

# **Citizens' Jury on QCovid<sup>®</sup>**

## **Report on the jury's conclusions and key findings**

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**Scottish Government**  
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# **Citizens' Jury on QCovid®**

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## Acknowledgements

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# Executive Summary

## Introduction

The QCovid® risk model was developed at the University of Oxford in 2020 to provide a sophisticated way of identifying people who were at the highest risk of death or a poor outcome should they contract Covid-19.

There are four main ways of using QCovid® that have been explored by the Scottish Government to date. These are referred to as ‘tools’ or ‘use cases’ and include:

- a clinical tool (for use by clinicians such as GPs to determine patient risk)
- a public-facing tool (for use by general public to determine their own risk)
- a population tool using non-anonymised data at the population level (to identify and notify people at high risk)
- a population tool using anonymised data at the population level (to inform planning and resourcing)

The Scottish Government recognised that there could be ethical issues associated with any use of a risk prediction model like QCovid®, but particularly in running one through large datasets of personal health information.

As part of the Scottish Government’s commitment to ensuring open, honest and transparent government, Ipsos Scotland was commissioned to conduct a Citizens’ Jury to better understand the public’s views on the use of a risk prediction model like QCovid®.

This work was overseen by an independent Ethics Panel which included external advisors with expertise in the use of ethics and data. The findings will feed into any wider assessment should the Scottish Government use a model like QCovid in the future to ensure that ethical considerations are at the heart of how any risk prediction models are deployed.

## Objectives and methodology

The objectives of the jury were to explore attitudes towards QCovid® and similar risk prediction models and the different ways in which they could be deployed. The public engagement aimed to understand specifically:

- any ethical concerns around deploying a model like QCovid® in different ways, particularly running the risk model through population level health records
- any ethical concerns around deploying a model like QCovid® in different scenarios

- any circumstances or scenarios when the public benefits of using QCovid® would outweigh private concerns over the use of personal data

The jury of 25 people representing a cross-section of the population from across Scotland met online across six three-hour workshops throughout February and March 2022. The jury was convened to answer the following key question:

**“What are the risks and benefits of using public health data to predict people’s risk of dying from Covid-19?”**

More specifically, they explored the risks, benefits and ethical concerns related to each potential use of a model like QCovid®, and the principles that would make its use acceptable.

## Main findings

Having learned about QCovid® as an example of a risk prediction model, and deliberated its relative risks and benefits, some clear themes emerged which cut across each of the tools. These were:

### Efficacy and accuracy

The jury generally felt reassured by the fact that the QCovid® model had been extensively validated by experts. There remained some concerns over the completeness of the data underlying the QCovid® model and the impact of gaps in medical records - such as information on ethnicity or through some health conditions not being known to the GP - potentially leading to inaccurate scores. The jury therefore emphasised the need for QCovid® or a similar model to be kept up-to-date and capable of adapting to changing circumstances such as new variants or booster vaccines.

### Data security

The jury recognised that there were clear protocols in place for accessing public health data and felt that data security should be in place for any use of the model, but particularly when using non-anonymised data at the population level.

### Transparency and communication

The reasons for applying a risk prediction model were understood and generally accepted by the jury. However, it was strongly agreed that clear communication would be necessary for informing the general public about the rationale for using QCovid® or similar risk prediction models in Scotland and explaining how this is done. This level of transparency was considered important for building public trust in the model.

### Targeted support

There was clear consensus among the jury that sufficient and targeted support mechanisms must be in place. These mechanisms would need to include emotional support (particularly for those receiving a high score), support to interpret what the score means, and practical support to help people take appropriate action.

## Justification

Attitudes towards risk prediction models could vary depending on the status of a virus like Covid-19. For example, in a low prevalence situation, there was a view that a clear rationale from the Scottish Government would be needed to justify its use.

As well as these overarching themes, the jury agreed principles and “red lines” for each of the four tools (summarised below). The principles act as guidance for the Scottish Government to consider if implementing the particular tool, while “red lines” are points that in their opinion, if crossed, would in the jury’s opinion make the use of this tool unacceptable. These principles can be applied to future, similar, tools.

## Clinical tool

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"><li>• Information is provided to explain to patients what the tool is and how it will be used</li><li>• There is clear communication on the use of the tool</li><li>• Practical and emotional support is provided to help patients according to their risk score.</li><li>• GPs or other healthcare professionals can help patients understand their risk score.</li><li>• GP resources are not placed under too much burden.</li><li>• GPs or other healthcare professionals are trained to use the tool effectively.</li><li>• Patients have the option to ask for their score and to refuse the option to discover their score.</li><li>• Results are confidential.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk and vice versa.</li></ul>	<ul style="list-style-type: none"><li>• It collects personal information which is not needed for the tool to work.</li><li>• The data is kept after you’ve received your score.</li><li>• If it detracts from GPs’ ability to address other, more critical, health needs.</li><li>• If your score is shared with other parties (i.e., anyone other than your GP) without your consent.</li></ul>

## Public-facing tool

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"><li>• There is sufficient support in place to help people understand their risk score.</li><li>• It is accessible (e.g., alternative formats – language translations, large print, braille or text to speech, and simple language).</li><li>• There are alternative ways of accessing the score for those who are not online or who require additional support.</li><li>• There is clear, simple guidance for using the tool and there are consequences for misuse.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li></ul>	<ul style="list-style-type: none"><li>• There is not adequate support in place to help people understand their score.</li><li>• It is introduced on its own without the clinical tool being available</li><li>• There is no alternative for people excluded from using an online tool.</li><li>• The information an individual inputs can be accessed and/or used by anyone else.</li><li>• Identifiable information is requested and/or stored.</li><li>• It doesn't reach everyone who needs it.</li><li>• There is any obligation for people to pass on information about their risk score.</li><li>• It cannot be guaranteed that the data put in is accurate.</li></ul>

## Population-level tool using non-anonymised data

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"><li>• There is sufficient targeted support in place to help people at high risk.</li><li>• There is clear information about the sources of support available and the support is easy to access</li><li>• Information about the use of the tool is available and clearly communicated to the general public.</li><li>• The score is confidential to the individual, with no legal requirement to share.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li><li>• There is a mechanism to challenge or change the outcome.</li><li>• There are data security protocols in place.</li></ul>	<ul style="list-style-type: none"><li>• Data about individuals is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.</li><li>• There is not adequate ongoing support in place to help people who are identified as being at high risk.</li><li>• The data is not held securely.</li><li>• The risk to public health from Covid-19, or another virus, at the time is minimal.</li><li>• It is used to discriminate against individuals (e.g., in the workplace or in accessing services such as insurance).</li></ul>

## Population-level tool using anonymised data

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"><li>• Information about the tool is available and clearly communicated to the general public.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk and vice versa</li><li>• The data is agile and able to adapt should new situations arise.</li><li>• The data is to be used by Scottish Government and NHS Scotland only.</li><li>• There are data security protocols in place.</li></ul>	<ul style="list-style-type: none"><li>• Data is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.</li><li>• Data is not protected from commercial companies accessing it.</li><li>• There is any collaboration with data farm companies.<sup>1</sup></li><li>• It is used to discriminate against certain groups (e.g., being denied access to certain services based on age or ethnicity).</li></ul>

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<sup>1</sup> Data farms are physical buildings that house a collection of processors or server infrastructure in one central location. Some companies create their own data farms to gather large amounts of data.

# 1. Introduction

## Background

### Development of the QCovid® model

At the beginning of the pandemic, the four Chief Medical Officers (CMOs) from across the UK identified people they believed were at the highest risk from Covid-19 based on a number of health conditions<sup>2</sup>. People who were identified through this process were placed on what became known as the ‘shielding list’ or the ‘highest risk list’ and asked to strictly self-isolate and minimise contact with other people.

Once there was more medical and other relevant evidence about Covid-19, the four CMOs asked the University of Oxford to develop a more sophisticated way to identify people who were at the highest risk of death or a bad outcome from Covid-19. The University developed a risk model, called QCovid®, that used a range of factors such as age, sex, ethnicity and existing medical conditions to predict an individual’s cumulative risk of hospitalisation and/or death from Covid-19.<sup>3</sup>

### The four QCovid® tools

There are four main ways of using QCovid® that have been explored by the Scottish Government to date. These are referred to as ‘tools’ or ‘use cases’ and include:

**Clinical tool:** an online tool which would be available to GPs and clinicians to determine patient risk. They would sit with a patient and enter the patient’s data into the tool to generate a risk score. Patients with a high risk score could then be added to the highest risk list by their GP.

**Public-facing tool:** available to the public online. An individual could enter their own data and a risk score would be generated by the QCovid® model.

**Population tool (using non-anonymised data):** running the risk model through health records at a national level to identify all those individuals at the highest risk. Anyone identified in this way would be informed that they were at high risk and could be added to the highest risk list.

**Population tool (using anonymised data):** running QCovid® through anonymised health records at a national or regional basis. This would not identify actual individuals at risk but would allow governments and health boards to see how many people in a certain area were at risk for research and planning purposes.

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<sup>2</sup> Full list of conditions is outlined by Public Health Scotland at [https://publichealthscotland.scot/media/3249/1\\_covid-19-search-criteria-highest-risk-patients.pdf](https://publichealthscotland.scot/media/3249/1_covid-19-search-criteria-highest-risk-patients.pdf)

<sup>3</sup> Full description of the QCovid® is available at <https://QCovid.org/>

## Use of QCovid® in England

In February 2021, the UK Government used QCovid® in order to identify people who should be prioritised for the first Covid-19 vaccines in England. They ran QCovid® through health records at a national level to identify which individuals were at the highest risk from Covid-19. Those individuals were then placed on England's shielding list and received a vaccine ahead of people who were deemed to be less vulnerable.

At the same time, the UK Government developed and gave GPs access to a clinical tool based on QCovid®. This allowed GPs in England to check an individual patient's risk from Covid-19 and add anyone with a high risk score to the shielding list.

A timeline summarising the development and use of QCovid® is shown in Figure 1 overleaf.

## Potential use of QCovid® in Scotland

The Covid Highest Risk Division within the Population Health Directorate at the Scottish Government considered ways to identify individuals at high risk from Covid-19 by deploying QCovid®. The clinical and public-facing tools based on QCovid® were considered for development, but in early 2022 it was decided not to proceed with either of those. This decision was largely based on concerns that QCovid® did not take account of vaccine boosters or the Omicron variant. The Scottish Government is still considering whether to use QCovid®, or a similar model, at a population level if it was updated to take account of vaccine boosters and the effect of the Omicron variant.

The Scottish Government recognised that there would be ethical issues associated with any use of a risk prediction model like QCovid®, but particularly in running one through large datasets of personal health information. As part of the Scottish Government's commitment to ensuring open, honest and transparent government, Ipsos Scotland was commissioned to conduct a Citizens' Jury to better understand the public's views on the use of a risk prediction model like QCovid®.

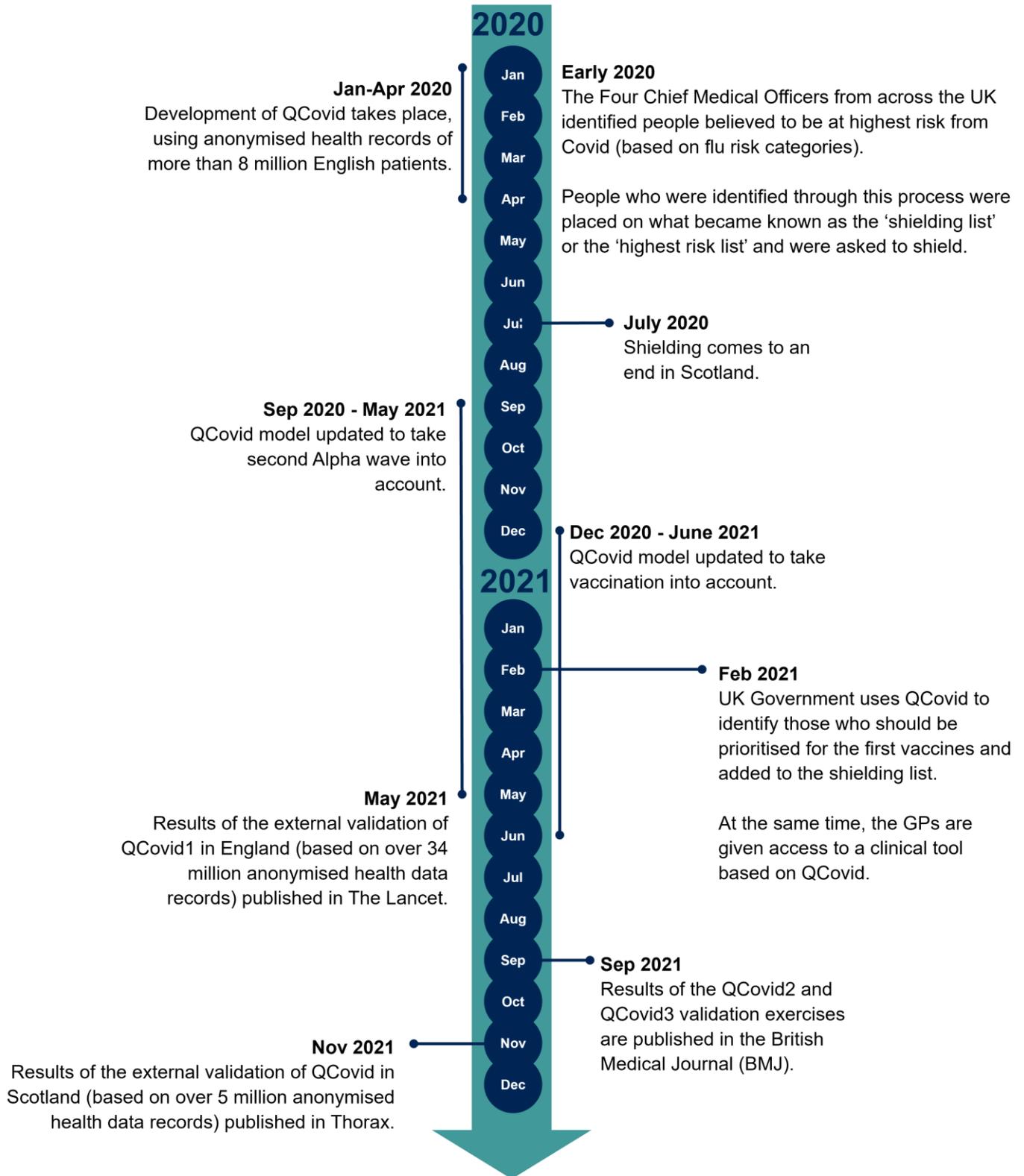
## Objectives

The objectives of this public engagement were to explore attitudes towards QCovid®, and similar risk prediction models, and the different ways in which they could be deployed. The public engagement aimed to understand specifically:

- any ethical concerns around deploying a model like QCovid® in different ways, particularly running the risk model through population level health records.
- any ethical concerns around deploying a model like QCovid® in different scenarios (such as the emergence of a new variant of Covid-19 that is resistant to current vaccines; a waning of current vaccines against existing variants; or low prevalence rates of Covid-19 in a world where vaccines are effective).

