

## NHS Test and Trace Public Advisory Group

### Independent Advisory Group Summary Note for 23rd April 2021 Meeting

<b>Attendees: Independent Advisory Group (IAG)</b>	
Michael Burgess, (Chair) Professor Biomedical Ethics, University of British Columbia	Mahlet (Milly) Zimeta - Head of Public Policy at the Open Data Institute
Abigail Gallop - Principal Policy Adviser at Local Government Association	Renate Samson - Principal Policy Advisor at Which?

Apologies from

- Hetan Shah, Chief Executive, The British Academy
- Mehrunisha Suleman - Senior Research Fellow at Health Foundation
- Paul Plant, Deputy Director, Public Health England (London region)

<b>Attendees: Project team</b>	
Amy Darlington, Director, ICHP	Mark Kewley, Director, ICHP
Michelle Mackie, Research Director, Ipsos MORI	Chloe Juliette, Project Manager, Ipsos MORI

Apologies from

- Simon Burall, Senior Associate, Involve
- Suzannah Lansdell, Associate, Involve
- Abeer Itrakjy, Associate Director, ICHP

<b>Attendees: T&amp;T team</b>	
Ben Stimson – Chief Customer Officer, UK HSA	Jason Caplin, Products Director, UK HSA

The note in the appendix below was summarised by T&T at the start of the meeting and comments that were raised by the group are noted below.

#### Points raised during the IAG meeting

- A question was raised asking for clarity around what is now in scope for the PAG and what has changed since the circulation of the Skeleton Discussion Guide was circulated a few weeks ago. It was explained that much of the content that was previously proposed will still need to be included, such as, educating the PAG about the test and trace service, the disease, self-isolation in the context of Variants of

Concern and enduring transmission. This is likely to be discussed as part of a dialogue process. Wastewater and contact tracing will then provide the focus for the discussion around the use of data. These two areas align more to a deliberative process as there will be policy dilemmas to deliberate.

- A comment was raised around the importance of including the local perspective as opposed to just the national approach noting that there are currently wastewater and contact tracing pilots underway in some local areas. Test and Trace colleagues agreed and are keen to ensure that the role of local teams is explored through the process particularly as it may be that the public are more likely to trust their local authority or local area teams and therefore this may impact the PAG's views about the policy areas being discussed.
- A concern was raised around the complexity of the policy dilemmas to be discussed and the way the topic questions are currently being framed. It was raised that it is not the PAG's job to write policy. They should be able to input and comment but not write policy. Test and Trace provided reassurance that this was not their intention and if the documentation provided is misleading the framing will be changed. The purpose of the PAG is to enable participants to explore the policy areas in depth, to understand what matters to them, their concerns, hopes and identify any red lines.
- Building on the above, another point was raised encouraging that the framing should be around the governance the PAG would like to see based on the level of granularity of the data, not just on the level of granularity that they are comfortable with.
- IAG members still have concerns around the ambiguity of the scope and the questions that have been posed. T&T and the consortium acknowledged that more work needs to be done to now flesh out the detail of the proposed areas and the associated questions to take to the PAG. The next phase of work will be to delve into these policy areas in more detail, updating the overall design, and then developing the detailed materials which the IAG will review.
- A question was raised about whether contact tracing is focused on just digital contact tracing which is what is described in the note (see appendix), or whether manual contact tracing is to be included. T&T replied that all contact tracing is to be considered, and that the language will be changed to reflect this.
- The consortium agrees to write to IAG members in the next week with regards to next steps and a revised timetable for meetings. If the IAG have preferences in terms of meeting times, ways of communicating etc. please feedback via email.
- There wasn't time to sign off the Terms of Reference and so it was agreed that the group will share any comments on the Terms of Reference via email with the view to making any changes and signing off at the next meeting.

## Appendix

The below note was sent around to the IAG ahead of the meeting to outline the revised topics that T&T are proposing the PAG focuses on. The purpose of the meeting was to update the IAG on the proposed areas of focus for the PAG, gain their input on design and outline the next steps.

### Wastewater

#### Key question:

What level of granularity should we be using for wastewater testing (building, street, sewage system, post-code, local authority)?

#### Context:

300,000 population level is so big a signal it's not actionable or useful to anyone, but three houses seem too individualistic. So, what IS the right scale and unit of measurement?

T&T currently operates at 'community scale' i.e., uses community level data and wants to understand how far the public are comfortable with going in terms of more granularity for wastewater testing, which could be an alternative to ongoing and permanent mass-testing going forward. There are clear policy options (i.e., differing levels of granularity) that can be provided for this, with implications for individuals and society, including the benefits and drawbacks for each.

T&T also has an interest in understanding what the public views on bio-banking are i.e. how these samples, or ongoing wastewater testing, could be used in future for other uses (e.g. chemical testing) given that the infrastructure may well be in place.

Points of nuance to be covered in deliberation:

- Resourcing – is this the best use of resource over other mechanisms to manage health risk e.g., regular mass testing? The more granular T&T goes, the more resource it takes.
- Legitimacy v. usefulness – the more granularity, the more difficult it is to say with certainty that the evidence is correct. The less granularity, the less useful it is to anyone.
- Invasiveness – what would each layer of granularity mean for individuals (noting that wastewater sampling cannot provide individually identifiable data), and what implications will that have during the pandemic and in the future?

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### Contact tracing

#### Key question:

What more could we be doing to enhance the effectiveness of contact tracing, and what would enable people to feel comfortable providing more data/having less anonymity?

#### Context:

Collecting data manually for contact tracing can be burdensome and unreliable but doing it fully automatically could feel like violating personal space. What is the right balance of personal and public responsibility when we are finding out who could have been infected?

When someone tests positive, having been for a test and provided their details, they are told to self-isolate. They are signposted to support and are also asked who they have been in contact with, and for those people's details. Despite the potential to stop more people being infected, we know some people might not want to participate in this discussion or be guarded about some of the facts. And it is a lot of effort for the participant at a very inconvenient time. T&T has an interest in two aspects here: it wants to understand what could help change people's attitude to contact tracing, and it wants to know whether, if it did some of the work for people, that would help.

For instance, some of the ways we could reduce the effort for the individual – all of which rely on consent from individuals, and assume a transparent explanation of what data would be used and why – could be:

- Reaching out to contacts of contacts – is this invasive? Would people think the NHS had permission to do this, or would be right to do it even if they did? The more people T&T reaches, the more chance to stop them being infected.
  - Retrieving their history of venue check-ins (from scanned QR codes) automatically – when Apple and Google set the app rules a year ago, this was banned. Have our attitudes changed since then? Would this help or hinder people from sharing data?
  - Personalising communication based on linked data from their health record – e.g., where they live, how old they are, or even communicating via a local connection (e.g., your GP) – the more personal the outreach, the more likely people are to respond to it.
  - Making data sharing a legal obligation, like self-isolating – would this have negative effects? Would it impact some communities more negatively than others?
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