, social media and in every other channel. One learning which has been reinforced by PAG and other research during the pandemic is that targeting our communications and our services, for instance through existing trusted voices, is an effective way to reach into those communities and groups who most need help to look after themselves and others.

With the help of narratives from sources including the Public Advisory Group, we made a successful case to extend the Targeted Community Testing programme until March 2022. This meant that groups disproportionately impacted by COVID-19 continued to have access to free testing. Targeted Community Testing is a joint effort between UKHSA and local councils and communities which has quietly, proactively and consistently taken the ‘trusted faces and places’ approach throughout the pandemic. As we wind down the Targeted Community Testing programme, we will ensure leaders across UKHSA remember the fundamental importance of what PAG has described as ‘communication, proactive transparency and education’ with local government, health and community partners for similar programmes in the future.

Introduction

In late 2020, Test and Trace [which from October 2021 onwards has formed part of the UK Health Security Agency (UKHSA)] commissioned a Public Advisory Group (PAG). The aim was to explore the public's expectations and values about COVID-19 testing, tracing, and isolation as a means to inform ongoing policy development. Through this approach, the agency wanted to also understand what might need to be in place to build public trust and demonstrate trustworthiness moving forwards. The agency commissioned the work in recognition that Test and Trace is responsible for supporting policy decisions that have far reaching implications for everyone in England. Test and Trace commissioned an independent consortium, of Ipsos, Imperial College Health Partners, and The Involve Foundation, to deliver this deliberative dialogue.

The PAG needed to draw participants from across England in a way which reflects the diversity of the country. Using an industry-standard best-practice methodology the independent Sortition Foundation was commissioned to send 20,000 invitations to participate to randomly selected households. From 1500 positive responses, the final 100 participants were randomly selected, using a quota-based method agreed with the independent advisory group.

The PAG workshops took place during a time when social restrictions to outdoor contact had been lifted, with the rule of 6 or a larger group of up to 2 households indoors being allowed. Indoor hospitality – pubs, restaurants, cinemas, children's play areas, and indoor exercise classes – had resumed. Legal restriction or permitted reason to travel internationally had also been lifted – with a traffic light system applying. Around two-thirds of the UK population had received a first dose vaccination, and half had received a second dose. Vaccine boosters had not yet been announced. The findings should be read in this light.

Participants were brought together for five 3-hour workshops in June 2021. The workshops covered 4 key policy areas: self-isolation, testing, contact tracing, and wastewater testing. Participants heard from specialists in these areas and drew on materials provided to them (reflecting then-current guidance and practice), as well as their own knowledge during the workshops. Elements of both dialogue and deliberative engagement methodologies were used to design a bespoke process that enabled participants to learn about a policy area and discuss it in enough depth to provide considered insight. The discursive approach allowed participants to explore their own opinions and reasons about the topics, and to hear the views and reasons of others. Encouraged to consider the range of views, participants were supported to express collective expectations that would support everyone to live and work together. The final workshop presented draft principles and expectations to the PAG based on their discussions, which they finalised and agreed.

This report presents the ‘expectations and principles’ (the Group’s agreed wording) they would wish UKHSA to consider when taking forward work to support changes to policy. It is important to note that the PAG recognised these suggestions are intended for consideration, and that UKHSA is not obligated to implement recommendations made in this report. In order to support the interpretation and understanding of their expectations and the principles they developed, the report also summarises the discussions held during their development

1. Methodology

Overview

The PAG met online across five 3-hour workshops throughout June 2021 to answer the following key question, set by UKHSA, and develop a set of principles and expectations to support UKHSA's policy making in this area:

> In a world where we know we have to live with the current and future viruses, how should testing and tracing help us to live and work together?

The Independent Advisory Group

Materials were developed by the Consortium in partnership with the UKHSA, with oversight and input from the Independent Advisory Group (IAG). The IAG's role was to help improve the quality of process and materials by contributing to and challenging their design, ensuring the deliberation questions and stimuli were relevant, appropriate, clear, robust and accessible.

The IAG was made up of public health, local governance, data, consumer rights and methodological academics and specialists independent to the commissioning and convening organisations (see Table 1.2 in appendix for a list of Advisory Group members).

Recruitment

The Sortition Foundation, a recruitment organisation specialising in representative random sampling, conducted the recruitment for the PAG by sending out 20,000 invitation letters across England, using the Royal Mail Postcode Address File. The Sortition Foundation selected 100 people from the members of public that applied to participate. From the responses to the applications, Sortition used a randomised stratification process that reflected the demographics of England's population, including age, socio-economic status, gender demographics and trust in government. Ethnic Minority groups and respondents living in Indices of Multiple Deprivation 1 to 3 areas were significantly over-sampled to ensure a stronger representation of the experiences of these communities given the adverse impact of the virus on these groups – for example, in shifting the balance of ethnic minorities from 13% in the general population to 40% in this sample. [See Table 1.1 in appendix for demographic profiles].

To support and enable participation in all workshops s, in line with industry standards, PAG members were each paid £70 per workshop, resulting in a total of £350 for full participation. Where necessary, participants were provided with laptops and dongles to provide a

connection to the internet and were supported with training on how to use the technology and access the meeting platform. This allowed us to increase the diversity of those taking part.

What a deliberative dialogue is

As we worked with Test and Trace to develop the design of the PAG, it became clear that there were a variety of issues that Test & Trace policy teams felt would benefit from in-depth public involvement and feeding into answering the overall question. For some of these policy areas the desired outcome of public engagement was rich insight about the issues at stake; and for others there was a need to weigh different options, to explore trade-offs, and to resolve tensions.

Given the breadth and complexity of some of the items being discussed, we developed, with the support of the IAG, a flexible approach using elements of dialogue and deliberation to draw out nuanced discussion and form principles that were both overarching and applied to specific policy areas. Figure 1.1 below summarises the fundamental elements of a dialogue, and a deliberation, as stand-alone methodologies.

Figure 1.1: Features of a dialogue and a deliberation

Dialogue

- Seeks to build understanding and relationships
- Participants listen, learn, exchange and reflect
- Outcome: rich insights, no decision, resolution or conclusion

Deliberation

- Seeks to solve shared problems, make decisions
- Participants weigh options, explore trade-offs, make choices
- Outcome: agreed decision, recommendations, resolution or conclusion

The deliberative dialogue

Each workshop consisted of plenary presentations, followed by breakout discussions, where PAG members engaged in deliberative dialogue with their peers. The breakout groups involved no more than 6 participants to facilitate deeper discussion. Each workshop had a lead facilitator, known as the chair, and each breakout room had a facilitator and note-taker. Facilitators used a discussion guide, to ensure that all members of the PAG were asked the same key questions. Observers were present, with no more than one per breakout room, along with roaming experts who could be called into breakout rooms to answer questions posed by the PAG to inform their discussions. Each workshop had people in technical

support roles present to manage the process and support participants with tech issues as they arose.

PAG members were assigned to a different breakout group for each of the workshops, to ensure they were exposed to as wide a range of opinions as possible, and to enable them to reflect, consider and challenge their own views in that wider context and to avoid participants anchoring to previous discussions.

Following the first workshop, each workshop began with the chair reflecting on what participants had discussed in their groups at the previous workshop. This provided a space for PAG members to reflect on where they had got to last time along with discussions they had had with friends and family. It was anticipated that participants would have varying degrees of knowledge about the subjects, and so the presentations were designed to provide members of the PAG with the same amount of baseline information needed to engage in the discussions and deliberation. Workshops 2 to 4 presented stimuli in the form of presentations, questions and answer sessions, and case studies. The range of stimuli supported participants to reflect on their own experiences, and to consider relevant situations and experiences different from their own.

Participants were sent hard copies of all materials. In addition, following each workshop, participants were able to view the expert presentations on an online platform, as well as see the answers to some of their questions. The platform also provided opportunity to share thoughts with other members and ask more questions.

Workshop structure and dates

The workshops took place online over Zoom during June 2021 and focused on different policy areas (Figure 1.2 provides a visual summary of the workshop structure). The workshops were held on the following dates and times and focused on these topics:

1. Introduction to the process and topic, Thursday 10 June, 6pm to 9pm

The first workshop introduced the PAG members to the process, to the UKHSA, to key aspects of COVID-19 (including how it spreads and what variants are), and to the key mechanisms used to control the virus (vaccines, testing, tracing, and isolation). This workshop focused largely on providing information and enabling PAG members to ask questions of the expert presenters.

2. Self-isolation and testing, Saturday 12 June, 10am to 1pm

The second workshop introduced PAG members to the concepts of enduring transmission and variants of concern. It explored how compliance with testing and isolation measures is necessary to break the transmission cycle, how prior socio-economic and health inequalities are associated with a disproportionate impact of COVID-19, and how these factors interact. In that context, the session explored current requirements and enabling measures for testing and self-isolation.

3. Contact Tracing, Tuesday 15 June, 6pm to 9pm

The third workshop introduced PAG members to how the UKHSA approaches contact tracing, with discussions focussed around the use of data to enable contact tracing.

4. Wastewater Testing, Saturday 19 June, 10am to 1pm

The fourth workshop introduced PAG members to how the UKHSA approaches wastewater testing, with explanation about the level of granularity of this testing.

5. Overarching Principles and Policy-Specific Expectations, Thursday 24 June, 6pm to 9pm

The fifth and final workshop played back analysis of discussions across the previous workshops. Participants reviewed draft overarching principles, formulated by the delivery consortia, as well as policy-specific expectations.

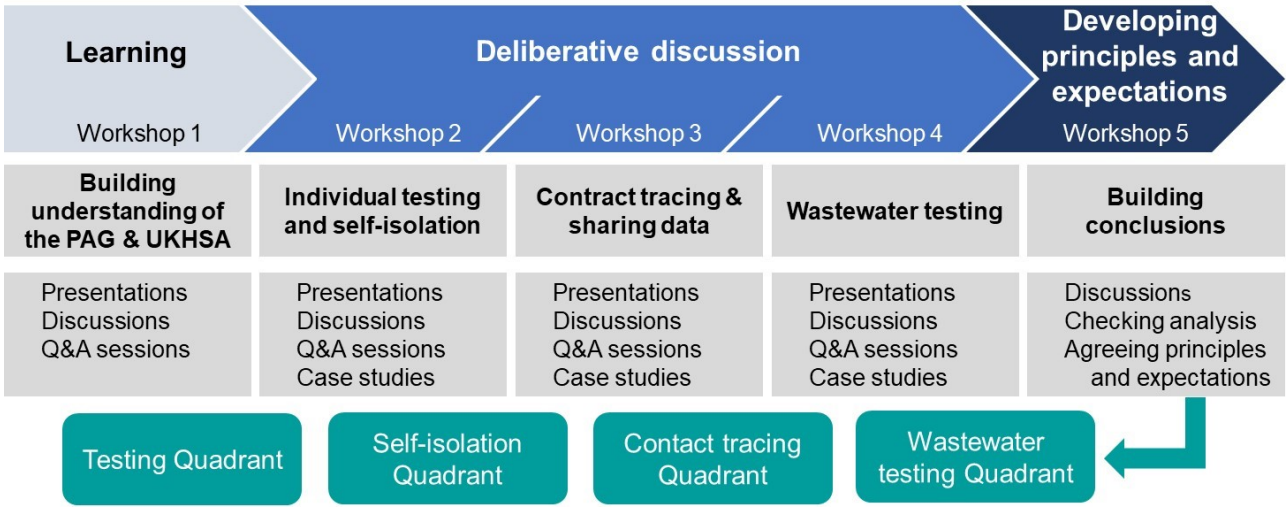
Overarching principles and policy-specific expectations

Based on rapid analysis of the discussions, and reviewed by facilitators of breakout room discussions, the final workshop provided PAG members with draft overarching principles from the workshops, for review and ratification in breakout rooms. The rapid analysis has since been validated with systematic analysis, which was conducted following fieldwork to inform this report.