- any circumstances or scenarios when the public benefits of using QCovid® would outweigh private concerns over the use of personal data.

Figure 1: image showing timeline of QCovid® development



## 2. Methodology

### Overview

To understand the views of the public towards QCovid® and similar risk prediction models, Ipsos designed and facilitated a Citizens' Jury. A Citizens' Jury brings together a randomly selected group of people who broadly represent the entire community. The people who attend listen to evidence from a range of experts, learn about key issues, discuss them with one another, and then deliberate and draw conclusions together.

The jury of 25 people from across Scotland met online across six three-hour workshops throughout February and March 2022. The jury was convened to answer the following key question:

**“What are the risks and benefits of using public health data to predict people’s risk of dying from Covid-19?”**

More specifically, they explored the risks, benefits and ethical concerns related to each potential use of a model like QCovid®, and the principles that would make its use acceptable.

### Ethics Panel

An independent Ethics Panel was established to advise the Scottish Government on its ethical assessment of QCovid®. It was agreed by the ethics panel that an essential component of the ethical assessment was understanding how the public viewed the use of a risk prediction model such as QCovid® in Scotland. The panel also provided a check and challenge to the process, ensuring that the methodological design was appropriate, relevant, robust and accessible.

The Ethics Panel was made up of one Scottish Government official as well as academics and specialists independent to the commissioning and convening organisations. A list of Ethics Panel members can be found in the appendix (see page 49).

### Sampling and recruitment

The Sortition Foundation,<sup>4</sup> a recruitment organisation specialising in representative random sampling, conducted the recruitment for the Citizens' Jury by sending out 6,000 invitation letters across Scotland, using the Royal Mail Postcode Address File. Those living in more deprived areas were over-sampled to account for the lower response rates that are typically found in these areas. The full recruitment report can be found on the Sortition Foundation's website.<sup>5</sup>

Based on all those who registered their interest in joining the jury, a randomised stratified selection process then took place that broadly reflected the demographics

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<sup>4</sup> <https://www.sortitionfoundation.org/>

<sup>5</sup> [https://www.sortitionfoundation.org/QCovid®\\_2022\\_report](https://www.sortitionfoundation.org/QCovid®_2022_report)

of Scotland, including age, gender, region, ethnicity, disability and deprivation (based on the Scottish Index of Multiple Deprivation, SIMD).<sup>6</sup> Ethnic minority groups were over-sampled at the selection stage to ensure sufficient representation of these groups. An additional measure was also included in the selection process to ensure a range of views were represented in terms of attitudes towards personal health data use by the Scottish Government.

Overall, 30 people were selected from the members of the public who registered to participate (allowing for some dropping out before or during the process). A table summarising the demographic profile of the final selected and confirmed sample can be found in the appendix (see pages 50-52).

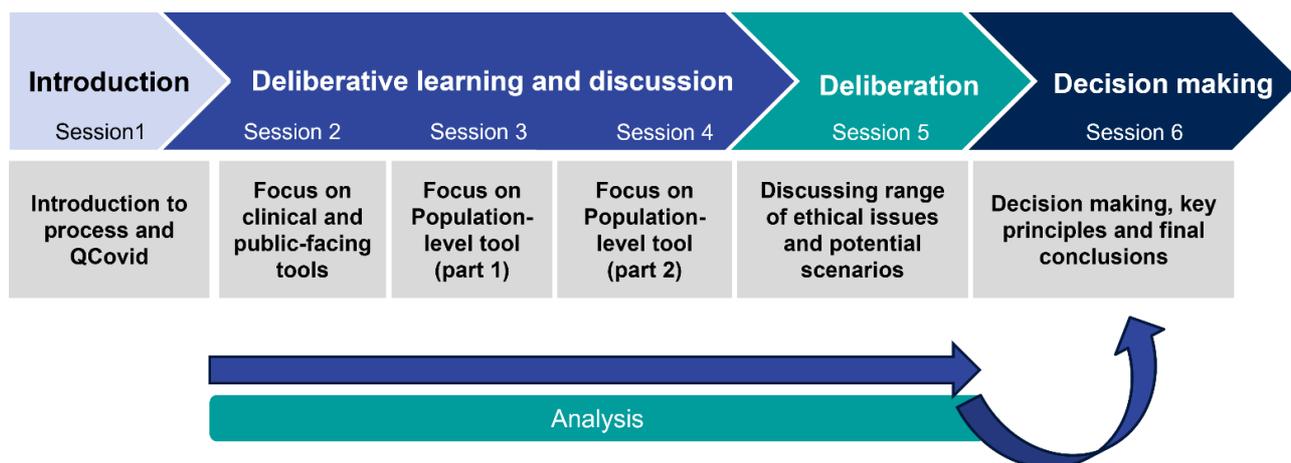
Once recruited, participants were onboarded by the Ipsos research team. To support and enable participation in all workshops, and in line with industry standards, participants were each paid £50 per workshop, resulting in a total of £300 for full participation. Where necessary, participants were provided 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.

### Jury process and structure

The QCovid® Citizens’ Jury was grounded in recognised industry best practice and followed key principles of deliberative engagement. More information on these principles can be found in Ipsos UK’s best practice guide, developed in partnership with experts in the field, such as Imperial College and Involve.<sup>7</sup>

The jury comprised six online Zoom sessions scheduled over four weeks in February and March 2022 (summarised in Figure 2).

**Figure 2 – Summary of the Citizens’ Jury structure and format**



During the learning and deliberation phase of the jury, participants learned about each of the QCovid® tools in turn: the clinical tool, the public-facing tool, the

<sup>6</sup> <https://simd.scot/#/simd2020/BTTTTFTT/9/-4.0000/55.9000/>

<sup>7</sup> <https://www.ipsos.com/en-uk/deliberative-engagement-best-practice-guide>

population tool using non-anonymised data, and the population tool using anonymised data. For each of the tools, expert speakers delivered presentations to introduce the tool and outline the key considerations of each. After each presentation, members moved into small breakout groups to discuss and reflect on what they had learned. In the breakout discussions, members agreed on clarification questions which were then answered by the speakers in the main plenary, or via a Question and Answer (Q&A) document which was shared with participants on an ongoing basis with written responses provided by the speakers, the Scottish Government and Ipsos.

Sessions two to six each began with the chair reflecting on what participants had discussed in their groups at the previous workshop. This provided a space for participants to reflect on where they had got to, along with discussions they had had with friends and family. Stimuli was in the form of presentations, Q&A sessions, and case studies. The range of stimuli supported participants to reflect on their own experiences, as well as to consider relevant situations and experiences different from their own.

Based on rapid analysis of the discussions by the research team, and reviewed by facilitators of breakout room discussions, the final session provided participants with draft overarching principles on each of the QCovid® tools 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.

### **Overview of jury sessions**

An overview of each session, including dates, times, content and presentations, is summarised in table 1 overleaf. A list of presenters is provided in the appendix (see pages 57-58).

**Table 1: overview of jury sessions**

	<b>Date/time</b>	<b>Objective</b>	<b>Session description</b>	<b>Presentations</b>
<b>Session One</b>	Saturday 12 <sup>th</sup> February, 10:00-13:00	<p>Introduction to the process and aims of the Citizens' Jury.</p> <p>Introduction to QCovid® and the four tools for deploying it.</p>	Introduced participants to the process and to key aspects of the QCovid® model, ethics around public health data, and the Scottish Government's decisions to date.	<ul style="list-style-type: none"> <li>• Introduction to QCovid®</li> <li>• Introduction to public health data ethics</li> </ul>
<b>Session Two</b>	Thursday 17 <sup>th</sup> February, 18:00-21:00	Clinical and public-facing tools – information provision and initial reflections	Introduction to the clinical tool and the public-facing tool. Participants heard presentations by expert speakers before moving into smaller breakout groups to discuss, reflect on, and raise questions about, what they had heard.	<ul style="list-style-type: none"> <li>• Introduction to the clinical tool</li> <li>• Introduction to the public-facing tool</li> </ul>
<b>Session Three</b>	Tuesday 22 <sup>nd</sup> February, 18:00-21:00	Population-level tool (part 1) – information provision and initial reflections	Introduction to the population-level tool. Participants heard presentations by expert speakers before moving into smaller breakout groups to discuss, reflect on, and raise questions about, what they had heard.	<ul style="list-style-type: none"> <li>• Introduction to the population-level tool</li> <li>• Applying the population tool (vaccination prioritisation example)</li> <li>• Considerations for using the population tool in an anonymised or non-anonymised way</li> </ul>
<b>Session Four</b>	Thursday 24 <sup>th</sup> February, 18:00-21:00	Population-level tool (part 2) – further exploration using scenarios	The jury considered the use of the population tool (both in terms of anonymised and non-anonymised use) and discussed the extent to which the tool would be acceptable or unacceptable in a range of scenarios, such as a new variant, waning vaccine effectiveness and low prevalence, as well as the current situation (at the time of fieldwork).	<ul style="list-style-type: none"> <li>• Data security protocols in relation to public health data</li> </ul>

<b>Session Five</b>	Tuesday 1 <sup>st</sup> March, 18:00-21:00	Deliberation and forming key ethical principles	The jury continued their deliberations on each of the four tools via two exercises: 1. Exploring the impact of each tool through case studies. 2. Assessing the risk/benefit of each tool. A more detailed overview of these exercises can be found in the appendix (see page 59-63).	<ul style="list-style-type: none"> <li>Recap on ethics in relation to public health data</li> </ul>
<b>Session Six</b>	Tuesday 5 <sup>th</sup> March, 10:00-13:00	Reaching conclusions	Based on rapid analysis of the discussions by the research team, and reviewed by facilitators of breakout room discussions, the final workshop provided participants with draft overarching principles on each of the QCovid® tools, for review and ratification in breakout rooms. Any edits made in breakout groups were then presented back to the whole jury in plenary.	No presentations

## Materials

Materials were developed by Ipsos and approved by the Scottish Government. Presentations were developed and recorded in advance by expert speakers and then recordings were played back live during the main plenary sessions and the speakers joined the sessions to answer questions from participants. Any questions that were not answered during the session were compiled in the Q&A document. Presentation recordings were hosted on YouTube and shared via private links for members to watch again in their own time.

## Interpretation of findings

The principles set out and discussed in this report are intended for consideration in the possible future use of QCovid® or similar risk models by the Scottish Government.

This exercise supported participants to express a range of views on the tools which QCovid® or similar risk models could deploy, and of their expectations and understanding of the ethical considerations in relation to using public health data in this way. 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 the tools. These are not intended as authoritative statements of fact, but even when misaligned to the ways in which QCovid® has or

would work in practice, they tell us something valuable about how key messages, support, or services can be perceived and understood by members of the public.

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), 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 public perceptions of the risks and benefits of QCovid®, and the ethical considerations that resonate most.

## **Report structure**

The following chapter summarises the overarching themes which cut across the whole of the jury's discussions on QCovid®, as well as the specific principles relating to each tool. The subsequent chapters detail the findings related to the individual tools. In each of these chapters we provide a brief overview of the content presented to the jury, followed by a summary of the ratified principles and a summary of the discussion points - risks, benefits and ethical considerations - which led to these principles. Relevant quotes and screenshots from the fieldwork are used to reflect the discussions held throughout the workshops.