Likewise, policy-specific draft expectations were generated for the 4 areas under discussion (covering self-isolation, testing, contact tracing and wastewater testing), again based on rapid analysis. These statements were then subject to discussion, co-development, review, and ratification.

That process of co-development was undertaken by participants who were each randomly assigned to look at one of the 4 policy areas in detail. These 4 ‘quadrant’ groups each comprised 25% of the PAG. Each quadrant was responsible for editing the policy-specific expectations for their nominated policy area. This was achieved in 3 stages: initially small breakout groups in each quadrant discussed the draft expectations and made edits with support from a facilitator; subsequently all groups within a quadrant converged in a larger group of circa 25 people to combine edits; and finally each of the 4 quadrant’s expectation were presented to the rest of the PAG, who then had the opportunity to discuss their final reflections in breakout groups before the workshop, and process, ended. This final stage allowed for further analysis and validation of the expectations based on commentary from all participants in the PAG.

Figure 1.2: Summary of PAG workshop structure



Summary of PAG workshop structure (Figure 1.2) in text format

Workshop 1: Learning phase. Building understanding of the PAG and UKHSA. Format – presentations, discussions, and Q&A sessions.

Workshops 2, 3 and 4: Deliberative discussion phase. Format – presentations, discussions, question and answer sessions and case studies:

- Workshop 2 – Individual testing and self-isolation
- Workshop 3 – Contact tracing and sharing data
- Workshop 4 – Wastewater testing

Workshop 5: Developing principles and expectations phase. Building conclusions. Format – discussions, checking analysis, and agreeing principles and expectations.

Participants in workshop 5 were split into 4 quadrants:

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

How to read this report

The principles and policy expectations set out and discussed in this report are intended for consideration in supporting the development of policy by UKHSA, in response to COVID-19, but as stated previously, it is not compulsory for UKHSA to implement them.

This exercise supported participants to express a range of experiences of the pandemic and of their expectations, understanding, and use of the testing and tracing system. This report synthesises those diverse and sometimes inconsistent expressions to draw out major themes of discussions and to draw attention to the way that participants – individually and collectively – described what mattered to them and why. On occasion, the report refers to verbatim assertions by participants and their understanding of what testing and tracing services do. These are not intended as authoritative statements of fact, but even when the statements provided by the PAG did not align with those formally articulated by Test & Trace services, they tell us something valuable about how key messages, support, or services can been perceived and understood by members of the public.

This report uses the following conventions: an indication via ‘a small number’ or ‘a minority’ to reflect views which were mentioned infrequently, and 'many' or ‘most’ when views were more frequently expressed. The use of ’some‘ is used to reflect views mentioned some of the time. These terms are indicative, not exact. Further, it should be noted that whilst the method of qualitative analysis is systematic and rigorous and the conclusions robust (being based on groups that are reflective of the diversity of the wider public, noting the conscious over-sampling from ethnic minorities as outlined above), the analysis does not seek to quantify findings nor does it indicate statistical significance from a representative sample. This report offers a valuable insight into public perspectives on the key questions posed to them after receiving and deliberating on key information relevant to the questions. As such, it opens up a deeper understanding of what drives public perspectives on self-isolation, testing, contact tracing and wastewater testing in a way that will be valuable for future policy making in this area.

The following chapter (chapter 2) summarises the overarching themes which cut across the whole of the PAG’s discussions and details the overarching principles that were agreed by the PAG to inform UKHSA’s decision making going forward. The subsequent chapters (chapters 3-6) detail the findings related to individual policy areas: self-isolation, testing, contact tracing and wastewater testing. In each of these chapters we introduce the content presented to the PAG, followed by the final drafts of the policy-specific expectations edited in the quadrants on behalf of the whole PAG, which is followed by illustrative statements and commentary that reflects the discussions held throughout the workshops.

2. Overarching themes

Themes emerging through the series of discussions

The vast majority of participants indicated that they had been impacted in some way by the pandemic either by isolation, illness, work or the loss of friends or family.

Throughout discussions, and particularly in the first 2 workshops, participants had a striking amount of questions about the virus and were often confused or misinformed about the interventions in place to stop the spread of the virus. They were surprised by the number of mutations of COVID-19 and reported feeling overwhelmed by the thought of potentially infinite mutations of COVID-19. They felt strongly that the public should have access to information about where Variants of Concern are in the country.

Most participants were aware of Test and Trace and understood its main purpose. However, only some participants reported that they had been contacted by Test and Trace or had used the app. There was a strong feeling among participants that Test and Trace services had not been working adequately and that some people were choosing not to engage with them. They felt that Test and Trace services had an unrealistic reliance on public compliance with stringent requirements (for example accurately volunteering information about where and with whom people had been). The vast majority were not aware of the upcoming merger between Test and Trace, Public Health England and the Joint Biosecurity Centre, to become the UK Health Security Agency, in October 2021.

Many participants were impressed by the vaccine rollout and recognised the process as a way out of the pandemic. Some participants were surprised to learn that COVID-19 could still be contracted and spread even after vaccination. After realising this, there was a strong feeling among many participants that measures such as testing, face masks and handwashing should still be in place after the vaccine rollout, and once restrictions have eased. However, this was not universal. Some felt testing would only be needed if cases were still high after restrictions had been eased, and a few felt that self-isolation and testing should be eased after the vaccine rollout due to the impact it has on mental health and financial security. Many participants stressed the importance of learning to live with the virus, and some expressed a preference for normalising surge testing and other measures over lockdowns.

> “I think it’s something we’re really going to have to come to terms with and almost live with this virus until it dies out, or it’s dealt with like the flu.” – Male, Workshop 1

Others were more cautious and felt that there was too much emphasis on society re-opening.

The key issues that PAG members wanted to discuss in the first workshop were their concerns about misinformation and lack of public awareness of important facts. Particularly in relation to:

- the seriousness of new variants
- vaccination does not mean there is no need to test
- the accessibility and usability of the track and trace app as well as inconsistency of the tracing practices in businesses and venues
- concerns about the effectiveness of Lateral Flow Device (LFD) testing and people avoiding testing due to fear of self-isolation
- the accessibility and fairness of financial support for self-isolation
- the disproportionate impacts of the pandemic on poorer communities and widening inequality
- the impacts of self-isolation on mental health, particularly for younger people

All these topics were covered in greater detail in later workshops and were reflected in the PAG's final expectations.

Overarching principles

Rapid analysis of discussions in workshop 1 to 4 (self-isolation, testing, contact tracing, wastewater testing), conducted by Ipsos , culminated in 3 key principles that cut across all policy areas and can be applied to future policy development by UKHSA in response to COVID-19 and possibly in the context of future pandemics:

- communication, proactive transparency and education
- supporting society to do the right thing
- equity

The principles below were presented to participants in workshop 5 for discussion and feedback in breakout groups, before the PAG spent the remainder of the workshop focusing on policy specific expectations. The overarching principles to be applied to future policy were:

Communication, proactive transparency and education

Make information about testing, tracing and self-isolation widely available as simple, clear and engaging communications.

Proactively research where people get their news from and invest in the use of multiple media platforms (television programmes, radio, social media) to communicate key

messages, accounting for people who do not engage with mainstream media for example Netflix, Spotify, YouTube and TikTok users.

Focus on getting messaging out to the public from trusted people, that is support and enable trusted individuals within communities (GPs and community leaders) to provide information and have national speakers from public health bodies rather than politicians, and also creating some independence of UKHSA from politicians.

Create a sense of shared purpose and community efforts, with positive messaging about measures that are effective – tell the public about the successes, and recognise weariness can be addressed with (realistic) positivity.

Make a UKHSA communications plan that proactively communicates how data is used, stored and shared, and who can use, store and share it, to reassure people that their data is safe. Privacy policies are not enough.

Wherever possible explain to the public how public money is being spent, how those decisions are made and what benefit that spending resulted in.

Give the public a clear, holistic, narrative about the way forward. How do all these measures fit together?

Supporting society to do the right thing

Enable employers to support their employees with testing and isolating through financial support and resources to make changes to their premises and company practices. No business should be out of pocket from employees doing the right thing.

Enable employees to hold employers to account by providing legal support for employees to whistle-blow and ensure consequences for employers who do not support their employees to adopt COVID-19-safe behaviours – testing and isolating, face masks and distancing. This is only justifiable if the first condition is in place.

Keep public data safe and protect public interests; data gathered through testing and tracing should only be used to protect public health. Data should be stored safely, and not be sold or used for purposes other than what it was collected for. This should be regulated and audited.

Take away barriers for the public to do the right thing, like lack of awareness, access or support – only then can the public be held to account for not abiding by the rules and guidance.

Lead by example, get across that tackling COVID-19 is everyone's responsibility, and share learning – the public wants UKHSA to be transparent, and show how mistakes are being learned from.

Equity

Do more to explore what financial, practical and emotional support is really needed for people to self-isolate, especially those who can't isolate as easily as others, and provide support in a timely way with the flexibility to adapt to public needs.

Seriously consider the disproportionate impact of COVID-19 faced by certain communities, and the context of inequality in society, in everything that UKHSA does and make efforts not to deepen inequalities further.

Prioritise reaching people who don't have the internet or access to a computer/mobile phone, so that they receive the same level of information and support as the people who are online.

Proactively reach out to the public with tailored messaging – especially those who are fearful over data use – and tell them the facts about data use and security, honestly and clearly (about contact tracing and wastewater testing in particular). Be clear what guarantees are in place for example data will not be shared with the Home Office.

Do further work to make PCRs more affordable, and understand what will make testing more accessible to more people through misunderstanding different audiences and communities (for example language barriers, mistrust in the Government), so that efforts are better tailored to what the public really needs and finds engaging.

As a national body, empower and support local leadership to enable and support their communities to isolate, test and trace (including local councils and community leaders).

Reflections on the principles

When these principles were presented in the final workshop, participants broadly supported them and agreed they were a fair reflection of the discussions held across the groups. Some felt that all 3 broad principle categories were equally important and should be implemented as a set, where others felt some principles were most important, particularly communication and support.

Communication, proactive transparency and education

For some, communication was felt to be the most important area. This was described as a complex task, given a key challenge for UKHSA is avoiding and reducing disjointed messaging across multiple channels from a range of different sources, including government, mainstream media and misinformed sources. However, participants recognised that messaging and communication alone is not enough, as awareness is only part of the challenge, suggesting there needs to be a focus on changing attitudes and behaviours too.

"I feel the information is out there if people want it. I think the difficulty is getting people to read the right information. I don't know how to change people's attitudes. There are people I've spoken to who are so against it [COVID-19]. The information is out there about how they've done it as fast as they have. I don't know how you get people to change their ideas." – Female, Workshop 2

Participants reflected on the need for consistent messaging from government related sources and were concerned that politicians appear to be moving in a different – and more positively confident – direction to UKHSA in terms of its approach to managing the pandemic. A few participants also emphasised the importance of using multiple channels to reach all parts of society, and having an holistic narrative that acknowledges all the measures and their interlocked nature going forward for example one that acknowledges that while wastewater is being tested, this does not replace the need for the entire population to do twice-weekly lateral flow tests and if people develop symptoms and/or test positive, they must take a confirmatory Polymerase chain reaction (PCR) test. Participants also felt it was important to clearly communicate that vaccines do not mean social distancing does not apply. A few participants felt positive messaging is very important, though flagged this should be truthful and contextualised so as not to 'whitewash' when measures are clearly still needed.

"You need a happy medium. Make it clear that there is light at the end of the tunnel, but that this isn't going away tomorrow." – Male, Workshop 5

Several participants felt that building trust was the most important aspect of communication. They repeatedly flagged needing to fund and better utilise trusted parties independent from national government, such as GPs and local leaders, to address misinformation for example about vaccines or data use, and misunderstanding or anxiety for example about how to do tests or access isolation support. A few said that UKHSA can serve this role as independent from government, though there was uncertainty on how UKHSA is held accountable and who it answers to within government.

A key part of building public trust was seen to be through transparency, which for some was the most important aspect of all the overarching principles. In summary, participants want to see transparency about how money is spent, about how the science informs decisions and about how data is stored and used. They described how important it is to the public that the Government share figures on how public money has been spent and how decisions have been made, in order to build trust.

Incidentally a few participants specifically described feeling like the politicians are not following the science and could not understand why some events can happen, where others cannot for example large sporting events vs. 30-person weddings, hence wanted to understand why such decisions had been made. They felt that the Government is not leading

by example and abiding by the rules themselves, and should be, referencing high profile incidents such as Dominic Cummings' trip to Barnard Castle. They also felt that audits should be taken of local organisations handling and storing personal data, the results of which should be published to build public trust in the testing and tracing infrastructure.

> "They [the principles] are equally as important, but the one about telling the truth... people are sick of lies and seeing politicians doing one thing and telling us something else. You have to be honest with people." – Female, Workshop 5

A few participants also reflected on the importance of communication focusing on a sense of unity, with reflections that hearing experts discuss learning from mistakes within the PAG presentations and Q&A sessions was appreciated (particularly when compared to the culture of 'political point scoring' in government-led communications).

> "I think a big thing for me is not just supporting society but encouraging people to want to do the right thing. It's all well to provide support but you've got to create that feeling so people want to do it, we are an individualistic country and not community minded as other countries and getting over that and creating a sense of unity is hard in this country. Pre-pandemic, political stuff that divided the country is a massive challenge."
> – Female, Workshop 5

Supporting society to do the right thing

For some, supporting society to do the right thing was flagged as especially important, particularly regarding employers. Participants felt that employer and employee support should be consistent across industries and wanted stronger emphasis on addressing 'dodgy practices' and employers not supporting employees on zero-hour contracts.

> "All employers feel they are being squeezed as they don't have enough business or whatever, but the people who lose out are the general public who have those jobs."
> – Male, Workshop 5

They also flagged the importance of support being timely, and right for each person, and that the public need to be reassured that help will be made available to them. They reflected on the need to stop people being evicted, to ensure job security, and to reflect wages lost. A few wanted the cost of living in different areas to be considered in financial support provision. The importance of policies taking account of additional emotional support that might be needed was flagged as important alongside financial support, and participants reflected on how closely this principle relates to equity.

Equity

For a group of participants, equity was felt to be the most important issue, especially for minority groups for example people on zero-hour contracts, and many felt strongly that this is an important principle. Participants reflected on how COVID-19 has exacerbated existing divides and inequality. A few participants said that they were concerned about ‘lumping communities together’ and losing the nuance of their situation, warning that UKHSA should not just be avoiding the worsening of inequality and inequity, but actively promoting equity. They want to see this principle taken into practice by UKHSA through tailored and specific actions for separate groups of people for example people living in inner cities, in poverty, on zero-hour contracts, in multi-generational households, with English as a second language and the digitally excluded (as opposed to a general approach to all groups who are disproportionately impacted).

3. Self-isolation

Introduction

Within workshop 2, participants were asked to consider information and stimuli on Variants of Concern and areas of Enduring Transmission. Stimuli and discussions explored how compliance with testing and isolation measures is necessary to break the transmission cycle, how prior socio-economic and health inequalities are associated with a disproportionate impact of COVID-19, and how these factors interact. In that context, the session explored current requirements and enabling measures for testing and self-isolation.

Draft policy expectations were developed after the workshop, based on analysis of the discussions, and then presented back to participants during workshop 5 to form the basis for their final expectations concerning self-isolation. The headline analysis is in Annex C, and the original draft expectations are in Annex D. More detail on this process can be found in the methodology, and the materials used in presentations and stimuli are in Annex B.

At the time of this and the second workshop (about testing), it had recently been announced that:

- England's Euro 2020 group matches at Wembley Stadium would become the first UK events where attendance would require proof of full vaccination
- the US FDA released a report raising significant concerns about lateral flow testing

The findings should be read in this context.

Expectations about self-isolation

Participants drafted the expectations below regarding self-isolation, for UKHSA to consider in future development of this policy area.

It is reasonable to expect the public to self-isolate when people are told that they need to, if the following conditions are met:

Provide more financial and practical support which is easy to access and in a simplified format and is given immediately and automatically, to all who are told to self-isolate.

Ensure that no-one is disadvantaged for doing the right thing. Support should be available regardless of personal circumstances for example employed, self-employed, unemployed. Reassurance about no wider repercussions if they give their details.

Provide a dedicated telephone / text / online help service (which will make it accessible to all people).

Provide more emotional and mental health support, following exploration of what is needed across the population (the importance of preventing, rather than reacting to, mental health or emotional problems).

Improve the process for monitoring people who are self-isolating and at the same time assess if there are any further actions required to support them.

Give the public legal protection from being penalised at work. Help employers and hold them to account.

Provide more clarity to the public on when we need to self-isolate, how long for and in what circumstances. Help the public to understand the risks and why it's important to self-isolate.

Provide regular free PCR tests while isolating so isolation can end as soon as possible.

Summary

Many participants recognised that effective policies of self-isolation are critical to the collective effort to break the cycle of transmission, and to reduce the emergence of new variants that are more harmful or which can evade existing vaccine-induced immunity. Most people also recognised that self-isolation itself is harder to do for some people, particularly those in precarious employment, because of the financial loss suffered and the perceived threat to employment of being away from work; and that these requirements could disproportionately affect some geographies experiencing enduring infections. Discussions also recognised the difficulty that this policy poses for employers, who are faced with the capacity gaps and financial consequences of their employees doing the right thing.

For that reason, the PAG put significant emphasis on government's obligations to support people who need to self-isolate, and to support those employers who are affected by staff self-isolation. Non-compliance around self-isolation was recognised as a health security risk to all and meeting reasonable expectations to enable individual compliance was therefore seen to be a key public health response to ensure protection of wider society. Most people in the PAG saw this as a central requirement for effective Test and Trace policy. Many participants felt that if those enabling measures were in place then, and only then, it would be fair to have stronger sanctions against those who did not act in the interests of public safety.

Detailed discussion

The need for more financial and practical support

Most participants felt strongly that financial constraints and worries about the implications of lost income were the key barrier to self-isolation, which is exacerbated by a lack of awareness about how to access the £500 support payment.

> "If I chose between feeding my children and infecting someone, I would infect someone." – Female, Workshop 2

Most participants felt that there should be additional funds ringfenced and more easily accessible financial support for self-isolation than is currently available, ensuring no-one is missed out. This was felt to be especially important for people losing significant earnings who are:

- in low-income families
- with zero-hour contracts
- working in the gig economy
- in vulnerable groups (including older people, those with mental health problems, homeless people and people living with addiction)

Participants did not feel it would be fair to fine someone for not self-isolating if they were experiencing financial hardship.

Some participants felt that financial support should be available to everyone and should be provided automatically to ensure simple and immediate access to support. This could – at least in part – be managed by employers. Some felt that not everyone needs their full salary level of support, where others reflected on people potentially losing their job even if they had a good income previously. Some participants felt that support for all who need it, or who are disproportionately impacted, would be hard to define.

A few participants felt that the amount of money provided should only replace days lost at work, where another few felt that the circumstances of self-isolation might increase outgoings, for example by needing to have shopping delivered, and that these additional costs should be accounted for, particularly for those on low incomes.

There was agreement that, fundamentally, financial support should be adequate for all people, and timely.

Participants felt that, alongside improved financial and practical support, more reassurance should be provided regarding that support, in other words that no-one will be disproportionately disadvantaged (for example providing support for undocumented people

residing in England, without the worry of being deported). They also reflected on self-employed people struggling to access financial support given the added complexity of providing evidence.

"They can check how long the business has been going through anything. Using your VAT number, NI number, how you paid your tax. They don't need a utility bill, this bill, another bill. It goes on forever." – Male, Workshop 5

The need for more emotional and mental health support

Some participants felt that mental health, including worries over the wellbeing of families and individuals and the disruption of daily routines, was a key barrier to self-isolation, especially for those living in small houses and bedsits without a garden. There were strong concerns about mental health support, especially for those living in areas that were experiencing variants of concern and enduring transmission, thus leading to increased requirements to self-isolate.

Participants were worried that those living in areas of enduring transmission are likely to be fed up with restrictions, and that there are increasing pressures in those areas with heightened social and emotional difficulties. They felt that due to the increasing pressures of lockdowns on financial, social and emotional wellbeing, people living in those areas are less likely to comply with the rules.

"It must be very socially and emotionally difficult, especially because they are in precarious employment and schools have to open. All of these pressures on people are much more in those communities which are struggling." – Male, Workshop 2

Some felt there should be more focus on targeted mental health support during self-isolation, including allowing for bubbles during self-isolation and providing buddy services for everyone, but a few felt this should be particularly targeted at those suffering the most, for example the elderly, children, students and young adults, and those who are most important for keeping society running, in other words essential/key workers. Ideas included employing more carers and providing counselling and remote zoom support for those isolating.

Participants felt that, as well as providing more support, awareness of this support would need to be raised across media channels, as people tend not to be aware of the support available to them. They felt that information on available support should be sent to people when they are asked to self-isolate, rather than expecting people to find this themselves. They also felt that a focus on prevention through emotional support should become central; reaching people who do not ask for support before it becomes a problem.