### 3. The jury's conclusions

The deliberative discussions of the Citizens' Jury facilitated a genuine conversation that empowered participants to explore the levels of acceptability of risk prediction models such as QCovid®, and the different tools that could be deployed. These discussions were analysed and presented back to participants as principles and “red lines”, with principles being guidance for Scottish Government to use if implementing this particular tool, and “red lines” being lines that, if crossed, would make the use of this tool unacceptable. These principles and red lines can be applied to future, similar, tools.

#### Overarching themes: QCovid® model and use of health data for risk prediction models

Prior to their involvement in the Citizens' Jury, participants generally had low awareness of how public health data had been used in the Scottish Government's management of Covid-19. Nonetheless, there was a sense of reassurance about the Scottish Government's use of data and evidence to inform decision-making and planning related to the pandemic.

*“[The Scottish Government's] expediency in making decisions and not being too quick to reverse decisions. It always reassured the public they were using science and not other factors, like economics.”*

*(Participant in session 1)*

Having learned about QCovid® as a risk prediction model, and deliberated its relative risks and benefits, some clear themes emerged which cut across each of the tools. These were:

#### Efficacy and accuracy

The jury generally felt reassured by the fact that the QCovid® model had been extensively validated by experts. There remained some concerns over the completeness of the data underlying the QCovid® model and the impact of gaps in medical records - such as information on ethnicity or through some health conditions not being known to the GP - potentially leading to inaccurate scores. The jury therefore emphasised the need for QCovid® or a similar model to be kept up-to-date and capable of adapting to changing circumstances such as new variants or booster vaccines.

#### Data security

The jury recognised that there were clear protocols in place for accessing public health data and felt that data security should be in place for any use of the model, but particularly when using non-anonymised data at the population level.

#### Transparency and communication

The reasons for applying a risk prediction model were understood and generally accepted by the jury. However, it was strongly agreed that clear communication would be necessary for informing the general public about the rationale for using

QCovid® or similar risk prediction models in Scotland and explaining how this is done. This level of transparency was considered important for building public trust in the model.

### Targeted support

There was clear consensus among the jury that sufficient and targeted support mechanisms must be in place. These mechanisms would need to include emotional support (particularly for those receiving a high score), support to interpret what the score means, and practical support to help people take appropriate action.

### Justification

Attitudes towards risk prediction models could vary depending on the status of a virus like Covid-19. For example, in a low prevalence situation, there was a view that a clear rationale from the Scottish Government would be needed to justify its use.

The principles and “red lines” for each tool, edited directly by participants in four breakout groups in the final workshop, are summarised below. The full wording, as well as the edits made by each group, can be found in the appendix (see pages 84-87).

## Clinical tool

<b>Principles: Use of the tool is acceptable if...</b>	<b>Red lines: Use of the tool is unacceptable if...</b>
<ul style="list-style-type: none"><li>• Information is provided to explain to patients what the tool is and how it will be used.</li><li>• It is communicated why this tool is available.</li><li>• Practical and emotional support is provided to help patients according to their risk score.</li><li>• GPs (or other healthcare professionals) can help patients understand their risk score.</li><li>• GP resources are not placed under too much burden.</li><li>• GPs (or other healthcare professionals) are trained to use the tool effectively.</li><li>• Patients have the option to ask for their score (and to refuse the option to discover their score).</li><li>• Results are confidential.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li></ul>	<ul style="list-style-type: none"><li>• It collects personal information which is not needed for the tool to work.</li><li>• The data is kept after you've received your score.</li><li>• If it detracts from GPs' ability to address other, more critical, health needs.</li><li>• If your score is shared with other parties (i.e., anyone other than your GP) without your consent.</li></ul>

## Public-facing tool

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"> <li>• There is sufficient support in place to help people understand their risk score.</li> <li>• It is accessible (e.g., alternative formats – language translations, large print, braille or text to speech, and simple language).</li> <li>• There are alternative ways of accessing the score for those who are not online or who require additional support.</li> <li>• There is clear, simple guidance for using the tool and there are consequences for misuse.</li> <li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li> </ul>	<ul style="list-style-type: none"> <li>• There is not adequate support in place to help people understand their score.</li> <li>• It is introduced on its own (without the clinical tool being available).</li> <li>• There is no alternative for people excluded from using an online tool.</li> <li>• The information an individual inputs can be accessed and/or used by anyone else.</li> <li>• Identifiable information is requested and/or stored.</li> <li>• It doesn't reach everyone who needs it.</li> <li>• There is any obligation for people to pass on information about their risk score.</li> <li>• It cannot be guaranteed that the data put in is accurate.</li> </ul>

## Population-level tool (using non-anonymised data)

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"> <li>• There is sufficient targeted support in place to help people at high risk.</li> <li>• There is clear information about the sources of support available and that support is easy to access</li> <li>• Information about the use of the tool is available and clearly communicated to the general public.</li> <li>• The score is confidentially to the individual, with no legal requirement to share.</li> <li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li> <li>• There is a mechanism to challenge or change the outcome.</li> <li>• There are data security protocols in place.</li> </ul>	<ul style="list-style-type: none"> <li>• Data about individuals is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.</li> <li>• There is not adequate ongoing support in place to help people who are identified as being at high risk.</li> <li>• The data is not held securely.</li> <li>• The risk to public health from Covid-19, or another virus, at the time is minimal.</li> <li>• It is used to discriminate against individuals (e.g., in the workplace or in accessing services such as insurance).</li> </ul>

## Population-level tool (using anonymised data)

Principles: Use of the tool is acceptable if...	Red lines: Use of the tool is unacceptable if...
<ul style="list-style-type: none"><li>• Information about the tool is available and clearly communicated to the general public.</li><li>• The tool is kept up to date in case of people moving from low risk to high risk (and vice versa).</li><li>• The data is agile and able to adapt as new situations arise.</li><li>• The data is to be used by Scottish Government and NHS Scotland only.</li><li>• There are data security protocols in place.</li></ul>	<ul style="list-style-type: none"><li>• Data is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.</li><li>• Data is not protected from commercial companies accessing it.</li><li>• There is any collaboration with data farm companies.<sup>8</sup></li><li>• It is used to discriminate against certain groups (e.g., being denied access to certain services based on age or ethnicity).</li></ul>

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<sup>8</sup> Data farms are physical buildings that house a collection of processors or server infrastructure in one central location. Some companies create their own data farms to gather large amounts of data.

## 4. Clinical tool

The clinical tool is a tool which could be used by GPs (or other healthcare professionals) who would enter a patient's data into an online form to view their risk score, which would be generated using the QCovid® model. In 2021, the UK Government had developed and given GPs access to a clinical tool based on QCovid®. Participants viewed a demonstration of the tool as an example of how it would work in practice in session two, following a presentation by an expert speaker (Professor Aziz Sheikh from the University of Edinburgh) who introduced the clinical tool.

Following exploration, Q&A, and discussions in session two, participants deliberated on the clinical tool, discussing the key risks, benefits, and ethical considerations in relation to it before drawing their conclusions on what would make use of the tool acceptable or unacceptable.

Initially, participants were surprised by how much personal information was needed to get the score. They were generally positive, but also surprised that the public is not more aware of this tool already being used in England. As participants deliberated, there was some (occasional but noteworthy) confusion expressed over whether the data inputted would provide information for the QCovid® model, and some interest in whether this tool could be used in combination with the non-anonymised population tool to identify people who need support.

**Nevertheless, the jury concluded that the use of such a tool in Scotland, as part of the QCovid® model or a similar risk model, would be acceptable if:**

- Information is provided to explain to patients what the tool is and how it will be used.
- It is communicated why this tool is available, including via GPs (or healthcare professionals) to flag that it is available when with a patient.
- Practical and emotional support is provided to help patients according to their risk score.
- GPs (or other healthcare professionals) can help patients understand their risk score.
- GP resources are not placed under too much burden (which may involve outsourcing to relevantly trained health professionals rather than GPs).
- GPs (or other healthcare professionals) are trained to use the tool and interpret and communicate the results effectively.
- Patients have the option to ask for their score (and to refuse the option to discover their score).
- Results are confidential.

- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. a new variant).

### **The use of a clinical tool was deemed to be unacceptable if:**

- It collects personal information which is not needed for the tool to work.
- The data is kept after you've received your score (although it was acknowledged that the QCovid® clinical tool does not retain data).
- If it detracts from GPs' ability to address other, more critical, health needs.
- If your score is shared with other parties (i.e., anyone other than your GP) without your consent.

### **Risks and benefits**

Through in-depth deliberation, the key risks identified for use of this tool were:

- **GP resource** – participants were concerned about the burden this tool could put on GP time, and that this could take away from other priorities and ultimately not provide enough in terms of a cost-benefit assessment for public health.
- **Availability of support** – while participants considered a benefit to be the offer of support, they also felt there is a significant risk that the availability of support would not be able to meet demand.
- **Accessibility** – participants were mindful that trust in GPs varies and so this may not be an accessible tool for all. They also expressed concerns about the risks associated with visiting a GP during a pandemic (if face-to-face).

The key benefits identified for use of this tool were:

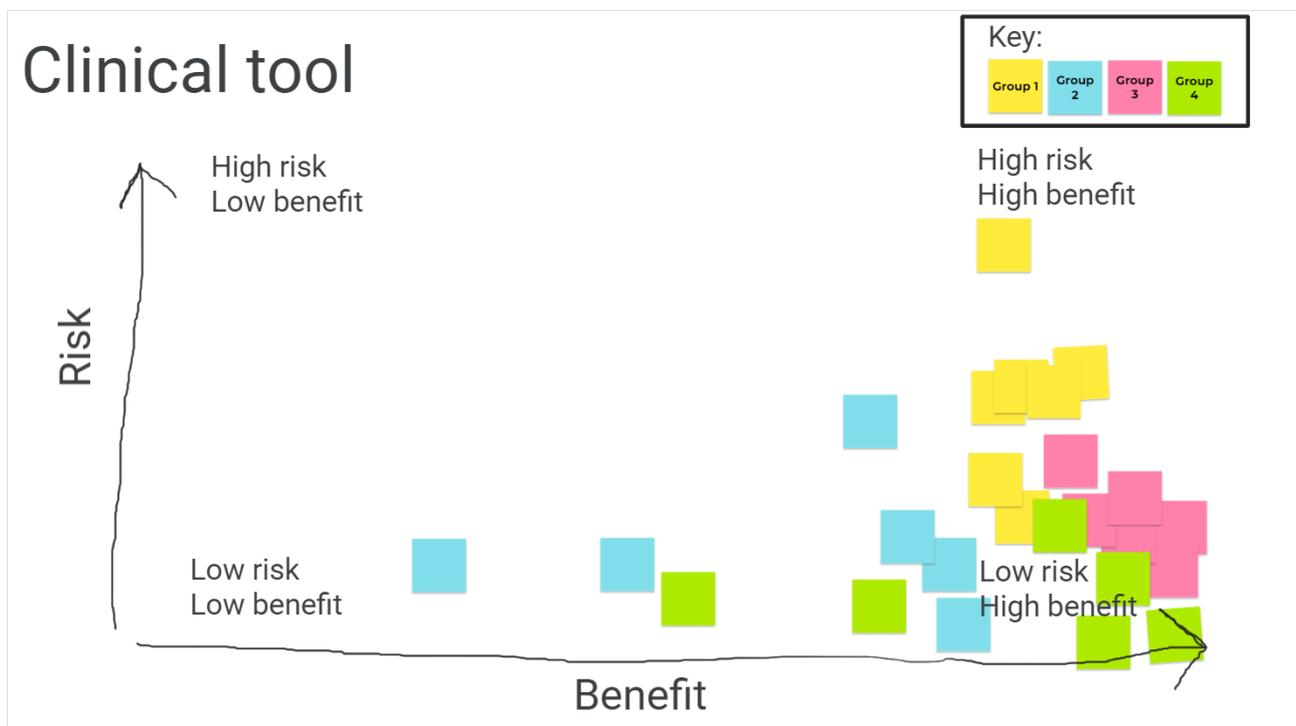
- **Support** – particularly in comparison with the public-facing tool, a key benefit was seen to be the availability of support and guidance on receiving the score as a GP, with a duty of care, would be present when the patient received their score (this was seen to be particularly important if the patient received a high-risk score). In comparison to the public-facing tool, participants valued the input of a medical professional who could accurately interpret the score and guide patients on what actions they should take.
- **Confidentiality** – participants were confident (more so than for the public-facing tool) that the information provided, if it was to be held for a risk prediction model to run, would be kept safely confidential.
- **Accuracy** – participants felt that GPs would have the information collected by the tool already (such as age, postcode and existing health conditions), or could ensure its accuracy while gathering it from the patient if needed, therefore

making it lower risk compared to the public-facing tool (which participants largely felt could produce incorrect results). However, there was some perceived risk that not all GPs would know how to interpret the result.

- **Immediacy** – participants liked that the results could be produced with an immediate professional interpretation, which patients could act on.

On balance, the jury concluded that the clinical tool could be highly beneficial and that the risks are relatively low, given the presence of a medical professional. This is depicted in figure 3, where participants each placed a digital post-it according to their own assessment of the risk-benefit of the clinical tool.