"If they are being asked to self-isolate, they should be sent information straight away on where to access all this support. I don't think it is the first thing on your mind to search the internet for where you can get mental health support for COVID when you have to isolate. Communicate where and how to get it rather than 'it is out there, go and find it." – Female, Workshop 5

They agreed that ease and speed of access to support was paramount for self-isolation, leading to the expectation of a dedicated help service; providing guidance on financial and practical support as well emotional. They also reflected on a need for there to be different approaches, in order to include everyone, and that COVID-19-related trauma should be considered separately to long term mental health issues.

The need to consider equity when developing new policies and services

Throughout discussions, some participants were concerned about the potential for alienation by singling out small geographic areas for having enduring transmission and that areas of enduring transmission are stereotyped as deprived, with a small number who were concerned that professionals based in London are attributing enduring transmission to the north of England. Participants suggested including surrounding areas to ensure regions with measures in place are not so small as to make those within them feel too targeted, and to help reduce the spread. While this suggestion, in practice, could mean bringing surrounding areas into lockdown unnecessarily, participants did not explicitly define the sizes of regions they had in mind, and were likely to have had areas with variants of concern (which are smaller geographic areas than enduring transmission) in mind, as well as areas with enduring transmission.

Participants felt that self-isolation should be taken seriously in all areas (not just those with enduring transmission). Some participants felt that enduring transmission areas should have more focussed support, surge testing and vaccination roll-out, with some expressing concern that enduring transmission areas are marginalised in terms of support offered due to their location and stigma.

"Everybody should behave the same. We're all in this together." – Male, Workshop 2

Participants also expressed concerns about the disproportionate impact or risk for the following specific groups of people, who they felt should be prioritised for PCR tests:

- people suffering due to health inequalities because of poverty
- people with cancer and compromised immune systems
- people with learning difficulties
- people with dementia

They felt that doctors and GPs should have a role in identifying those most clinically vulnerable to ensure they are provided with food and medicine if they are self-isolating.

A few participants also flagged the importance of providing alternative routes to support for those less familiar with technology and raised the need for more long-COVID clinics to provide long-term support for people who are living with long-term impacts of COVID-19.

The need to support people to work safely

Protecting people at work was a key priority, including protecting workers' rights. There were a small number of PAG members who said that frontline workers should be provided with physical protection at work, and prioritised for support with self-isolation and testing, including delivery drivers, carers, postmen and rubbish collectors along with doctors and nurses. It was also suggested that more financial support should be available to the hospitality sector, to get them through lockdowns.

> "I think the most important groups are doctors, nurses and front-line staff. The minute you lose them from work temporarily or permanently, what chance do the rest of us have? Those people should be top of the list for support financially, emotionally. Our NHS have been fantastic through this. I don't envy them. Clapping on Thursday is a public opinion. But frontline staff who are there to protect and treat us should be at the forefront."
> – Male, Workshop 2

Supporting employers and holding them to account

Participants wanted to see more collaboration between UKHSA and employers, who should be supporting staff to self-isolate. They also wanted to see UKHSA working with employers and legal representatives to protect employee rights if they need to self-isolate.

Participants emphasised the importance of legal protection for employees, to protect them from penalisation by holding employers to account. For this to be acceptable, they wanted to ensure employers don't feel targeted and are supported to enable their staff to self-isolate for example with resourcing.

A few participants also flagged the importance of providing support for tenants and landlords and to address the potential spread of COVID-19 through tradespeople visiting homes.

Making more of the potential for partnership working

The PAG inferred the importance of bringing support closer to communities, with participants saying they would like to see more partnership working at different levels, and by different actors, with UKHSA enabling this. The PAG identified a number of different ways that this could be achieved. These included UKHSA working with local councillors and MPs and providing more funding to councils (to ensure those isolating get the financial support, mental health

support and information they needed); with GPs and community nurses (to provide self-isolation support); with schools (who could be actively checking in with and ensuring support for parents and families); with local supermarkets (to ensure those who need food supplies can access them); and with community schemes (that is those organising sharing school runs).

The provision of clear rules around self-isolation and building public trust in this information

A final barrier to self-isolation identified by PAG members was a perception that self-isolation is not mandatory and not everyone is engaging with Test and Trace services. Participants described public uncertainty over appropriate procedures to follow in what situation, and a deep-held concern that people are not following the rules. This was – in part – attributed to a perception that people do not know where to access information they can trust. Some felt that rules and restrictions should be harsher, where others felt that restrictions should be eased as we work towards living with the virus.

When forming their expectations, participants reflected on whether the public should be provided with information to make informed decisions about risk, or about rules which they should be following. They decided providing rules around self-isolation is a reasonable expectation, as otherwise people may not come to the same conclusion and this poses a public health risk.

> "If there are expectations, why do they need to weigh up the risks? If they're being told, 'You need to do it and this is how long you need it to do it for,' then you're taking the thinking out of it." – Male, Workshop 5

Participants felt that monitoring of self-isolation needs improvement, and that monitoring should check in on support needs as well as adherence to rules. Some participants felt that UKHSA needs to give more focus to the consequences of not self-isolating when required to do so, alongside monitoring, as the public may not be adhering to the rules due to the perception that others are not being held accountable for breaking them. Others, however, expressed concern about civil liberties. A few participants reflected on needing to be clear with the public about why some people need to self-isolate in some circumstances where others don't in other circumstances, as otherwise people will continue to be confused by what they perceive as different rules around exemptions.

The importance of ensuring no-one is self-isolating unnecessarily

Participants felt that PCR tests should be provided to people who are told to self-isolate because they have been in close contact with someone who has tested positive, in order to bring their isolation period to an end and ensure no-one is isolating unnecessarily. However, they questioned whether a PCR test can end isolation given it is still possible to fall ill with the virus after several days.

4. Testing

Introduction

Within workshop 2, alongside self-isolation, participants were asked to consider information and stimuli on Variants of Concern and areas of Enduring Transmission in context with existing health inequalities, and how UKHSA currently approaches testing. Draft policy expectations were developed post-workshop based on analysis of the discussion and then presented back to participants during workshop 5 to form the basis for their final expectations concerning testing. The headline analysis is in Annex C, and the original draft expectations are in Annex D. More detail on this process can be found in the methodology, and the materials used in presentations and stimuli are in Annex B.

Expectations about testing

Participants drafted the below as their final set of expectations regarding testing, for UKHSA to consider in the future development of this policy area.

It is reasonable to expect the public to engage more with testing, if the following conditions are met:

Provide more adequate, timely financial, practical and mental health support, which is easy to access, to all who are told to self-isolate, so that all those who – but especially to those who need it and/or who are disproportionately impacted – are identified and have access to support. No-one should be disadvantaged or suffer a financial loss for doing the right thing. Communicate directly and clearly to those who need support (including where and how).

Make it clear we will be living with the virus going forward and we will need to adapt our lives to accommodate it. Provide accessible, compelling, precise and validated evidence to the public about what they need to do and why it matters for all forms of testing (PCR, LFD, and include wastewater testing in why it matters) that reinforces the narrative that whilst vaccines are important, they are only one tool to get us out of the pandemic.

Communicate with the public through people they trust, using a range of channels with support from local leaders (including religious leaders) to engage their communities and keep them informed.

Enable the public to engage with timely testing by providing easy, free, safe, contactless (that is does not require having to travel to access PCR tests) access to PCR testing in all circumstances.

Build and publicise a compelling reason for the public, including people travelling to the UK from abroad, to do regular LFD testing. This should include reassurances and visible/tangible development of LFD tests to improve the accuracy of these tests. Including holding testing labs accountable to audits and agreed standards, as well as publishing results.

Reduce the need to do routine testing (LFD twice weekly) by working with the wastewater testing mechanism alongside others, on a local level and making the public aware of this. Don't ask people to self-isolate if it isn't necessary.

Summary

The PAG members recognised the importance of widespread testing in breaking the transmission cycle, though very few were aware of the formal requirements for individuals to routinely self-test using lateral flow devices, nor the expectation that people take confirmatory PCR tests during the self-isolation period. Additionally, there was a range of beliefs expressed about the accuracy of routine LFD tests.

Given uncertainties within the PAG about the requirements for routine testing, widespread recognition of the discomfort in taking tests, and uncertainties about the accuracy of tests, many participants doubted that current policy approaches are effective. The likely low compliance was recognised as a significant risk to public safety, but there was doubt that compliance would be increased unless people had a much clearer understanding of the requirements of them, and the practical challenges of self-isolation were addressed (so that people had fewer disincentives to test). This was felt to be particularly the case during times of low infection rates when the risk to people would feel low, but the discomfort and impact would feel relatively high.

Discussions in the workshop on testing placed significant emphasis on communication as a route to better compliance, which reflected the widespread uncertainty in the group about the core expectations of the routine testing policy. However, in the later workshop on wastewater testing, many people expressed the view that broad spectrum and non-discretionary methods of sampling, supported by targeted surge testing, offered a much more credible, effective, and efficient route for testing. Some participants noted that a downside of large-scale routine testing is the expense of providing the kits and self-isolation support, which could be reduced if a more targeted approach could be adopted.

Detailed discussion

Improving the provision of financial and mental health support

As per the previous chapter on self-isolation, many participants felt that a key barrier to testing was fear over testing positive, in other words the implications of self-isolation such as financial concerns and mental health, and that provision for financial and mental health support should be improved in order to increase public engagement with testing. Participants felt that it is only a reasonable expectation to expect the public to engage with LFD and PCR testing, and to self-isolate when necessary, if the support available is improved.

Addressing misinformation, and building public trust and confidence in testing

Communication and education were key themes throughout discussions on testing. Participants consistently voiced concerns about misinformation, with complex and inconsistent messaging from multiple sources of information leading to confusion, lack of awareness and misinterpretation. Participants expressed concerns about:

- the perceived lack of effectiveness of tracing leading to disengagement with testing
- that people are even less likely to see why testing is needed following the vaccine roll-out
- the lack of public trust in – and awareness of – testing, including LFDs and PCRs
- a lack of engagement in testing, particularly those in areas of enduring transmission who, as per earlier discussion on self-isolation, were felt likely to disengage with COVID-19-safe measures due to growing frustrations about ongoing restrictions in these areas

> “I think Bolton have got a vengeance because we were closed down the whole period. It got beyond a joke and I know people weren’t sticking to it because they were fed up to the back teeth.” – Female, Workshop 2

Participants called for more to be done by UKHSA to overcome misinformation and to emphasise the need for regular testing (despite the vaccine roll-out) and actions to be taken following a test; with clarity on multiple channels including television, leaflet-drops and social media. They reflected on various concerning misinformation, including a need for UKHSA to clarify that testing positive does not mean you cannot contract COVID-19 again afterwards.

Participants also emphasised the importance of information being seen to be trustworthy, with a small number of participants expressing suspicions about the information being provided to the public by the Government. For example, questioning whether a Variant of Concern can be attributed to a specific area, and why the G7 summit gathered given the emphasis on the Delta variant at the time. While a small minority felt that the Government should be proactively opposing conspiracy theorists, others felt that communication should come from health bodies due to mistrust in the Government.

"We need to make sure that even though UKHSA is answerable to government, it isn't dictated by it. People will see it as independent." – Male, Workshop 2

Participants felt that the efficacy of each type of test should be reviewed, evidenced and published including their value for money. This should take into consideration:

- low compliance
- the practices of organisations gathering and recording data
- the discrepancy between LFDs and PCRs in terms of accuracy of monitoring (given that LFDs are administered at home without supervision)

It was felt that if the decisions following this review were made transparently, based on publicly available evidence, then this would help to build public confidence. A few participants felt strongly that LFDs should not be promoted if they are not well evidenced, or the public will not trust or comply with regular LFD testing. Others said that they had been surprised by the information on LFD accuracy shared within the PAG by experts, and that these should be better known as part of a communications effort towards providing proof that testing is effective.

Participants also felt that the public needs a cohesive narrative which emphasises that while the vaccines are a positive step in the right direction, they will not end the pandemic; vaccination one tool that will help us to live with the virus (rather than overcome it). They felt this should be communicated in a way that does not deter people from getting the vaccine (due to no longer seeing the point), but also be clear that it does not stop the spread, so testing is still necessary. Whilst there is a desire to reduce the need for everyone to be testing twice weekly using LFDs, some participants recognised why this is still currently needed.

In-keeping with this, participants felt that wastewater testing should also be actively presented as part of a holistic narrative, where wastewater testing is just one tool for society to use to live with the virus; it will reduce the need for individual testing, but it does not eliminate it. Expectations about wastewater testing is discussed in more detail in the wastewater testing chapter.

Addressing concerns about the accuracy of testing

In-keeping with the above concerns, most participants considered LFDs to be (significantly) less accurate than PCRs.

"The LFD is nowhere near as accurate or as useful are the PCR test. In every case we've experienced from an LFD positive, it was later proven to be false" – Male, Workshop 2

Participants valued LFDs for their ability to provide quicker results and identify those who are asymptomatic, but repeatedly voiced concerns about accuracy due to both the perceived inherent accuracy of the test compared to the PCR, and reliance on people testing accurately at home and reporting results honestly. Their key concerns regarding the implications of this were:

- LFDs leading to a false sense of security in an inaccurate negative test, leading to the person who is assumed to be negative still spreading COVID-19
- LFDs leading to unnecessary self-isolation, due to a false positive test

They were also concerned about whether there is capacity to carry out mass LFD testing across the UK, logistics (for example teachers not being trained to administer tests to students), whether people would do it (that is due to forgetting or avoiding it, or no longer seeing the need for testing given the vaccine rollout), and whether it is really necessary to ask everyone to do this all the time.

The fact that twice weekly LFD testing is an expectation of the entire population was a surprise to most participants. When asked for their views on the expectation of the population to test twice weekly, using LFD tests, the PAG was split on this. Many participants felt this to be reasonable given the need to reduce transmission, despite their concerns as outlined above. However, there were others who did not agree.

Some felt that expecting the public to self-isolate following a positive LFD would be acceptable, where others did not (due to the potential for inaccuracy and thus self-isolating unnecessarily) and a positive LFD test should instead be followed by a PCR test to determine the need for self-isolation. They flagged that the public need more information about LFDs regarding how accurate they are, and what to do following a positive LFD test, as well as the difference between LFDs and PCRs, highlighting a lack of knowledge of this. They also felt that making LFD reporting systems quick and easy for everyone should be a priority, to help address the disparity between LFD and PCR accuracy due to reliance on self-reporting. Further reflections included:

- a recognition that there is value in PCRs confirming the strain of COVID-19 (which LFDs are unable to do)
- an interest in the provision of more antibody testing to better understand those who may have immunity to COVID-19

The importance of making PCR tests, or a test that is similarly accurate, more accessible

Some participants were concerned that accessibility is a key barrier to testing, such as those who are not online being unclear how to access home-tests and supported increasing focus on accessibility. Their ideas included:

- providing more mobile testing centres and surge testing
- providing tests to companies and local businesses to provide to their employees
- targeting key workers in supermarkets

Participants also reflected on the discomfort associated with testing and questioned whether a more comfortable test could be developed.

Linked to their concerns about the accuracy of LFD testing, participants wanted the UKHSA to make regular PCR testing free in all circumstances and more widely available. Some participants were confused by this, as they thought PCR tests were already free (though participants are likely to have been operating from different levels of understanding regarding the circumstances in which a PCR is provided, and that payment is only needed when traveling). They felt that PCR testing could be provided more easily, for example by community nurses providing PCR tests to those isolating at home. Throughout discussions, there were concerns about lack of awareness on how to access PCR tests and what to do if an LFD provides a positive result.

There were concerns over accessibility to both types of test too, but particularly PCRs, though a few felt that there are suitable facilities and walk-in centres available to access PCR tests, and LFDs are easy to access at home via ordering them online.

In the absence of knowledge about how feasible it would be, participants ultimately supported the exploration of an alternative to the PCR test that is quicker and less expensive, but just as accurate.

The need for more collaboration and supporting community-based leaders and organisations

Participants felt local organisations should play an important role in the delivery of testing and self-isolation support. Schools, churches, local councils and GPs were repeatedly flagged as key local actors that UKHSA should be working with. Participants felt that GPs should be providing clear instructions for twice-weekly testing and information about self-isolation, and that churches – along with other established community networks and centres – should be acting as hubs for financial support, food supplies (including delivery) and education. Schools were named as key actors who should be enabled to make regular contact with parents, encouraging and checking in on self-isolation compliance. They felt schools could also provide information and guidance around testing and self-isolation measures, alongside employers.

The need to work with local actors was described as a way of promoting greater awareness of variants of concern, the vaccine rollout and test sites, and – crucially – overcoming mistrust in government. They supported this by reporting that communities tend to trust their local services, organisations, religious and community leaders more than government. While

they felt this would be effective, participants also felt that local actors should be better supported and funded for their communication and support efforts.

> "So many people have so little trust in the Government at the moment. They'll be more inclined to listen to community places like churches." – Male, Workshop 2

Local councils – including councillors and local MPs as well as core services – were also flagged as key actors that UKHSA should be working closely with. They felt councils should be engaging with and listening to the public, educating people and employers about transmission, and supporting people to stay at home when needed, including actively protecting employee rights while self-isolating. This last point links to a view expressed by participants that employers should be responsible for protecting their employees' rights and ensuring they are financially supported to self-isolate.

Participants felt other actors could be made use of locally too, including using local shops to provide clinics and local hubs for easier access to testing kits, and the citizens advice bureau as a source of information for example about the vaccine.

When forming the final set of expectations, religious community leaders were specifically identified as important as participants felt many people in society would listen more to religious leaders than those in government. However, participants in other groups, when reflecting, felt that local leaders is a more appropriate, all-encompassing term, particularly regarding providing testing hubs (as opposed to communication).

From the perspective of participants, better communication is needed between scientists and policymakers, and politicians should be more transparent regarding which (geographic) communities are likely to have to undertake surge testing and / or endure other restrictions, and why. They echoed the expectations expressed around the self-isolation policy, in that they felt that targeted testing should be applied to areas and not individuals, to enable people to feel less singled-out.

Testing data should be used solely for the protection of public health

While this did not form part of the final set of expectations for testing, when asked how data should be used, participants said they were comfortable with testing data being used to track the percentage of infection rates in different areas (as well as contact tracing more broadly) with this information being used to form strategies to stop the spread where transmission is higher. They also expressed interest in, and support for, using tests to identify and track prominent strains of the virus, and health research, for example looking for the most common blood groups of those that contract COVID-19.

It was important to participants that data gathered in relation to testing be used solely for the purpose of better understanding the virus itself, as well as contact tracing and understanding

infection rates, and nothing else; serving the sole purpose of informing the response to COVID-19. There were concerns about using LFD test data for this purpose, due to the potential for false test results.

There were mixed views on whether testing data should be anonymised or pseudonymised (so less identifiable) and in what circumstance, and who should have access to the data:

- some felt it should be publicly available while ensuring individuals are not identifiable
- some recognised that the UKHSA need to know identifiable information, where others do not
- other participants felt that employers should be informed

The key reasoning in all instances was to protect public health while also ensuring that no-one – especially private companies – can use personal data for anything other than supporting the efforts of stopping the spread of COVID-19. They noted that fears over providing data about yourself or others may be a barrier to testing. There is further discussion on this in the next chapter.

5. Contact tracing

Introduction

The third workshop introduced participants to contact tracing: what it is, who is involved and how it works, including via the NHS COVID-19 app. They were introduced to some of the barriers to contact tracing and asked to consider whether more information should be collected, such as location history and details about people's personal situations (how much they earn, how many people they live with, to support contact tracing). Draft policy expectations were developed after the workshop, based on analysis of the discussion, and then presented back to participants during workshop 5 to form the basis for their final expectations concerning contact tracing. The headline analysis is in Annex C, and the original draft expectations are in Annex D. More detail on this process can be found in the methodology, and the materials used in presentations and stimuli are in Annex B.

At the time of this workshop, it had recently been announced that the relaxation of coronavirus restrictions planned for 21 June would be delayed by 4 weeks.

The findings should be read in this context.

Expectations about contact tracing

Participants drafted the below as their final set of expectations regarding contact tracing, for UKHSA to consider in the future development of this policy area.

It is reasonable to expect the public to engage more with contact tracing, if the following conditions are met:

Communicate with the public in a clear and simple way how contact tracing has been improved (if you can prove it) and how it is now working and why we should do it and how important it is. And implement some specific changes:

– for example revise the app so the instructions are clear especially regarding people who have to self-isolate when not displaying symptoms
– train staff to be consistent

Don't rely too much on technology to ensure the system works (for example some don't have smart phones).

Communicate with the public through people they trust, using an accessible range of channels with support for local leaders to engage their communities and keep them informed.

Communicate that there are clear rules being implemented around data use, storage, sharing and destruction for all tracing data.

Support / provide guidance to venues to implement in a more effective and standardised way rather than using pieces of paper and then make them more responsible for ensuring people do it right.

Do further work to consider who should have access to what data, and what should and shouldn't be mandatory and for how long – always keep data sharing and mandatory measures and length of time as minimal as possible and only for 21 days, and for the sole purpose of protecting public health during current and future pandemics. Whatever you decide, tell the public clearly and be transparent about it.

Provide better and more focused financial, practical and mental health support, which is easy to access, to all who are required to self-isolate, and especially to those who need it and/or are disproportionately impacted – no-one should be disadvantaged for doing the right thing. Make sure the advice and support keeps up with changes and that people are informed what help is available and are offered it.

Summary

Participants highlighted that the effectiveness of the contact tracing system relies heavily on people choosing to use it, whether that is by using the NHS COVID-19 app or by properly signing into venues, or by providing complete information to contact tracers when a person is contacted. Many participants felt more positive about the contact tracing system when they had heard more detailed information about how it works and felt clear explanations of what is involved would build wider public confidence. There was generally a low level of understanding of the relationship between the national and local contact tracing systems and app contact tracing. Very few people were aware of the role of local public health teams, and they valued that element; whereas there was a wider concern about the involvement of private companies, particularly in relation to the collection and use of personal information. Overall, participants tended to highlight positively the involvement of local teams and local leadership, and to raise concerns in relation to aspects of central surveillance and the involvement of private companies.