**Figure 3: image showing participants’ assessment of the risk-benefit of the clinical tool (session five)**



## Key ethical considerations

### Accuracy

Participants expressed concerns about accuracy in terms of the QCovid® risk model used, given missing audiences (e.g. pregnant women and younger people) and concerns about how up-to-date the information is. They also expressed concern about the difficulty of keeping data up-to-date and accounting for the complexities of prevalence in a community when giving someone a risk score. Specifically for the clinical tool, they also raised questions and concerns about the accuracy of the information a GP currently holds on a patient, a lack of access to relevant health records (such as cancer treatments) and the implications of peoples changing health status for the accuracy of their score. Overall, it was of high importance to participants that a risk model like QCovid®, which provides a risk score, is kept up to date in order to justify using this tool, particularly in the case of Covid-19 and new variants arising.

*“I could see a GP tomorrow and have a low risk, but then a new variant could come across and then I might be really high. If that data isn’t getting saved anywhere, [would I] have to make an appointment to get another risk factor? Is it just wiped again?”*

*(Participant in session 2)*

## **Confidentiality**

It was important to participants that not only should the risk score be held confidentially in terms of data storage, but also in terms of any pressure or incentive for this information to be passed on to, or used by, other actors such as insurance companies. However, the choice should be given to patients if they want proof of risk level e.g. for their employer.

## **Support**

Participants felt strongly that support should be in place for those informed of being high risk, and that the GP should be able to offer or direct them towards this. It was acknowledged that different levels of support would be needed; immediate emotional support for those receiving a high risk score, and also signposting to practical support for making necessary lifestyle adjustments (such as help with groceries or financial assistance). However, they were concerned this support may not be available to the extent that it would be needed by the high-risk population. Participants highlighted the potential impacts on mental health and behaviour, which underscored the importance of adequate support being in place for patients who are provided with their risk score, particularly if they are high risk.

The GP was viewed as an essential communicator in terms of helping people understand their score, and an essential provider of emotional support and practical guidance. However, there was concern over the burden that this could place on GPs and whether they would receive training on how to use the tool effectively.

*“Everybody has a different perception of risk, [it] is better to have somebody with knowledge there to discuss that at the time.”*

*(Participant in session 2)*

## **Accessibility**

Participants were mindful that trust in GPs varies and so this may not be an accessible tool for all. They also expressed concerns about the risks associated with visiting a GP during a pandemic (if face-to-face) along with broader concerns about those who would not be invited or able to make use of this tool e.g. pregnant women and younger people. They wanted a revision of this, so that access to the benefits of the tool is more open to all. They also reflected on the importance of having telephone options available rather than face-to-face in the scenarios of a new variant, high prevalence or a lockdown, in order for patients to safely utilise this tool.

## Resourcing

Participants felt it important that support to correctly interpret the score, and any actions needed, be provided in order for this tool to provide its benefits, though had significant concerns about resourcing i.e. the impact on GP time and whether this would be worthwhile compared to other uses of GP time. Participants suggested widening the scope to other medical professionals (such as pharmacists), while still providing the benefits of offering support and guidance. They felt that GPs, and by proxy of the previous statement potentially other medical professionals, should be provided with training to ensure they know how to interpret the score and what support to offer.

*“With the time pressure on GPs and the fact people need to make time to go to the GP to talk about it, takes the benefit down. I think there could be more benefit if you could go other places like the pharmacy. That would increase the benefit as there is more access to the clinical tool.”*

*(Participant in session 5)*

## Choice

The importance of personal choice and the use of the tool being driven by a patient (as opposed to a patient simply being given their score, particularly if this could then be used to negatively discriminate against them in some way) was another ethical consideration raised by the jury. This also linked to an interest in focusing on high-risk patients in order to ease resourcing which was met with reservations as conditions and health status is not always known by the GP or could be out-of-date.

## 5. Public-facing tool

### Summary and key principles

The public-facing tool is an online tool which could be used by the general public. With this tool, an individual would enter their data into an online form to view their own risk score, which would be generated using the QCovid® model. A public-facing tool had not been deployed anywhere in the UK at the time of research.

In session two of the Citizens' Jury, members heard from an expert speaker (Professor Alison McCallum from the University of Edinburgh) who introduced the public-facing tool, explaining how it would work and what the key considerations would be for its use. Following exploration, Q&A, and discussions in session two, participants deliberated on the public-facing tool, discussing the key risks, benefits, and ethical considerations in relation to it before drawing their conclusions on what would make use of the tool acceptable or unacceptable. Over the course of deliberation, views on the public-facing tool remained mixed. This was the tool that met the most criticism from participants, with some saying that the risks (particularly the lack of accessibility, susceptibility to misuse and perceived lack of support that would be available) outweighed the benefits.

*“The only people that would use it are people who are following the rules and are interested, and are more engaged to begin with, or people trying to game the system, to get a low score, and use that as a justification. I don't think it would help the people it's intended to help. How I perceive risk, and the actual risk, are different things.”*

*(Participant in session 2)*

**The jury concluded that the use of such a tool in Scotland, as part of the QCovid® model or a similar risk model, would only be acceptable if:**

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, braille or text to speech, and simple language).
- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is clear, simple guidance for using the tool to reduce the risk of misuse, and there are consequences for misuse along with a way to report suspected misuse.

- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. a new variant).

Reflecting the generally negative sentiment towards this tool, there were more issues identified to render the tool unacceptable than was the case for the others.

**The jury concluded that the use of the public-facing tool in Scotland would be unacceptable if:**

- There is not adequate support in place to help people understand their score.
- It is introduced on its own (without the clinical tool being available).
- There is no alternative for people excluded from using an online tool.
- The information an individual inputs can be accessed and/or used by anyone else.
- Identifiable information is requested and/or stored.
- It doesn't reach everyone who needs it i.e. exacerbates inequalities.
- There is any obligation for people to pass on information about their risk score.
- It cannot be guaranteed that the data put in is accurate.
  - Note that the group who deliberated this final “red line” recognised this would not be plausible without a medical professional present, at which point it becomes the clinical tool. They therefore suggested changing the intended use of the public-facing tool to maintain intentions of empowerment but reduce the risk e.g. using the score from a clinician, provided using the clinical tool, to input onto a public-facing tool that provides information about actions that should be taken and how to access support.

## Risks and benefits

As part of their deliberation on the public-facing tool, participants considered the risks and benefits of it, as well as any key ethical concerns.

The key risks identified were that:

- There is a **potential lack of immediate emotional support** for people finding out their score. This was deemed to pose a significant risk to peoples' mental wellbeing, particularly when presented with a high risk score.

- It could be **difficult for people to interpret their score** and understand what it means for them. There was a sense that this could lead to problematic behaviours when receiving a low or high risk score.
- People may input **incorrect information** about themselves and get an incorrect score. It was felt among participants that this could be done deliberately or by accident, which would undermine the usefulness of the tool.
- It **could be misused** to get a score for someone else. For instance, there was one view that an employer could enter information on behalf of an employee which could result in the employee being treated differently.
- The online tool is **not accessible for all groups in society** and might not be used by those who need it. Not having accessible formats was considered to be 'discriminatory' and it was felt that those most likely to benefit from the tool would be least likely to use it, thus widening existing inequalities.
- The **information put into the tool could be hacked**. Although over the course of the jury participants were reassured that the QCovid® public-facing tool would not store any data, this remained a concern for some.

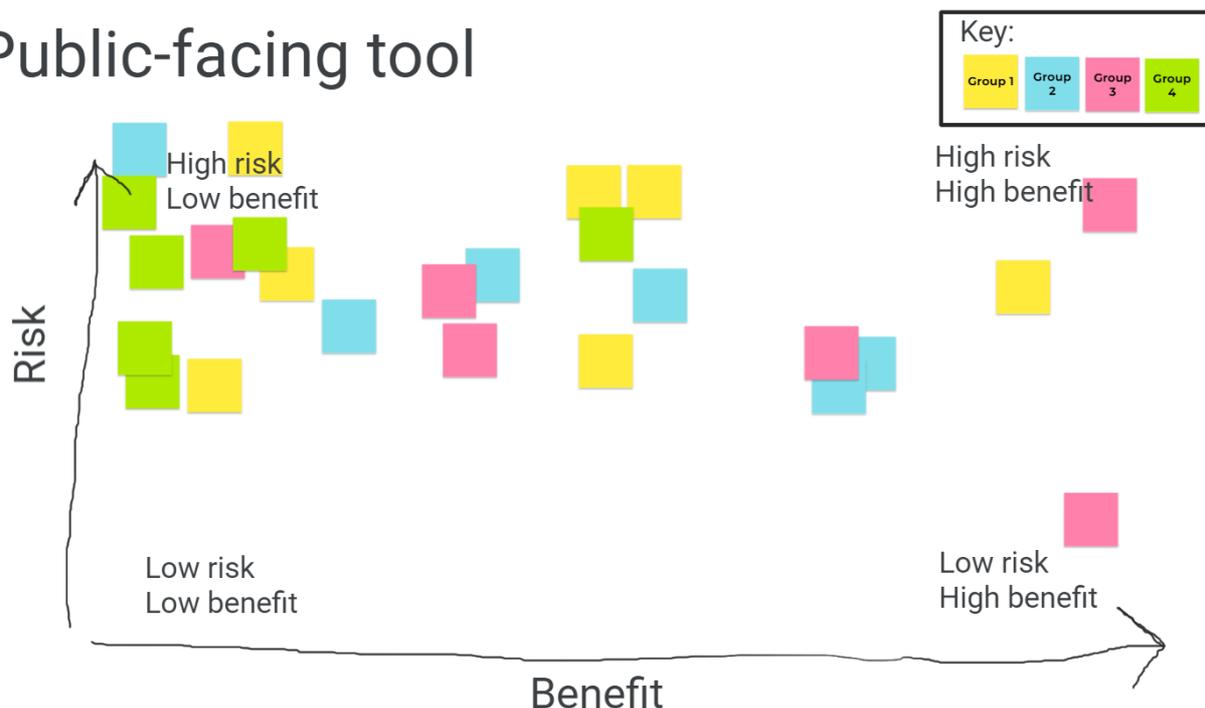
The key benefits of the public-facing tool were that:

- It enables those with access to the internet to find out their score **in private**. One view was that most people have access to the internet nowadays and so it provides a useful alternative to the GP.
- It is **publicly available**. The availability of such a tool was considered to be a benefit because, if well-designed, it could help encourage action. Conversely, there was a sense that not having a tool publicly available could deny someone life-saving information.

On balance, the jury concluded that the public-facing tool presents a number of significant risks and there remained mixed views on the benefits. This is depicted in figure 4 overleaf, where participants each placed a digital post-it according to their own assessment of the risk-benefit of the public-facing tool.

Figure 4: image showing participants' assessment of the risk-benefit of the public-facing tool (session five)

## Public-facing tool



### Key ethical considerations

Having learned more about the public-facing tool, the jury discussed the ethical considerations for QCovid® being deployed in this way. These concerns remained prevalent throughout the jury's deliberation and formed the key principles underpinning the possible use of a public-facing tool in Scotland.

### Availability of support

The availability of support to help people understand and deal with their risk score was the most prominent issue for participants when considering the ethical issues with the public-facing tool. The type of support participants discussed were:

- Emotional support, particularly when receiving a high risk score.
- Interpretative support to help people understand what their score means.
- Practical support to help people take appropriate action based on their risk score.

It was generally felt that receiving a risk score online would have potentially harmful impacts on peoples' mental wellbeing, particularly if being informed that they are at high risk from Covid-19. There was consensus that the risk score would also be subjective and that people would interpret their score in different ways.

*"If it's a good result.. it might make people too confident. 'Oh, I am fine even if I get it' attitude. Even it's not affecting you personally, you can still spread it and I feel like, if they get a good result, it doesn't matter if I get it when you can really affect other people. But if you get a bad result, it can badly affect*

*your mental health and if you do talk to friends and family, it could worry them. It could cause panic or worry in general.”*

*(Participant in session 2)*

Therefore, they felt that a public-facing tool would need to have immediate support available to help people interpret their score and consider their options. For some, this led to the conclusion that the clinical tool would be the most effective way to ensure that people received their score in a supportive environment.

*“There is too much uncertainty and risk. Risk of putting people under stress when they don’t need to be. It’s a GP’s job, not everyone’s job.”*

*(Participant in session 2)*

For one participant, however, the perceived lack of adequate support with the public-facing tool was considered an insurmountable challenge which rendered this tool unworkable.

### **Accessibility and equalities**

Another prominent concern was the lack of accessibility, which participants understood to be a current limitation of the public-facing tool. Without accessible options, such as language translations, large print, text to speech, or alternative formats for those who are not online, it was felt that this tool would be ‘discriminatory’ and would prevent some groups in society from accessing their risk score, such as disabled people, those with learning difficulties and those who are digitally excluded.

*“I would assume by default it would be developed and made more user-friendly already [...] Everybody should have access to it in some way. Either everybody has access or it doesn’t work.”*

*(Participant in session 2)*

Participants also learned about the concept of the inverse care law, which states that those who most need medical care can be least likely to receive it.<sup>9</sup> This raised some concerns among members that a public-facing tool, if used on its own, would not reach the people it needed to and would therefore widen inequalities.

Deployment of the public-facing tool was considered acceptable only if accessible and alternative versions were made available.