Participant's personal experience of checking into venues was widespread and people highlighted practical issues that they felt require further development and refinement. These include processes to provide more information back to an individual about how many contacts their app had registered in given venues and making it clearer how to check out of

venues. Similarly, it was felt that there needs to be some development of the manual paper processes used by venues, particularly to ensure appropriate storage and deletion of people's private contact information to avoid misuse.

In relation to personal data, most participants expressed reassurance that the app stored minimal information and for a time-limited period. Many people expressed agreement that this information has been collected for a particular purpose and should not be used more widely, specifically being shared with the police. Likewise, and related to wider discussions about health data, most people felt that it was important to be explicit about data not being shared with other agencies or with private companies, such as insurance companies. Many described that clear commitment and communication of these points would help increase confidence in the system and use of the app.

Detailed discussion

Overall lack of awareness of how contact tracing works and confidence in it

Most participants were positively surprised to learn how contact tracing works, the rates of effectiveness and about the role of the NHS COVID-19 app, showing the value of transparent information. Participants expressed a widespread prior belief that the app, and contact tracing more generally, had low penetration.

Questions around the accuracy of contact tracing and the effectiveness of the NHS COVID-19 app were underpinned by a general lack of trust in government and recall around previous negative press coverage of Test and Trace. For some, this remained a deterrent for using the app.

> "The contact tracing system has been so discredited that I'm just not sure what faith people have in it." – Female, Workshop 3

Although in the minority, there were participants who viewed contact tracing to be an extension of general government surveillance, which was felt to be invasive. Some participants reported that the original 'track and trace' branding had not helped with this perception, continuing to refer to this throughout the discussions even though it was not used in any of the information provided.

> "There was a sense they could see everywhere I am going, what I'm doing"
> – Female, Workshop 3

There was also a strong view expressed that the app is not a universal solution to contact tracing, given that it is still not compatible with certain devices, and that some people do not

have a smart phone. Further, there was a recognition that even with telephone contact tracing, there will still be people for whom it will be more difficult, or impossible, to trace. For example, those without a landline, homeless people, and undocumented immigrants.

Additional limitations in manual contact tracing and the app that were raised in initial discussions included:

- the perceived delay between contact and being notified to self-isolate being too long
- fear, in some, around picking up the phone to unknown numbers or assumptions that the contact tracing calls were scams
- the app not being able to know when you have left a venue

Almost universally, participants called for better information and an explanation of how the app works, as well as greater demonstration of both the accuracy and success of contact tracing (included via the app). A few participants suggested a visual demonstration of how the app works and how it traces people.

> "If we all thought it [the NHS COVID-19 app] was working, I think far more people would sign up to it." – Female, Workshop 3

Participants wanted to know how contact tracing is directly contributing to reducing the number of people transmitting the virus. It was felt this would help convince people that the app is worthwhile to download and use, while also justifying the importance of self-isolation; they felt this would essentially drive trust.

> "Why are you going to spend 15 minutes talking to somebody on the phone if you don't think it's going to help, or nothing is going to come from it." – Male, Workshop 3

Participants also indicated that it would be useful if the app provided more feedback to the user. For example:

- the number of other people with the app that your phone had been in contact with
- the time and location the person encountered someone who had tested positive (some suggested that this could help individuals gauge the level of risk)
- the number of people who have developed COVID-19 from those asked to self-isolate by Test and Trace
- an inclusion of a pop up that reminds the user that the app is anonymous
- clearer instructions for those who have to self-isolate
- notifications to assure users that data is securely deleted after 21 days

> “I can't think of any app that gives a more definite indication that it's secretly doing something in the background but doesn’t tell you what it is, and I am a programmer.” – Male, Workshop 3.

There were several suggestions around the tone and approach of manual contact tracers (those on the phones). Contact tracers should be supportive and personable and ideally forewarn the public about the kind of questions that they are going to ask, providing reassurances around why they are collecting this information.

The need to support local communities

There was a general lack of awareness around how different regions were supporting their local populations, and it was reassuring to hear that this was already happening in practice. It was felt that this should be better promoted to drive trust. There was also a sense that information about contact tracing, and reassurances concerning how it works, should come from trusted local individuals, rather than from politicians. There were references here to how this has been effective in the vaccine programme.

> "What they did with vaccinations was good, when they got community leaders to explain to people, for example coming into churches. The success of the vaccinations is because of this." – Female, Workshop 3

Driving uptake of the app

Participants commonly reflected that contact tracing relies heavily on honest behaviour within the general public (using the app, reporting tests, reporting contacts).

> "It’s always sprung to mind that we really are relying a lot on public cooperation. There is no rights involved here. They [the Government] don’t have any rights legally or anything…This [contact tracing] doesn't work well when people are fed up" – Male, Workshop 3

Linked to this, some raised the point that many would rather not know that they have been in contact with someone who has tested positive, because of the financial and mental health implications that come with self-isolation (see below). As well as the inconvenience this would cause, with reports of increasing ‘COVID-19 fatigue’.

There were other suggestions for how to drive uptake of the app, including:

- creating a sense that it is socially irresponsible to not use the app

> "You do it, other people will hopefully do it as well. If other people are doing it to protect their loved ones, you should do it as well, it's about mutual respect."
> – Female, Workshop 3

- emphasising messaging on the ability for the app to help keep people safe
- demonstrating value in using the app

> [Reflecting on the presentations and information provided] "I got nothing about the value of why we should use the app." – Male, Workshop 3

Some participants went so far as to suggest requiring businesses to only allow customers to enter venues (restaurants, nightclubs) if using the app. This idea of creating incentives (that is the entitlement to freedom), was also coupled with suggestions around legal consequences. These suggestions came up across several groups, though this was not a majority view.

Suspicion about how data is used, handled, stored and deleted

The discussion about data in the context of contact tracing and the NHS COVID-19 app came hand-in-hand with a lack of trust in how data is used by government and fears over the NHS sharing data with commercial organisations. There was occasional reference to the NHS Digital data opt-out.

> "They've got it with the opt out thing for the NHS, they're trying to grab all our information at the moment." – Male, Workshop 3

Participants were reassured to hear that the app is anonymous and confidential, but they wanted reassurance that data (that is test results) is not shared with bodies unrelated to public health such as the Home Office.

However, there were concerns – and a degree of suspicion – about the risk that data could be sold or misused (profit making, alternative agendas of commercial entities), because of the involvement of third-party contractors.

Participants also raised concerns regarding how some businesses (restaurants, pubs, bars) continue to store personal details on paper, which was noted to be uncompliant with data security and protection standards. Some raised the risk of data being misused (for example barmen knowing female customers' phone numbers), and that paper reporting could encourage misreporting by customers (sharing fake personal details).

It was reassuring for participants to learn that data is stored on the app for 21 days only: a previous unknown fact to many. While at the same time concerning to hear that the

Information Commissioner's Office only recommends – and does not stipulate – that local authorities store data for 21 days and that the data deletion is not mandatory.

Participants were looking for reassurances around how contact tracing and the app works, how data is being used, who data is being shared with and that data is deleted after 21 days.

In some groups, the UKHSA and NHS was viewed far more favourably in the context of data use, motivated by health concerns, while government was seen less so due to the perception that its' interest is broader.

> "If it came from the UKHSA and you trust they focus only on the public health, you'd believe it. From the government they have conflicted views as they're talking about politics and economy too." – Male, Workshop 3

Data to be used for the purposes of the pandemic only

Participants universally agreed the following groups should be able to access data, including test results:

- public health authorities and health agencies (though some argued this should be anonymous)
- clinicians (GPs, hospital staff, those working in health hubs)

Participants were divided, however, on whether employers should have access to data, including test results.

Some felt they should, because of safety and public protection, but that this should not be shared with other employees and should be minimal necessary information (for example positive test results only).

Others felt that employers should not have access to data, because of a right to privacy and fears that could soon extend to employers accessing all kinds of health data. There were suggestions that this should be governed by personal choice.

Additionally, most participants identified a red line in relation to routine personally identifiable data being shared with the police (unless it is absolutely necessary for public security or enforcing self-isolation), due to mistrust and fear that data would be used for other reasons (for example to deport people).

Participants also universally identified a red line that data should not be shared with insurance companies, because of fears that this could lead to prejudice around health and life insurance (that is if COVID-19 was known to be a pre-existing condition). As well, many voiced an expectation that commercial companies should not have access to personally identifiable data, including companies that are directly involved in the delivery

of contract tracing services. This demonstrates a lack of appreciation for the need for commercial partners to access and process identifiable data for the purpose of COVID-19 contact tracing, and highlights that participants appeared unaware of the communication that has happened around what safeguards are in place.

Some suggested that it would be reasonable for venues to ask to see test results, to enable a return to normality. However, there were concerns over the ability of all venues to store data securely and an expectation that any data sharing with venues should be time-limited and they would not need to see personal data.

> "If the venue is going to ask you for a negative test result to allow you in, that's enough. They don't need to have your name and your medical history." – Male, Workshop 3

In the context of discussions about data sharing with different bodies, many participants raised the expectation that this should be driven by consent, and/or that there should be a data opt-out.

Acceptability of requesting more personal data for the purpose of contact tracing

The presentations, and case studies discussed with participants, introduced the idea of UKHSA and its partners collecting more personal data for the purpose of contact tracing. There were mixed views on this.

Some reflected on how reassured they had been, during the presentations, that currently the bare minimum data is collected.

> "I found myself a bit reassured they're only going to ask for as much information as is needed. I feel somewhat reassured our information will be secure and they require us to give as little information as they need." – Male, Workshop 3

While others said that they would have to understand the full reason why additional data was needed and this would need to outweigh the benefit of protecting personal privacy, or the privacy of others. This came hand-in-hand with a general lack of understanding about why certain information is needed for contact tracing.

> "Why do I need to give my date of birth for the Track and Trace?"
> – Female, Workshop 3

Financial data was noted as being particularly sensitive to provide given the lack of trust in how information could be used. But also because of the involvement of third parties, with concerns about data breaches and the motivations of private companies.

"I think there's a general mistrust of data usage, because we know that our data is used and manipulated and shared and that there is very little faith when you're told that's not going to happen, because there are data leaks, there's hacking, there are all kinds of problems…just because a government says they won't use it in certain ways that they won't. That's just walking into disaster." – Female, Workshop 3

Self-isolation as a major barrier to contact tracing

Throughout the discussions, participants returned to self-isolation as a barrier to testing and to engagement with contact tracing and the app. The fact that there is still no general test to release mechanism for those who are self-isolating frustrated some, on the basis that people must self-isolate even though it is not proven that they are positive.

Some participants said that they knew of situations where employers were actively advising their employees to switch off the contact tracing function of the app.

"I was helping deliver something to a care home, and it said upon request please turn your app off. If your app pings in there, it will wipe out the entire staff." – Male, Workshop 3

The delay in reporting and receiving the self-isolation payment was also identified as a reason why people are dissuaded from engaging with contact tracing (including use of the app).

Participants called for better financial support and for this to be automated.