### **Protecting against misuse**

The susceptibility of the public-facing tool to misuse was also an ongoing concern for the jury. A common example was the potential for employers to use the tool to find out their employees’ risk scores. For some, this concern was rooted in their

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<sup>9</sup> <https://www.kingsfund.org.uk/publications/articles/inverse-care-law>

own experiences and views of their employers' handling of the pandemic. Another concern was that people might 'game the system' for their own benefit.

Over the course of deliberation, while some questions over this were addressed by the expert speakers through the Question & Answer sessions, reassuring participants to some extent, there remained some concern about the scope for misuse, particularly among employers.

It became important to the jury that there were mechanisms to report suspected misuse and clear consequences for those misusing the tool. The jury also concluded that there should be no obligation for people to pass on information about their score to mitigate against any discriminatory treatment (for example with insurance providers).

### **Accuracy and security**

Early in the deliberations, participants raised concerns about the accuracy of the data being input to the public-facing tool. For instance, someone could generate their risk score without full knowledge of their health status, resulting in them either taking or not taking action based on inaccurate information. This underscored the importance of ensuring that the data input is accurate, although it was acknowledged that this is difficult to control for.

It was suggested by one group that, to mitigate the risk of inaccuracy, the public-facing tool should be designed to support the clinical tool; an individual would find out their risk score via their GP and then could input their score to the public-facing tool for resources and guidance on interpreting and acting on the score.

A related issue was raised around data security. In the early stages of learning about the tools, this concern was largely based on the perception that the public-facing QCovid® tool would store data. Over the course of deliberation, with clarifications provided by speakers to reassure participants that the QCovid® tool would not store data, there was a greater sense of reassurance over data security. However this remained a risk for some participants.

*"If you have a website, there is always a risk - anything that is a website open to the public is open to being closed and copied and information being taken that way."*

*(Participant in session 5)*

## 6. Population-level tool: using non-anonymised data

### Introduction

Using non-anonymised data at the population level would involve running a risk prediction model like QCovid® through health records at a national level to identify those individuals who would be at the highest risk of dying or becoming seriously ill from Covid-19. Anyone identified in this way would then be informed that they were highest risk and could be added to the highest risk list.

Information about this tool was provided to participants in stages. In sessions three and four, participants heard presentations from expert speakers on how QCovid® was used at the population level in England (by Professor Aziz Sheikh) and specifically its use by the JCVI to identify people who should be prioritised for vaccines (by Professor Jeremy Brown). They then heard presentations explaining the potential risks and benefits of using data at the population level (by Dr Helen Stagg), and the current processes in place for collecting and protecting health data (by Professor Alison McCallum). Participants reflected on the presentations and had the opportunity to ask questions.

In sessions five and six, participants deliberated on the tool, including its application for different individuals (who varied in terms their age, health, risk level and attitudes towards data privacy), and under different scenarios related to the pandemic (e.g. a new variant, waning vaccine effectiveness, low prevalence) before drawing conclusions.

### Summary and principles

Views on the use of this tool developed over the course of the jury and it was clear that the process of learning and deliberation had an impact on participants' attitudes. In the early stages of the process, participants were somewhat apprehensive about this tool, raising several questions and concerns about its application in terms of data accuracy, security and potential stigmatisation. In later sessions, they moved to a position of general support for this tool, having had some of their initial concerns addressed. It is important to note, however, that support for this tool was predicated on certain conditions being met.

**The jury concluded that the use of such a tool in Scotland, as part of the QCovid® model or a similar risk model, would only be acceptable if:**

- Information about the tool, including the reasons for using it and what a person should do if they are notified as being at high risk, is available and clearly communicated to the public (without jargon).
- There is sufficient targeted support in place to help people notified understand their risk score and infrastructure in place for people (e.g. for essential items or services).

- There is clear information about the sources of support available and that support is easy to access.
- The score is stored confidentially to the individual with no legal requirement to share, to minimise risk of stigma or discrimination.
- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. new variant), and people are duly notified of changes to their risk level.
- There is a mechanism to challenge or change the outcome.
- There are data security protocols in place to ensure the tool is used only by the Scottish Government and NHS Scotland. In the case of QCovid®, this would be for the purpose of identifying and supporting people at risk of Covid-19 or other serious viruses.

The jury concluded that the use this tool would be unacceptable if:

- Data about individuals is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.
- There is not adequate ongoing support in place to help people who are identified as being at high risk.
- The data is not held securely.
- The risk to public health from Covid-19, or another virus, at the time is minimal.
- It is used to discriminate against individuals (e.g in the workplace or in accessing services such as insurance).

## Risks and benefits

There was broad agreement on the risks associated with the use of non-anonymous data at the population level. Some of these echo the risks already noted in relation to the clinical and public facing tools. The perceived risks were:

- If the underlying **data is not accurate** (i.e. if it does not reflect changes in the circumstances associated with the pandemic) then it could incorrectly identify some people as being at high risk. This could lead to negative impacts on people's wellbeing.
- **Potential lack of support** for people notified as being at high risk, which could, again, lead to emotional distress and negative impacts on their wellbeing.

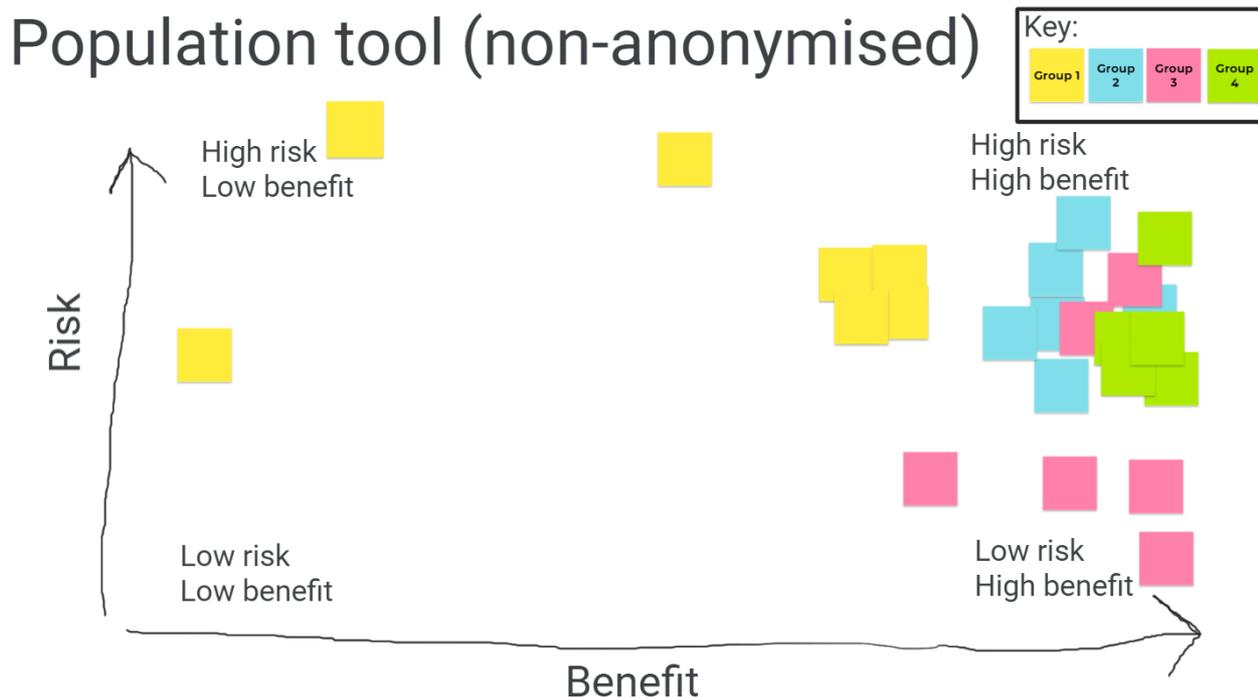
- **Issues around stigma** could arise (for example, being treated differently in other areas of healthcare or in employment as a result of the risk score).
- **Data security**, with the risk of possible breaches or data getting into the wrong hands. Linked to this was a perceived risk of scope creep, with questions raised about whether the data might be used for purposes beyond the risk prediction.
- **Consent would be difficult (if not impossible) to obtain**, leaving people with limited control over how their data is used.

The key perceived benefits of this tool were that:

- It would **enable individuals to be informed about their risk**. Participants generally felt that the ultimate aim of the tool – to identify those at risk and help them to take the right course of action with the right support – was a good thing (though questions were raised about how individuals would be informed, as discussed below).
- It would allow **a targeted response** to the management of the pandemic, which keeps people at higher risk safe while avoiding large-scale interventions (such as national or regional lockdowns).

Overall, as illustrated in figure 5 overleaf, the population tool using non-anonymised data was seen as relatively of benefit. In particular, the ability to target individuals most at risk and help them to respond accordingly was seen as one of the most important benefits of this tool, making it stand out from the others. Views on the risks of the tool were more mixed, but overall it was seen as relatively high risk. The most pressing risks were those related to support for high risk individuals, and risks of data security - as one participant put it “by the very nature of making the data non-anonymised, this is going to be a higher risk than the other population tool”.

Figure 5: image showing participants' assessment of the risk-benefit of the population tool using non-anonymised data (session five)



## Key ethical considerations

The key ethical concerns that remained for participants at the end of the process centred around the following themes.

### Accuracy

The need for accuracy of the population level tool, both in terms of the data underlying it and the outcome it produced, was underpinned by a concern about the impact on individuals identified as being at high risk. Participants highlighted the negative impacts of a high risk classification on an individual's mental health and wellbeing, and reference was made to how difficult the shielding experience had been on individuals (including some of the participants themselves) early in the pandemic. Because of these potential risks, the accuracy of the risk prediction was considered essential.

*"I think when they're using big data, it's good for making broad decisions about how to deploy vaccines and resources because you don't need a very accurate model to do that. When you're asking people to sit at home and not see anyone for 6, 12, 18 months, that requires a higher level of accuracy."*

*(Participant in session 1)*

On the other hand, there was also a view that non-anonymised data allowed for a more targeted, and therefore more accurate, response to managing the pandemic than if anonymised data was used. Indeed, this was ultimately seen as one of the benefits of this tool.

*“My brother has a rare condition and wasn’t told to be on a shielding list and is healthy in all other aspects apart from that one condition. Only non-anonymised data can pick up on those conditions that people can have. Anonymised data may not be as accurate or personalised when it comes to healthcare delivery.”*

*(Participant in session 4)*

## Support

The need for support for individuals identified at risk was one of the strongest themes to emerge in the discussions around the non-anonymised population tool. As noted above, participants were aware of the potentially negative impacts on individuals’ mental health and wellbeing if they were told they were at risk. It was therefore seen as essential that support was provided to those individuals and this support would need to have multiple elements:

- Emotional – to offer reassurance to people receiving a score which is upsetting to them.
- Interpretative - to help people understand their risk score and what it means.
- Practical – to help people understand what steps they needed to take to protect themselves and others, and support to help make sure they could access what they needed (e.g. access to food and essential items if they were being asked to shield).

## Data security

The security and privacy of data was another core consideration for this tool, because the data would contain information that could identify individuals. Following the presentation on the existing data protocols that NHS Scotland have in place (including the process used by the Public Benefits and Privacy Panel), participants felt more reassured about the security of public health data than they had been at the beginning of the process. Nonetheless, potential data breaches or data getting into the wrong hands remained risks they associated with this tool.

The overall importance of data privacy led the jury to establish the principle that data security protocols should be place to ensure that the data is only used to identify and support people at risk of Covid-19 or other viruses. Protecting the data against unwarranted access from third parties was also a key consideration for the jury – and one of the unacceptable aspects of the tool was the sharing of non-anonymised data with third parties that might use it for purposes not aligned with public health benefits related to the pandemic.

## Consent

Related to data security and privacy is the issue of consent. It was acknowledged that gaining consent from everyone whose data might be used at the population level would be very difficult if not impossible. Lack of consent, however, was not an issue that would make this tool unacceptable to the jury; they felt that the overall

benefits of the tool warranted the use of data without individuals' consent, as long as the principles around data security were in place.

### **Confidentiality**

One of the perceived risks of this tool was the potential stigma that an individual with a high risk score might experience. For example, that score might impact on what type of medical treatment they get access to in future or might impact beyond the healthcare setting and into decisions around employment, insurance, or other services. To help counter this risk, participants felt it was important that an individual's risk score remained confidential and was not shared outside of the healthcare setting (for example with employers or insurance companies). Added to this, participants felt that there should be no legal requirement for the individual to share that information themselves.

### **Communication**

Participants felt it was important that the public was made aware of the use of the population tool using non-anonymised data. They felt this would help make the process more transparent and help make clear to the public how their data was being managed and used. There was general agreement that the scale of the data (with potentially millions of health records being used) made it difficult to inform every individual that their non-anonymised data had been used. However, two levels of communication were suggested for this tool.

Firstly, providing information in a centralised place – such as the NHS Scotland website or the Scottish Government website (with alternatives for those not online) – explaining what the risk prediction model was, along with why and how people's data were being used. Secondly, communication with the individuals identified as being at high risk. This latter form of communication was seen as a key part of the process of providing support for those at high risk, and the overall sentiment was that individuals should not only be informed about their risk score but provided with advice and signposting to resources that could help them take appropriate action.

### **Circumstances for using the non-anonymised population-level tool**

In session four, participants considered a range of scenarios in which the population-level tool might be deployed using non-anonymised data, and discussed the extent to which its use would be acceptable or not.

The scenarios included:

- If a new variant emerges which appeared to be resistant to the vaccine.
- If the effectiveness of the vaccine was waning against the existing variants.
- If there was a low prevalence of Covid-19 in society.

Generally, participants felt the public health benefits of the non-anonymised population level tool justified its use, as long as certain conditions (the jury's principles) were met. This sentiment did not change much under the scenarios, with the exception of low prevalence (see below). Across each scenario, participants stressed the importance of having a clear rationale for using non-anonymised data and for that rationale to be communicated in some way to the public.

### New variant

If a **new variant** emerged, it was felt that use of the population tool with non-anonymised data might become more important than it is now, as the need to identify those most at risk would be heightened. The nature or severity of a new variant was not defined in this hypothetical scenario. However, participants felt that use of the tool would become even more acceptable if that new variant was more transmissible, or had more serious health impacts, than current variants. It was felt that the potential severity of the variant and its impacts on people's health could make the benefits of using the tool outweigh the risks – even more so than in the current situation.

*“It's even more important to use the non-anonymised version in this scenario... The intensity for using it is greater in this circumstance and the actions that people are advised to take might need to be modified if it's a very resistant and damaging variant.”*

*(Participants in session 4)*

The perceived benefits of using the tool under this scenario were that it would help individuals get prioritised for vaccines or vaccine boosters, and that it would generally help the health service prepare its response to the variant. Reflecting on this scenario, participants also emphasised the importance of people “doing their bit” to help manage virus, and that we should therefore be prepared to accept non-anonymised data being used in these circumstances.

*“I think, we should be doing everything within our power to help the frontline... we have to take a bit of a reality check and do everything we can. So, if [the Covid-19] comes back, everybody is prepared. Especially those who are vulnerable, to ensure they get the care they should.”*

*(Participant in session 4)*

However, there was still caution expressed about use of this tool if a new variant emerged. Participants emphasised the need to maintain the principles of transparency and the importance of data not being shared with third parties unrelated to managing public health during the pandemic. They also felt that a new variant might emphasise the need for the tool to be updated to reflect any differences in the level of risks to particular groups from the variant.

In one group, there was a preference for using the anonymised population-level tool in the first instance, with the non-anonymised population-level tool being introduced

only if a new variant would significantly impact particular groups and that there was a clear rationale for identifying and notifying those affected.

*“The default should always be anonymised data. If there was another strain and you were rolling out another vaccine, I don’t think you need to know specifically who needs it, you could use a group of people. If the variant is worse for people in a certain age range with a certain disease, non-anonymised data use might make sense. When it comes down to using the tool, it should be anonymised data first.”*

*(Participant in session 4)*

### **Waning vaccine effectiveness**

If **vaccine effectiveness was waning**, views on the use of this tool did not change much compared to other situations discussed, such as the current situation (at the time of research) or a new variant. Participants were still broadly supportive of the use of the population level tool with non-anonymised data, if the conditions previously discussed were in place. One group put forward the view that this scenario was actually fairly close to the current position, as vaccine effectiveness can ultimately wane over time.

In either of the above scenarios, the same principles applied related to accuracy, support, data security, confidentiality and communication. In considering the possibility of a new variant or waning vaccines, participants also emphasised the importance of the tool being able to adapt to changing circumstances.

### **Low prevalence**

If there was **low prevalence**, then the benefits of using this were less clear – it was felt that with less need to manage the spread of the virus and lower risk of transmission, then the risks associated with this tool (data security, stigma, potential lack of support) might outweigh the benefits.

*“If the risks to society are on a whole low, I’d start to question what’s the reason to do it at all. It goes back to what the benefit is of telling people they are high risk, if there is a low risk in general of catching it. I would start to move against [support for this tool] in that case.”*

*(Participant in session 4).*

This scenario also led to questioning of the value for money of the investment in this tool, and the view that it would potentially be a waste of resources. For some, this meant that use of the tool would no longer be acceptable.

*“If it was low [prevalence] I would have to ask why they are using non-anonymised data. I would say there is a need for a public tool rather than a population tool. Why waste money and a huge number of resources for non-anonymised data? That would be a red line for me.”*

*(Participant in session 5).*

# 7. Population-level tool: using anonymised data

## Summary and principles

The population-level tool could be utilised in an anonymised way. This would involve running the QCovid® model, or a similar risk prediction model, through anonymised health records at a national or regional level. The tool would not identify individuals at risk (as is the case with the non-anonymised population tool) but would allow governments and health boards to see how many people in a certain area were at risk for research and planning purposes.

In sessions three and four of the Citizens' Jury, members were introduced to the population-level tool (both the anonymised and non-anonymised forms) and heard from expert speakers explaining how both tools would work and the key considerations for their use. An overview of the speakers and topics is provided in the previous chapter. Participants reflected on the presentations and had the opportunity to ask questions about the population-level tool using anonymised data. In sessions five and six, participants deliberated on the population-level tool and discussed the key risks, benefits and ethical considerations in relation to its use with anonymised data, before drawing conclusions.

The jury were generally favourable towards the population-level tool utilising anonymised data and there was consensus that the public benefits outweighed concerns over data privacy. Nevertheless, there were a number of principles that would still apply to the use of this tool in Scotland.

### **Use of the anonymised population-level tool in Scotland, as part of the QCovid® model or a similar risk model, is acceptable if:**

- Information about the tool, and reasons for using it, is available and clearly communicated to the general public i.e. without jargon. Note that some felt the information should be available where others felt it should be presented i.e. during a public briefing by a medical professional. Some also felt medical professionals should be kept up to date in order to keep their patients up to date.
- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. new variant).
- The data is agile and able to adapt as new situations arise (including change in profile of the population).

- The data is to be used by Scottish Government and NHS Scotland only for the purpose of resource planning, research and informing the public.
- There are data security protocols in place to ensure the tool is developed and used appropriately (e.g. resource planning or valid/justifiable research by verified third parties e.g. non-profit research institutes).

### **Use of the tool becomes unacceptable if:**

- Data is shared with third parties for purposes that do not align with healthcare-related public benefits (e.g. in the case of QCovid®, relating to the pandemic response).
- Data is not protected from commercial companies accessing it.
- There is any collaboration with data farm companies.
- It is used to discriminate against certain groups (e.g. being denied access to certain services based on age or ethnicity).

### **Risks and benefits**

As part of their deliberation on the anonymised population-level tool, participants considered the risks and benefits of it, as well as any key ethical concerns.

The key risks identified were that:

- There are **limitations with using large datasets** (e.g. the data is not complete, such as missing data on those outwith the 19-100 age range or information on ethnicity, and the data may not always be up-to-date).
- If the **accuracy** of the data is not high it would undermine resource planning.
- The anonymised data **might not be enough** and could result in people being at risk but not being aware of it as they would not be identified.
- It is **not targeted enough to the individuals at risk**. Decisions made at a regional level (such as a local lockdown) could therefore restrict and impact negatively on peoples' lives who are not at risk, rather than focusing on those who are at risk.
- Consent is not possible to obtain, leaving people with **limited control** over how their data is used.

The key benefits of the were that:

- It would **allow Scottish Government and NHS Scotland to allocate resources effectively.**

*“You need the right care and equipment at the right time. You need to be strategic about this and use high level statistical data, which is what the tool is.”*

*(Participant in session 5)*

- It could be used to **support research**, which provides significant wider benefits.
- It could be used to **help the Scottish Government prepare for, and respond to, future pandemics** more effectively.

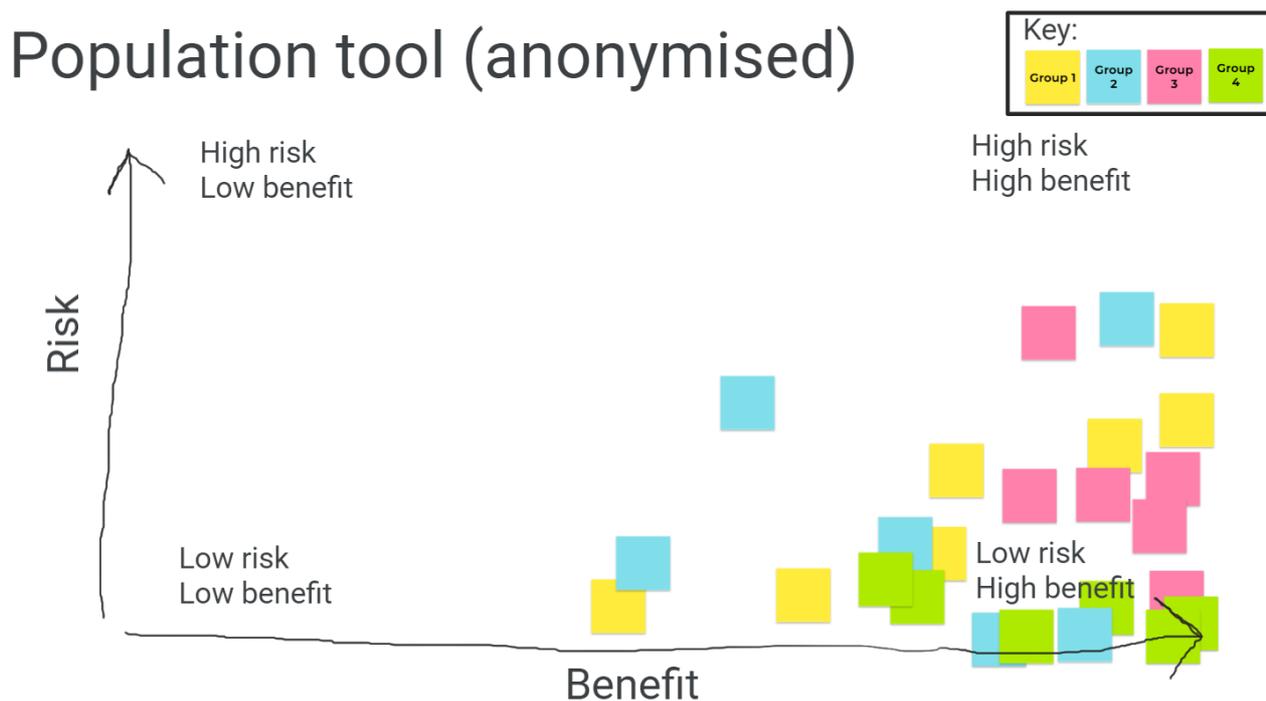
On balance, the jury considered the anonymised population-level tool to be fairly uncontroversial, concluding that it would present a relatively low risk, as no personally identifiable information is used, while having broad public health benefits.

*“I see no drawback in using the anonymised version of the population tool. It can only be a good thing if it helps with planning and prioritisation.”*

*(Participant in session 5)*

Where views were more nuanced, this was driven by concerns over data being used for purposes unrelated to public health planning and some uncertainty over the usefulness of this tool when not targeting individuals at risk. This is depicted in figure 6 overleaf, where participants each placed a digital post-it according to their own assessment of the risk-benefit of the anonymised population-level tool.

Figure 6: image showing participants' assessment of the risk-benefit of the anonymised population-level tool (session five)



## Key ethical considerations

As with the non-anonymised population-level tool, views on the anonymised version of the tool developed as participants learned more about it. Having raised some initial concerns about the population-level tool overall (such as on the accuracy and security of the tool), the jury came to view the anonymised population tool as a sensible option for Scottish Government and NHS Scotland to plan resources at on a regional and national basis, with the benefits generally outweighing the risks. However, there were some key ethical considerations which participants highlighted, which formed the key principles underpinning the possible use of the anonymised population-level tool in Scotland.

## Data accuracy and agility

It was generally agreed that these large, anonymised health datasets lend themselves well to making decisions, citing the example of the JCVI using the QCovid® model on anonymised data to recommend which groups should be prioritised for vaccination against Covid-19. However, participants noted that some data can be missing, for example from medical records, which led to some concern that data inaccuracies could lead to poor decision-making. One participant, reflecting on their experience of living under regional restrictions while pregnant, found the blanket restrictions difficult.

*“Even though I was in the early stages of pregnancy, I didn’t have a vulnerability. I wanted to do some things, but I couldn’t do them, and it was frustrating [...] I feel it should be more nuanced.”*

*(Participant in session 4)*

In this sense, the non-anonymised population tool was considered to strike a better balance between protecting individuals without restricting the wider population.

*“It seems like a smart way of reacting and people being able to allocate resources. And I suppose it’s only as good as the process and sciences keeping on top of it. It needs to be agile and respond to new developments, for instance the new variants.”*

*(Participant in session 4)*

It was acknowledged by the jury that the underlying model would need to be kept up-to-date and be constantly evolving as pandemic events occur (such as the emergence of the Omicron variant and booster vaccine rollout).

### **Data privacy**

Although consent was an issue raised by participants early in the deliberative process, after further learning it was recognised that consent is not possible to obtain when working with such large datasets. It evolved into an issue around data privacy and ‘unforeseen consequences’ in terms of how the data is used in future (an ethical concern which cuts across all of the tools). Participants felt strongly that the data should not be passed onto third parties, and agreed that the population-level tool would be acceptable only if there were clear parameters set around its use by Scottish Government and NHS Scotland for the purposes of resource planning, research and informing the public, and not for profit.