6. Wastewater testing

Introduction

Workshop 4 introduced participants to wastewater testing. They were asked to consider information and stimuli that framed this approach as an alternative or supplement to routine mass-testing and presented the UKHSA's role in supporting this type of testing. Draft policy expectations were developed post-workshop based on analysis of the discussion and then presented back to participants during workshop 5 to form the basis for their final expectations concerning wastewater testing. The headline analysis is in Annex C, and the original draft expectations are in Annex D. More detail on this process can be found in the methodology, and the materials used in presentations and stimuli are in Annex B.

At the time of this workshop, it had recently been announced that the Office for National Statistics figures for the week ending 12 June suggest one in 540 people are infected with COVID-19, with the Delta variant counting for the majority of cases reported by Public Health England.

The findings should be read in this context.

Expectations about wastewater testing

Participants drafted the below as their final set of expectations regarding wastewater testing, for UKHSA to consider in the future development of this policy area.

It is reasonable to expect the public to accept the carrying out of wastewater testing, if the following conditions are met:

Provide immediate, proportionate financial, practical and mental and physical health support, which is easy to access, to all who are told to self-isolate, and any businesses affected, but especially to those who need it and/or are disproportionately impacted. No-one should be disadvantaged for doing the right thing.

Ensure that data gleaned from wastewater testing cannot be used by private organisations, non-public health related government departments or state services for profiling communities and discriminatory practices – wastewater testing data should only be used for pre-approved public health purposes and should be tightly regulated (including legislation) with oversight from senior public health professionals. Offer protection in the form of consequences for anybody that uses wastewater testing data for discriminatory practices, as well as regulation to stop private organisations from accessing wastewater testing data.

Create a strategic communications plan that proactively educates and informs the public about wastewater testing and frames it as part of a suite of measures we will use in the future to live with the virus.

Explore whether to make wastewater testing data publicly available on a wider area scale. Whatever you decide, tell the public clearly and with great care.

Make PCR surge testing the first step in response to wastewater testing identifying high-prevalence of COVID-19 in an area and lockdown should be a last resort – where COVID-19 is found in wastewater (clarification) people who test negative with a PCR test shouldn't be forced to isolate, nor businesses closed, unless necessary.

If the purpose of what is a great public health tool is expanded beyond COVID-19, then there needs to be a proper dialogue with the public about conditions of use. Ensure regulations and legislation are in place to ensure the public have protection from discriminatory practices or data breaches before it is implemented.

Summary

The workshop discussion on wastewater testing introduced members of the PAG to an innovative approach that is in use, but where implementation policy is relatively new and being developed. Many participants expressed satisfaction that public input was being sought at this stage and felt that they could make effective contributions to help shape and inform how this approach could be used.

Many participants noted the potential for this approach to be applied more broadly, to locate samples of other diseases in the water system. In that respect many people expressed the need for transparency about the use of the approach and clear communication about the limits of its application.

When applied for the purposes of detecting COVID-19 the vast majority of participants were strongly supportive of the use of this approach, and they recognised how this measure could be used in conjunction with surge testing to overcome many of the limitations already considered in relation to self-testing. Whilst this method was recognised to operate without individual consent many felt that the non-discretionary element was an important feature for providing wider public protection.

The level of spatial specificity to the testing was also recognised to be important, with more targeted approaches offering greater potential benefit but also posing a greater risk of individuals and communities feeling under surveillance. The general principle expressed by many was that a greater explanation should be given to communities in instances where the sampling becomes more geographically focused.

There was also some divergence of opinion about how the results of wastewater testing should be communicated and made public. For some participants it was important to be directly alerted to results, in a manner similar to a flood warning, for some it was important to have the results accessible to the public (for example published online), but for others there was a concern that the display of this type of information could be used to stigmatise communities that continue to experience enduring transmission. The PAG felt that this was an important part of the policy and requires further exploration and development with the public.

Note that due to wastewater testing being explored and discussed as a policy measure in isolation, participants may not have understood that wastewater testing is always used as part of a wide variety of insight and information to reach a decision. It does not inform decision-making about appropriate action by itself.

Detailed discussion

Initially participants expressed excitement or interest at the prospect of wastewater testing being a less invasive, more effective and cost-efficient method of testing that would be a cheaper alternative to PCR or LFD testing as a first step. It was generally viewed as a positive advancement in being able to detect COVID-19 in areas without the need for uncomfortable tests, relying on people remembering to self-test or having certain technology for contact tracing, such as smart phones.

> “I think it’s excellent. It overcomes many questions we had in the last session about who you’re missing. It doesn’t miss anybody, people that don’t have technology.”
> – Male, Workshop 4

The need for clarification on wastewater testing in conjunction with other forms of testing

Participants generally accepted that COVID-19 would likely circulate indefinitely and felt wastewater testing could help balance the public’s fatigue with lockdowns, their mental health and individual liberties with people’s safety. Many participants considered wastewater testing as advantageous compared with other types of testing and surveillance because it provided anonymity to members of the public, rather than pinpointing individuals who are testing positive for COVID-19.

> "It is not intrusive on you personally, that is a really good thing, plus it looks at a wide area. It’s not picking just on individual people." – Female, Workshop 4

There was some uncertainty about the use of wastewater testing in relation to other forms of testing, however. As discussions progressed, wastewater testing was perceived by many participants to be a way around national lockdowns as it could be used as an early indicator that restrictions may have to increase in a particular area, rather than all areas across country having to endure this. There were 3 main responses to this:

- firstly, some participants felt this would eliminate the need for biweekly LFD testing, believing that only areas with high COVID-19 wastewater testing results would then need to conduct surge testing
- alternatively, participants reasoned that wastewater testing should not be advertised as a replacement to regular testing, as this could cause a false sense of security and remove individual responsibilities
- lastly, and most prevalent, was the view that wastewater testing would need to be carried out in conjunction with other testing; maintain easy access to and encourage the use of PCR and LFD testing, as well as providing intense surge testing following high COVID-19 signals in the wastewater testing before further restrictions were put in place

> “It's a case where further testing with PCR could eliminate concerns and put everyone more at ease.” – Female, Workshop 4

Preventing unnecessary lockdowns within a particular area was a key priority for most participants. Participants were conscious of the negative impacts isolation and restrictions had on people’s mental health and the economy of an area. It was therefore felt that people in areas where COVID-19 signals were identified through wastewater testing should, with a negative PCR result, be allowed to continue their usual routines.

Participants were split in their opinions of which type of testing would be preferable in areas where wastewater testing showed signals of COVID-19, despite general agreement that PCR testing was more accurate than LFD testing.

Some participants felt funding meant for LFD testing should be focused on improving and speeding up the process of returning PCR test results as they are more accurate and reliable.

Despite contentions around the accuracy of LFDs (as reported earlier), and the unpleasant nature of using them, some participants still felt it would be best for people living in these areas to have both PCR tests available and mass LFD testing to ensure maximum accuracy and confidence in results.

While views on LFDs were contradictory, participants widely agreed that wastewater testing alone was not enough to manage the virus going forward. Some participants reiterated their confusion as to whether people would still need to isolate if they received a negative PCR result. It was generally acknowledged that clarification was needed about which test

outcomes required isolation. It was stated this needed to be made very clear to the public to ensure everyone is aware and understands what will be expected from them.

"If you don't set that precedent from the start it's hard to undo what people think they already know. You've got the difficulty of trying to get people to change their minds. So setting a precedent from the start, with the right information, is paramount."
– Male, Workshop 4

Concerns over potential uses of wastewater testing

How data collected from wastewater testing would be used was a primary concern for most participants. There was some disagreement about who should oversee this; suggestions included the Information Commissioner's Office or public health professions, but no real consensus was reached.

Many participants strongly stated that wastewater testing data should never be used to profile communities or pinpoint individuals and anxieties were raised about the potential use of wastewater testing data as a tool for policing. Mistrust and scepticism of government continued to be raised by some participants, and others acknowledged more widespread societal feelings of conspiracy and paranoia, perceived to be as a result of misinformation relating to the cause and handling of the pandemic from various sources including social media and online media outlets. This led to some participants contemplating the potential for it to be used for purposes outside of public-health related reasons, such as to test for illicit drugs or to monitor undocumented people.

"Two concerns I've heard from communities round here; The sewage system might be used to identify populations of people who are illegally in the country. That may lead to raids. The second is the link to criminal justice systems. They may find links of class A drugs. They need to be aware we're collecting for health reasons." – Male, Workshop 4

A small number of participants questioned whether it was possible for DNA to be tested through wastewater testing. Experts responded to these questions and confirmed that wastewater testing did not use DNA, however a minority view that it would still be possible for government to monitor DNA persisted. Despite wastewater testing not collecting personal data and the data it does collect being anonymous, some participants were very protective over data they deemed as both personal and their own, and still held deep concerns about the potential for privacy breaches or data getting into the hands of financial institutions, non-health related government departments or corporations. A few participants highlighted the potential impact on housing prices in areas where wastewater testing continued to show high COVID-19 signals or how people's insurance may be affected.

"We discussed this a lot … This information shouldn't be given to any financial institutions, just health institutions really. It should be treated similarly to having doctor/patient confidentiality. It shouldn't be released to anybody else, other than the medical professions." – Male, Workshop 4

Participants were cautious about setting a precedent for wastewater testing to be used outside of health-related reasons, they were also mindful of not limiting wastewater testing to specific purposes. Participants appreciated that 'public health' was a broad term open to interpretation, and therefore, wanted to specify wastewater testing should only be used for pre-approved public health purposes.

"It's very broad isn't it. In the interest of public health is a very broad term. They need to let everyone know what they're looking at. If you put a too general term on it then they can find loopholes." – Female, Workshop[1]

Wastewater testing infrastructure as a wider public heath tool

There were concerns held by a few participants about the possibility of discarding the use of a public health tool over fears of some of the potential uses of wastewater testing. Participants expressed enthusiasm at the potential for using this approach for future disease management and felt it would be a mistake to restrict the purposes purely to COVID-19. There were still concerns about the possibility of organisations exploiting these purposes and participants discussed the need for regulation and legislation to be in place to safeguard boundaries, ensuring wastewater testing is not used for any reason than public health, or used for purposes undisclosed to the public or to monitor groups of people in a discriminatory manner. However, no resolution was agreed as to who should regulate this. Most participants agreed that if wastewater testing was expanded to monitor other diseases, there would need to be a considered debate (for example in parliament) and dialogue with the public before educating them around the new purposes.

"We may voluntarily abandon a public health tool. The potential for monitoring heart disease, cancer, dementia and obesity. If we have a tool for showing where we have these illnesses specifically, I think it would be foolish to ignore that." – Male, Workshop 5

[1] Some participants suggested this without recognising that a parliamentary debate would only take place if new legislation was required.