*“What are the boundaries of use in each version of the tool? and then how can we really know they won’t be transgressed?”*

*(Participant in session 3)*

### **Transparency and trust**

To allay any potential concerns around data privacy, the jury agreed that there needs to be a robust and clear rationale for using anonymised health data at the population level using this tool. This was borne out of participants themselves not being clear early in the process as to how the tool would be used:

*“You can’t say how you will support something without knowing how it’s going to be used.”*

*(Participant in session 3)*

Over the course of the deliberation, and as the jury cultivated greater understanding of risk prediction models and the different tools, they concluded that the benefits of the anonymised population tool outweigh the risks, but that it would be important for Scottish Government to build public trust in the tool by clearly explaining its purpose and use.

## Communication

Clear communication about the use of QCovid® or a similar risk model was deemed 'essential' by the jury. In the case of the population-level tool, which the jury felt would be broadly acceptable to most people, it was felt that information on the NHS Scotland and Scottish Government websites - with alternative versions for those who are not online - would suffice for those wishing to learn about it. It was important to some participants that the information should come from the medical officers and not politicians.

## Circumstances for using the anonymised population-level tool

In session four, as they did for the non-anonymised version, participants considered a range of scenarios in which the population-level tool might be deployed using anonymised data, and discussed the extent to which its use would be acceptable or not.

The scenarios were the same as those discussed for the non-anonymised version and included:

- If a new variant emerges which appeared to be resistant to the vaccine.
- If the effectiveness of the vaccine was waning against the existing variants.
- If there was a low prevalence of Covid-19 in society.

The anonymised population-level tool was acceptable to the jury across all scenarios and it was agreed that the key principles of transparency, communication, accuracy, and protection against misuse still applied in any of these situations. For one group, considering the different scenarios reinforced the importance of ensuring the tool can adapt to such changing circumstances.

Although the use of the tool was considered acceptable in a low prevalence scenario, views did diverge in terms of the usefulness of having the tool in this situation. One view was that it would be important to keep the tool operational so that it could adapt to and take account of events in case of any changing circumstances. Furthermore, it was felt that an up-to-date risk prediction model could be repurposed in future. An alternative (and more exceptional) view was that there would be less of a clear rationale for running and resourcing the tool if the prevalence of Covid-19 was low.

## 8. Conclusions

This Citizens' Jury set out to help understand how the public in Scotland view any ethical issues associated with the Scottish Government's proposed use of QCovid® or similar risk prediction models. Through an in-depth process of learning and deliberation, the Citizens' Jury provided clear messages on the ethical concerns around deploying a model like QCovid®.

The jury looked in detail at each of the four possible tools associated with QCovid®, and this report has set out their principles (i.e., what would make use of each tool acceptable) and "red lines" (i.e., what would render use of each tool unacceptable). Rather than restate those principles and "red lines", here we highlight the overall themes that emerged from this public engagement exercise and the implications for future policy in this area.

**Findings underscore the importance of transparency around the use of any such tool.** Participants were generally accepting of the reasons for applying a risk prediction model, feeling that they could help minimise some of the most serious outcomes of the pandemic. However, a theme throughout the jury was the need to keep the public informed about how the model was being used and what that meant for individuals who were identified as at risk. This level of transparency was considered important for the Scottish Government to build public trust in the tool.

**Linked to the need for transparency was the importance of communication.** If the Scottish Government was to decide to use QCovid® or a model like it, participants felt that this should be clearly communicated to the public. Communication of the outcome of the risk prediction was also seen as an important consideration, with care needed in relation to how a high-risk individual is informed of the outcome.

**The need for support for individuals deemed at high risk was one of the strongest themes to emerge.** Participants stressed the potential severity of being told you are at high risk of serious outcomes from Covid-19, and the negative emotional impacts of being asked to isolate or reduce contact with others. In this respect, the timing of this public engagement exercise seemed to have had an impact – having lived through almost two years of Covid-19, participants were able to draw on their own experiences, or that of their family members, of being asked to shield early in the pandemic. If adequate support cannot be provided, then some felt the model should not be used. Any future use of the model should therefore consider what means of support will be available to high risk individuals and how this will be communicated to those individuals. Support would include three elements:

- Emotional – to offer reassurance to people receiving a score which is upsetting to them.
- Interpretative - to help people understand their risk score and what it means.

- Practical – to help people understand what steps they needed to take to protect themselves and others, and support to help make sure they could access what they needed (e.g. access to food and essential items if they were being asked to shield).

**The Citizens' Jury also highlighted the importance of having data security and privacy systems in place.** Concerns around data security have been covered in previous public engagement exercises on this topic, so it is not surprising that they formed a key part of the deliberations in this Citizens' Jury. Across all the tools that were discussed, the general point raised was that an individual's data should be kept safe and not used for purposes unrelated to managing the health risk of the virus. This was particularly important in the case of the population tool using non-anonymised data. For any future use of the tool, it will therefore be important that data security protocols are in place and that these are clearly described to the public.

**Findings suggest that attitudes towards risk prediction models can vary depending on the status of the virus.** In particular, if there is low prevalence of the virus and vaccines are effective, participants felt there would need to be very clear justification from the Scottish Government for a model like QCovid® to be used. This was particularly the case for tools that carried relatively higher risk, such as the population level use of non-anonymised data (which had higher risks associated with data privacy and need for support for individuals). In the case of a new variant resistant to vaccines, participants felt that a model like QCovid® could potentially become more important, as the need to manage the impacts of the virus would be more serious and urgent. However, the same principles and conditions around its acceptability would still apply under that scenario.

**Finally, our findings also highlight the impact that the process of deliberation can have on attitudes towards use of public health data.** Participants' views developed over the course of the Citizens' Jury as they learned more about the tools and deliberated with each other. The wider public, who will not have taken part in deliberation, may receive information about a risk prediction model differently. If the Scottish Government is to use a model like QCovid®, it will therefore be important that the public engagement messaging draws on, and responds to, the range of ethical considerations highlighted by the Citizens' Jury.

# Appendix

## Ethics panel

The ethics panel included:

- Doreen Grove, Scottish Government
- Lara Macdonald, Centre for Data Ethics and Innovation
- Dr Mavis Machirori, Ada Lovelace Institute (from January 2022)
- Reema Patel, Ada Lovelace Institute (until January 2022)
- Professor Shannon Vallor, University of Edinburgh.

Secretariat

- Úna Bartley, Scottish Government
- Gary Todd, Scottish Government
- Tom Speight, Scottish Government
- Albert King, Scottish Government
- Ryan Anderson, Scottish Government

# Recruitment and sampling

Figure 7: image showing random selection of addresses for invitation (source: Sortition Foundation recruitment report)<sup>10</sup>



Table 2: the demographic profile of the Citizens' Jury

Quota	Group	% in population	Number selected (and confirmed) for the Jury
Age	16-24	11%	4
Age	25-34	18%	6
Age	35-54	32%	9
Age	55+	38%	11
Gender	Female	52%	16
Gender	Male	48%	14
Scottish region	Central	12%	3
Scottish region	Glasgow	13%	3

<sup>10</sup> [https://www.sortitionfoundation.org/QCovid®\\_2022\\_report](https://www.sortitionfoundation.org/QCovid®_2022_report)

<b>Scottish region</b>	Highlands and Islands	8%	3
<b>Scottish region</b>	Lothians	15%	5
<b>Scottish region</b>	Mid Scotland and Fife	12%	4
<b>Scottish region</b>	North East Scotland	14%	5
<b>Scottish region</b>	South	13%	3
<b>Scottish region</b>	West	13%	4
<b>Ethnicity</b>	African, Caribbean, Black or Black Scottish/British	1%	1
<b>Ethnicity</b>	Asian, Asian Scottish or Asian British	3%	2
<b>Ethnicity</b>	White Scottish/Other British/White Other	96%	26
<b>Ethnicity</b>	Other ethnic group or mixed/multiple ethnic groups	0%	1
<b>Disability</b>	No long-term physical or mental health condition	70%	21
<b>Disability</b>	Long-term physical or mental health condition which is limiting	24%	7
<b>Disability</b>	Long-term physical or mental health condition which is not limiting	6%	2
<b>SIMD</b>	1 – most deprived	21%	7
<b>SIMD</b>	2	21%	6
<b>SIMD</b>	3	20%	6
<b>SIMD</b>	4	20%	6
<b>SIMD</b>	5 – least deprived	19%	5
<b>Attitude towards data access<sup>11</sup></b>	Very comfortable	N/A	11

<sup>11</sup> A minimum selection was set on each response on the data attitudinal measure to ensure that each response was represented by at least 2 jury members. The full question wording in the sign-up survey was as follows: How comfortable or uncomfortable would you be about the Scottish Government having access to your personal health data?

<b>Attitude towards data access</b>	Somewhat comfortable	N/A	9
<b>Attitude towards data access</b>	Somewhat uncomfortable	N/A	2
<b>Attitude towards data access</b>	Very uncomfortable	N/A	2
<b>Attitude towards data access</b>	Don't know	N/A	6

# Onboarding materials: welcome pack

## Welcome

Thank you for agreeing to become part of the QCovid® Citizens' Jury.

The purpose of the Jury is to consider the use of a tool called QCovid®, which uses health data to identify factors that put people at a higher risk of being seriously unwell or dying because of Coronavirus. These factors – like age and medical condition – were used to build what's called a risk prediction model, which estimates an overall risk level. More information on QCovid® is provided below.

There are different ways in which risk prediction models, like QCovid®, can be used in Scotland. The role of this Jury will be to consider the benefits and risks of tools such as QCovid®, and to discuss the ethical issues around using people's health data.

Before taking part, it is important that you understand why the research is being carried out and what it will involve. If you have any questions, please do not hesitate to get in touch (contact details are at the end of this document).

## What is a Citizens' Jury?

A Citizens' Jury brings together a randomly selected group of people who broadly represent the entire community. The people who attend will listen to evidence from a range of experts, learn about key issues, discuss them with one another, and then deliberate and draw conclusions together.

Due to the uncertainty of the ongoing COVID-19 pandemic, we have decided to run the Citizens' Jury virtually using the online platform Zoom, rather than face-to-face. We did not want to take any unnecessary risks and felt that it was better to seize the moment rather than wait until we can safely meet face-to-face. You will be able to view all supporting materials, such as recordings of presentations, slide packs, and summary documents – all from the comfort of your home.

The Jury will meet over six sessions to learn, deliberate and discuss QCovid® before drawing conclusions about the use of this type of tool. The Jury will answer this important question - **'What are the risks and benefits of using public health data to predict people's risk of dying from Covid?'** – with a focus on the ethical issues surrounding the use of tools like QCovid®. By ethical issues we mean the benefits, risks and wider social harms that should be considered with a risk model such as QCovid®.

At the end of the process, Ipsos MORI will produce a report outlining the Jury's conclusions. The report from the Jury will be presented to the Scottish Government in April 2022 and the Scottish Government will consider the Jury's conclusions. This is a fantastic opportunity to help the Scottish Government decide how it might use tools such as QCovid® in its response to the pandemic.

## **What is QCovid®?**

QCovid® was commissioned in 2020 by the Chief Medical Officer for England on behalf of the UK government. The first QCovid® tool was developed using the QResearch database hosted at Oxford. This database has anonymised data from GP and hospital records, COVID-19 test results and death registries. Factors such as age and medical conditions, which were found to increase risk relating to coronavirus, were used to build a risk prediction model. The model, QCovid®, estimates someone's combined risk of catching coronavirus and being admitted to hospital and their combined risk of catching coronavirus and dying.

The tool has now been updated to include factors such as vaccination status and background infection rate. There is a need to identify those at highest risk of severe outcomes if infected with COVID-19, even if individuals are vaccinated.

The model was tested to find out whether it accurately predicted severe outcomes due to COVID-19 during the first wave of the pandemic in England. More recently, it has been tested on vaccinated individuals between December 2020 and June 2021.

The research, published in the British Medical Journal (BMJ), showed that the model performed well in predicting severe outcomes due to COVID-19 (death and hospitalisation) in both models. You can view the research on the BMJ's website at <https://www.bmj.com/content/374/bmj.n2244>.

The research team is led by Professor Julia Hippisley-Cox at the University of Oxford. The QCovid® team includes researchers from:

- University of Nottingham
- London School of Hygiene & Tropical Medicine
- University of Leicester
- Swansea University
- Queen's University Belfast
- University of Edinburgh
- Department of Health and Social Care
- NHS England and Improvement
- Queen Mary University of London
- University of Liverpool
- University College London
- NHSx
- NHS Digital

For more information about QCovid®, you can visit the website at <https://qcovid.org>.

## **Who is carrying out the Jury?**

Ipsos MORI is an independent research agency carrying out this work on behalf of the Scottish Government.

## What is involved in taking part?

You are one of 25 people selected to take part in the QCovid® Citizens' Jury which will be answering the important question:

### **What are the risks and benefits of using public health data to predict people's risk of dying from Covid?**

The Jury will run across six online sessions in February and March and you need to be able to attend all six sessions.