Justification needed for granularity of wastewater testing

Participants compared the benefits of wastewater testing granularity and accuracy with people's need for privacy and not seeming to target certain areas. This was particularly important for participants as people in those areas would then be expected to participate in surge testing and potentially need to self-isolate. Participants did not come to an agreed opinion as to which level of wastewater testing would be more acceptable but did discuss considerations for the different levels:

- for street level testing, many participants stated there needed to be justification as to why it was happening so that communities do not feel targeted – it also needs to be balanced against people being able to get on with their daily lives and the health of others
- some participants felt that neighbourhood level testing was as localised as wastewater testing should become and that focussing on a smaller area would be an invasion of privacy – this level of testing was perceived by some participants to be a good balance of accuracy and anonymity; experts responded to this and provided reassurance that wastewater testing is completely anonymous in that individuals or households cannot be identified at any feasible level of testing
- postcode level testing was perceived by some participants as being more cost-effective but there were concerns over visitors into areas with high prevalence of COVID-19 detected in wastewater testing impacting the accuracy of the data – this was particularly so for areas associated with high levels of visitors, such as holiday destination towns or large cities

> "If a lot of people who had the virus came into an area it might completely swap the results round. It's not always the locals." – Female, Workshop 4

Contentions over whether and how wastewater data should be made public

Most participants felt that public health organisations, such as UKHSA, needed to have access to wastewater testing data. As the wastewater testing programme will be part of UKHSA, they will have access to data, but participants felt it was important that this should be clearly communicated so people know who is responsible for handling their data. There was less agreement among participants about whether UKHSA should hold this data alone, or if local health authorities (public health teams) should also have access to this data.

Scepticism over data being unidentifiable seemed to impact participants views on whether, and how, wastewater data should be shared publicly. Despite it not being possible to identify individuals through wastewater testing, participants continued to stress the importance of avoiding central government or pharmaceutical companies having access to personal details about themselves.

Many participants seemed to make instinctive distinctions between data and information; data often being discussed in relation to personal data, whereas information was discussed more in relation to wastewater testing signals being used to understand where COVID-19 was prevalent so people could make informed, safe decisions. Use of language was considered to be important in how data collection is communicated with the public. Some participants asserted they would feel comfortable for wastewater testing data to be shared, providing it was for a valid reason and reasoned that as this data is anonymous then it could be used to gain a better understanding of the virus.

> “I’m generally of the view that personal information should be kept personal, but, because this is anonymous information, it might identify a street or community, but it doesn’t identify us individually, I think I am quite comfortable with the idea of it being shared if there is a reason for it.” – Male, Workshop 4

Opinions on what information relating to areas with high prevalence of COVID-19 detected through wastewater testing should be shared with the public were varied:

- most participants shared the view that people in an affected area should be notified and supported to follow any interventions or restrictions, but there was discrepancy about whether to share this information with wider community areas where detections were not made
- some participants suggested making information from wastewater testing available to surrounding areas so that people could take appropriate actions for ensuring their own safety and others

> "We need some pragmatism. If you’re in an area where the wastewater testing says things are high, you need to show a bit of common sense and do the things you can do yourself to keep you and others safe.” – Male, Workshop 4

- some participants felt that sharing this information with even wider areas and neighbourhoods was necessary in order to effectively control the spread of the virus
- other participants felt strongly that sharing information from wastewater testing about a particular area with the wider public could lead to misinterpretation, causing panic or leading to negative reactions and even discrimination – there were concerns that making information public would promote a culture of blame in society and cause people to feel resentful or targeted

> “If you’re talking about areas with the highest rates of the virus they’re already disadvantaged enough and already experience enough discrimination based on their postcode. Postcode discrimination happens in job applications and all sorts and that’s just another layer to it." – Female, Workshop 4

Participants generally agreed that making information publicly available should be explored in more detail to fully understand the benefits and risks associated with doing so. Participants felt any information should be generalised and should not identify an area too precisely so as not to impact people's insurance (that is the link between poor COVID-19-related health outcomes and insurance premiums). To avoid discrimination, some participants recommended that information should be only available to the public about an area in a way that is useful and would help people make informed choices. A small number of participants felt it should only be made available to those in public facing jobs so they could make decisions about whether to work in an area or not.

Wastewater testing assured by routine mass testing to support people to make safe decisions

Many participants perceived wastewater testing as a way of allowing people to live more normal versions of their lives as they considered the impact that repeated lockdowns and continued restrictions had had on the public's general wellbeing. Some participants reflected on people having to choose between seeing family or following restrictions.

> "There are issues with people suffering from this and where you have this rapid response to local changes it's yet more changes to what people can and can't do and that feeling of people constantly ping-ponging between things puts so much strain on people…These changes strain people's mental health and strain their ability to make decisions."
> – Female, Workshop 4

Wastewater testing combined with clinical testing was considered by many participants to give people reliable information to enable them to make decisions about their safety and the safety of others sensibly. It was strongly emphasised by many participants that for subsequent testing to be effective following a high prevalence of COVID-19 being identified, communications needed to be very clear and provide clarity on what was expected of people. There was a lack of consensus as to whether this could be reliably conducted with just PCR testing or whether LFD testing should also be used. A need for clarification was requested by many participants.

Communications need to be clear, transparent and accessible to all

As with other policy areas, participants wanted transparency and upfront communications about when and where wastewater testing was to take place. This was perceived to help encourage trust in government and COVID-19 measures as participants again emphasised the amount of misinformation circulating throughout the pandemic.

> "The information needs to be there that this is what we're doing so that everyone knows and it doesn't come as a surprise. Anything that hits you without you being aware of it tends to have extreme reactions." – Male, Workshop 4

Most participants agreed that getting the messaging around wastewater testing right was vital for this type of testing to be accepted and effective. The public would need to be educated as to what would be expected of them if a high COVID-19 prevalence was detected in their area. While wastewater testing does not rely on individual behaviour, participants raised concerns about how effective wastewater testing would be if not everyone understood or followed the same subsequent guidelines of routine mass testing and isolation. Many participants felt it was important for everyone within an area of wastewater testing to be given the same information at the same time so as to avoid hearsay or misinterpretation.

> “It goes back to education. One person knows and one person doesn’t know. This seems to be an ongoing thing through this time of COVID."
> – Female, Workshop 4

There were mixed views from participants about the best way to communicate messages so that they are accessible to all and it was widely acknowledged that no one way would reach everyone. It was noted by some participants that news coverage around COVID-19 tended to be negative and that messaging around wastewater testing should be framed as a positive advancement in detecting early signs of COVID-19.

Without any discussion (or reported knowledge) of how effective such channels are, participants suggested the public should be contacted using various methods of communication, mentioning written information (letters, leaflets), personalised updates (texts and phone calls), television and local radio station announcements and via community engagement mechanisms.

> "We mentioned about communication. I live in an area where I get flood alerts, by email, on my phone, everywhere… I got a letter from the post from Network Rail about the changes they’re going to make. The information we need on COVID is rarely disseminated in the post, email, or other ways. It’s about communication." – Male, Workshop 4

Participants shared a need for information around wastewater testing to come from an authoritative but non-governmental body that was perceived to be accountable. As with other forms of testing and contact tracing, a few participants felt that engaging with local community leaders was important to ensure that communities understand why wastewater testing is being carried out in their areas and the impact this would have on them. Similar to what was reported in previous chapters, it was suggested that the UKHSA should work closely with local leaders and councils to ensure they use the correct language in the messaging around wastewater testing to incentivise people to follow the guidance and prevent different groups feeling targeted or stigmatised.

"The Government or agencies need to think about the language they use for these messages. Words like containment and control could be quite divisive. I think a lot of it is the language." – Female, Workshop 4

Financial support to encourage self-isolation compliance in areas identified through wastewater testing

The notion of wastewater testing led participants to repeat the issue of financial support, mostly relating to barriers to self-isolation discussed in Chapter 2. As with previous chapters, providing appropriate and immediate financial support for people required to self-isolate was a key priority for participants to assist and encourage people to make the right decisions.

In relation to wastewater testing specifically, it was widely felt that government should have financial support ready for areas with high COVID-19 as they will know the testing is taking place. This support should then be available immediately for people living in those areas as it would not be necessary for the whole country.

Appendices

1.1 Public Advisory Group demographics profile

The 'Target Quotas' column are the target quotas for the PAG, including the representative percentage based on the data source and the actual target number of people for the PAG. The 'PAG' column is the demographic make-up of the final selection, and those who attended. Of the 93 who attended, 84 attended all 5 workshops, 6 attended 4 workshops, 2 attended 3 and one person attended one workshop.

Please note that applicants self-defined their gender, and those who were non-binary were randomly assigned a gender for the purposes of random selection only.

Table: Gender (source: ONS estimate mid 2020 – England only)

Gender	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
Male	50.6	51	51	42
Female	49.4	49	48	51
Other	0	0	1	0
Total	**100**	**100**	**100**	**93**

Table: Age

Age	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
0-15	0	0	0	0
16-29	21.5	21	21	20
30-44	24.1	24	24	23
45-64	31.7	32	32	30
65+	22.8	23	23	20
Total	**100**	**100**	**100**	**93**

Table: Geographical area (source: ONS estimate mid-2020 – England only)

Geographical area	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
East Midlands	8.6	9	9	7
East of England	11.1	11	11	10
London	15.9	16	16	15
North East	4.7	5	5	4
North West	13	13	13	13
South East	16.3	16	16	20
South West	10	10	10	7
West Midlands	10.5	10	10	8
Yorkshire and the Humber	9.8	10	10	9
Total	**100**	**100**	**100**	**93**

Table: Occupation (Source: ONS / Nomis) Annual Population Survey – Employment by occupation (September, 2020)

Occupation	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
Not in the labour force	39.3	39	39	35
Operator or elementary occupation	9.8	10	10	6
Professional occupation or technician	29.4	29	28	31
Service occupation	15.5	16	16	17
Skilled trade	6	6	6	4
Total	**100**	**100**	**99**	**93**

Table: Ethnicity (source: ONS census 2011)

Ethnicity	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
BAME	13	40	40	38[2]
White	87	60	60	55
Total	**100**	**100**	**100**	**93**

Table: Trust in the Government (Source: Ipsos UK – Global Advisor Survey)

Trust in the government	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
Very Trustworthy	3	3	3	2
Trustworthy	10	10	10	10
Neutral	33	33	33	33
Very Untrustworthy	28	28	28	21
Untrustworthy	26	26	26	27
Total	**100**	**100**	**100**	**93**

Table: Index of Multiple Deprivation, via postcode

Multiple deprivation	Target Quotas: Representative %	Target Quotas: Target for PAG	PAG: Selected	PAG: Attended
1-3	30	40	40	39
4-10	70	60	60	54
Total	**100**	**100**	**100**	**93**

[2] Of the 38 participants from non-white backgrounds, 7 were Black African, Black Caribbean or Black British; 20 people were Asian or Asian British; 5 were a Mixed or identified as multiple ethnic group; and 6 were another ethnic group.

1.2 Independent Advisory Group membership

Name	Role
Michael Burgess, (Chair)	Professor Biomedical Ethics, University of British Columbia
Paul Plant	Deputy Director, Public Health England (London region)
Hetan Shah	Chief Executive, The British Academy
Renate Samson	Principal Policy Advisor at Which?
Abigail Gallop	Principal Policy Adviser at Local Government Association
Mehrunisha Suleman	Senior Research Fellow at Health Foundation
Mahlet Zimeta	Head of Public Policy at the Open Data Institute

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.

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