The sessions will run as follows:

- **Session 1: Saturday 12th February: 10am-1pm**
- **Session 2: Thursday 17th February: 6-9pm**
- **Session 3: Tuesday 22nd February: 6-9pm**
- **Session 4: Thursday 24th February: 6-9pm**
- **Session 5: Tuesday 1st March: 6-9pm**
- **Session 6: Saturday 5th March: 10am-1pm**

We will give you £300 to thank you for your time. This will be split into two payments of £150 after the third session and £150 after the final session. You can choose to receive this either as cash (BACS transfer) or in the form of an e-voucher (Amazon). Please just let us know which option you would prefer when we contact you in advance of the first session. Receiving a bank transfer for this amount may impact on any benefit payments or tax positions, so it is worth checking this before choosing a payment method. **Receiving an e-voucher will not impact on any benefit payments or tax positions.**

You don't need any prior knowledge to take part in the Jury; all we require from you is a willingness to listen to the information presented and share your opinions with us and your fellow participants.

## What information will be used?

The findings from the Jury will be anonymised, and we will not reveal personal details without obtaining your explicit consent.

Please note that there may be observers in attendance throughout the Jury. These may be people from academia (for example university researchers) or from Scottish Government (such as representatives from the Highest Risk Division). We will inform you of the presence of any observers and the reasons for their attendance in each session. This is a normal part of Citizens' Juries and helps to foster a sense of openness and transparency in the process for those with an interest in understanding how it is being conducted. They will not contribute to or shape the discussion in any way but will simply listen in on some conversations and plenary sessions. There are strict controls on the number of observers for each session as well as guidelines that observers must agree to before attending.

If you have any queries about this aspect of the Jury, please get in touch (contact details below).

## How will we record what you say?

We would like to audio-record our discussion but will only do so with your agreement. Recording the discussion enables us to accurately capture what has been said and helps our researchers with note taking.

## How will the information be used?

A report will be published on the Scottish Government's website. It will also be used internally by the Scottish Government to help determine how QCovid® or similar risk prediction models are used in Scotland. The report is likely to use quotes, but we will not name or identify anyone when we use quotes. If you do not want us to quote anything you say, please just let us know.

## Do I have to take part?

No. It is your choice whether or not you participate. You can also choose not to answer individual questions and/or leave the discussion completely. You can change your mind at any point, and you do not have to give a reason. If you would like to withdraw your consent to participate, please contact us.

## Can I talk about my participation with others?

We encourage you to talk to family and friends during your time as a juror. It is also okay to talk about the fact that you are part of a Citizens' Jury on social media, but **we ask you not to share the content of the discussions, as it will be out of context for the general public, and to respect the anonymity of everyone else taking part.**

## Privacy Notice

We have a legal duty to inform you about why we are collecting information from you for the research. We provide this information in our Privacy Notice which should be read alongside this information sheet. The Privacy Notice outlines what information we will collect and why, and your rights. If you would like another copy of the Privacy Notice, please contact us (see below).

Importantly, you need to know that:

- We will never use your personal data for anything other than this project
- Only Sortition (the organisation who invited and selected you to take part in the Jury) and the Ipsos MORI project team will have access to your personal data
- Only members of the research team will hear the recording and all recordings will be destroyed at the end of the project.
- Your personal data will be securely deleted three months after completion of the project
- You will not be identifiable in any of our reporting.

## Where can I get more information?

For more information about the research, or if you have any questions, please contact: [redacted]

For more information about Ipsos MORI visit <https://www.ipsos.com/ipsos-mori/en-uk>

If you have questions or concerns about your role and rights as a juror, would like to obtain information or offer input, or would like to register a complaint about this study, please contact us.

## Next steps

If you are happy to continue to take part in the QCovid® Citizens' Jury, please complete the consent form slip and return it to the researcher by email.

# Presentations and speakers

Session One:

- Úna Bartley, Scottish Government – 'Introduction to QCovid® model and the different tools'.
- Professor Sarah Cunningham-Burley, the University of Edinburgh – 'Introduction to public health data ethics and previous public engagement on this topic'.

Session two:

- Professor Aziz Sheikh, Director of the Usher Institute at the University of Edinburgh – 'Introduction to the clinical tool'.
- Professor Alison McCallum, Usher Institute at the University of Edinburgh (and former Director of Public Health and Health Policy at NHS Lothian) – 'introduction to the public-facing tool'.

Session three:

- Professor Aziz Sheikh, Director of the Usher Institute at the University of Edinburgh – 'Introduction to the population tool'.
- Professor Jeremy Brown, University College London and member of the Joint Committee on Vaccination and Immunisation – 'Applying the population tool (vaccination prioritisation example)'.
- Dr Helen Stagg, Usher Institute at the University of Edinburgh – 'Considerations for using the population tool in an anonymised or non-anonymised way'.

Session four:

- Professor Alison McCallum, Usher Institute at the University of Edinburgh (and former Director of Public Health and Health Policy at NHS Lothian) – ‘data security and privacy in relation to public health data’.

Session five:

- Professor Sarah Chan, University of Edinburgh – ‘data and risk prediction: personal or public health? Thinking about the ethical issues’.

# Session five materials

## Case studies

As part of the fifth workshop, the jury was put into small breakout groups and asked to continue exploring the risks, benefits and ethical issues by putting themselves in the shoes of someone else. Each group was given a different avatar (a fictional person and scenario) which represented a low, medium or high risk case. Copies of each avatar presented to the jury are shown below:

**Figure 8: case study 1**

### Case Study 1

**Assume that Taj would be categorised as at low risk**

Taj is 19. He is a student living in Aberdeen. He is from Glasgow. When he first started at University, he lived at home with his parents in Glasgow and studied remotely due to Covid. This year, he has been able to move into student accommodation. He currently lives with seven other people.

Taj is a non-smoker and lives an active lifestyle. He is on the University's swimming and badminton teams and regularly travels at the weekends for competitions.

He has no underlying health conditions and would be considered at low risk from Covid-19.

When he's not training or studying, Taj likes to go out and spend time with his friends. He doesn't use social media much as he is nervous about sharing his personal information.

The pandemic has made it very difficult for him to have a 'normal' University experience and he has only just been able to start enjoying the sociable side of things, so he hopes that things stay as they are.



Figure 9: case study 2

## Case study 2

### Assume that Jenny would be categorised as at medium risk

Jenny is 43. She lives in a block of flats with her partner and two children. She works full-time as a taxi driver. Her partner is unable to work, so she supports the family.

Because of her job, Jenny comes into contact with a lot of people. On several occasions during the pandemic, she was 'pinged' by the track and trace app to say that she was a close contact of someone who had tested positive and was asked to self-isolate and test. She is self-employed as a taxi driver and is not entitled to sick pay from her employer, so not being able to work when she was 'pinged' caused her stress and financial worry. Other financial support available to her during the pandemic was limited.

Jenny has other health conditions which sometimes affect her daily life, although she has never been on the highest risk list. But she has had issues with her employer in the past when her condition has prevented her from working. Because of her condition, she has been very careful to avoid catching the virus. But as the sole earner, she also needs the money to support her family. She heard on the news recently that the vaccine is becoming less effective against existing variants.



Figure 10: case study 3

## Case study 3

### Assume that Benjamin would be categorised as at high risk

Benjamin is 68. He is retired and lives with his wife in the village of Strathblane in Stirlingshire. His wife is registered disabled, so he tends to be responsible for day-to-day tasks such as grocery shopping and collecting prescriptions.

Benjamin is very active in his community and is a member of the local community council.

During the lockdowns, Ben was involved in a number of voluntary initiatives, such as befriending elderly residents living alone and running errands for those who were shielding or isolating. The community response to the pandemic has inspired him to form a community group to continue the befriending service.

In the earlier stages of the pandemic, neither Benjamin nor his wife was identified as being at high risk and so they were not asked to shield. He does not like going to the GP and does not trust the doctors there. However, he has recently been diagnosed with a serious health condition. The diagnosis has affected his life insurance policy, which has worried Benjamin and his wife. He is also becoming increasingly worried by news of an emerging variant of coronavirus which appears to be resistant to the current vaccine.



Figure 11: case study 4

## Case study 4

Assume that Mabel would be categorised as at high risk



Mabel is 82. She lives in a care home on the island of Islay, where Covid cases have been low.

Before the lockdown came in early 2020, Mabel was able to go out and visit friends, to go on outings with her family when they visited, and to attend appointments. In the early stages of the pandemic, Mabel was identified as being at high risk from Covid and was asked to shield during pandemic. She was very worried about catching the virus, so she followed the advice and did everything she could to keep herself and others safe. Mabel has been grateful to her GP for keeping her informed.

Mabel feels lucky that she has a community supporting her, as the care home and residents who live in the area have been kind and looked after each other during the pandemic.

Her family lives on the mainland and they were unable to visit her for a long time. Although the care home did their best to support her, this has had a negative impact on Mabel's wellbeing and she has been feeling very lonely. Cases of Covid in Islay continue to be low, so she hopes that her family will not be prevented from visiting again.

## **Risk-benefit exercise (Google Jamboard)**

As part of the fifth workshop, participants were asked to assess the balance of risk and benefit of each of the tools based on their discussions so far. This was facilitated via Google Jamboard,<sup>12</sup> a collaborative digital whiteboard. Each facilitator shared their screen so that all participants could see the same whiteboard, which depicted a risk/benefit quadrant chart. Taking each tool in turn, participants were asked to place a digital post-it on the chart according to their assessment of the risk-benefit of the tool. Each group's post-its were assigned a different colour, so that members could see in real-time where other participants were placing themselves. Once plotted on the diagram, participants explained and discussed their reasoning. Screenshots of the completed quadrant charts are shown in the main report.

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<sup>12</sup> <https://support.google.com/jamboard/answer/7424836?hl=en>

# Session six materials

## Benefits and risks summaries

Figure 12: anonymised population tool conclusions

### Population tool (using anonymised data) conclusions

#### Benefits

- Would allow Scottish Government and NHS Scotland to allocate resources effectively.
- The use of anonymised data for research has wider benefits.

#### Risks/drawbacks

- There are limitations with using large datasets (e.g. the data is not always complete).
- There are concerns over the accuracy of the data when planning resources.
- The anonymised data might not be enough and could result in people being at risk but not being aware of it.
- Decisions could be made at a regional level which impact negatively on peoples' lives.
- Consent is difficult to obtain, leaving people with limited control over how their data is used.

Figure 13: non-anonymised population tool conclusions

## Population tool (using non-anonymised data) conclusions

### Benefits

- Enables people to be informed about their risk.
- It is used in a more targeted way, which keeps people at higher risk safe while avoiding large-scale interventions (such as national or regional lockdowns).

### Risks/drawbacks

- If the data is not accurate it could mis-identify an individual as being at higher or lower risk.
- Issues around stigmatisation could arise (e.g. being treated differently in other areas of life).
- Potential lack of support for people notified as being at high risk.
- There could be data breaches or personal information could be leaked.
- The data could be misused and sold to third parties without people's consent.
- Consent is difficult to obtain, leaving people with limited control over how their data is used.

Figure 14: clinical tool conclusions

## Clinical tool conclusions

### Benefits

- GPs are professionals and used to using these tools, so could help patients understand their score.
- Could offer immediate support to patients at the moment they receive their score.
- The data it requires is mostly information that the GP has from medical records already.

### Risks/drawbacks

- Trust in GPs vary so it may not be an accessible tool for all.
- It may not be a good use of GP's time, which is already stretched.
- The support options may not be sufficient or may be limited by GP availability.

Figure 15: public-facing tool conclusions

## Public-facing tool conclusions

### Benefits

- It offers a quick way for anybody to find out their score at any time.
- Knowledge of risk could empower people to take action.

### Risks/drawbacks

- People may input incorrect information about themselves (either deliberately or by accident) and get an incorrect score.
- It could be misused to get a score for someone else.
- Potential lack of support for people finding out their score.
- It could be difficult for people to interpret their score and understand what it means for them.
- The online tool is not accessible for all groups in society.
- The tool might not be used by those who need it.
- The information put into the tool could be hacked.

## Population tool (anonymised) – group edits

Figure 16: anonymised population tool group 1 edits

# Population tool (using anonymised data) conclusions

G1

## Principles

“Use of the tool is acceptable if....

- The use of the tool, and reasons for using it, are clearly communicated (i.e. non-jargon and everyone can understand it, presented in public briefing from medical professionals (not politicians). Make sure medical professionals are kept up-to-date so they keep patients up-to-date) to the general public.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.
- The data is agile and able to adapt as new situations arise.
- The data is only be used by Scottish Government and NHS Scotland for the purpose of resource planning.
- There are data security protocols in place to ensure the tool is used appropriately (e.g. resource planning or legitimate research).

## Red lines

“Use of the tool becomes unacceptable if...

- Data is shared with third parties without consent for commercial purposes that do not align with healthcare-related public benefits.
- Data is not protected from commercial companies accessing it.
- There is any collaboration with data farm companies



Figure 17: anonymised population tool group 2 edits

# Population tool (using anonymised data) conclusions

G2

## Principles

“Use of the tool is acceptable if....

- **Information about** the use of the tool, and reasons for using it **is available** ~~are clearly communicated to the general public.~~
- The tool is kept up-to-date in case of people moving from low risk to high risk (**and vice versa**) based on new evidence or changing circumstances.
- The data is agile and able to adapt as new situations arise.
- The data is only be used by Scottish Government and NHS Scotland for the purpose of resource planning.
- There are data security protocols in place to ensure the tool is used appropriately (e.g. resource planning or legitimate research).

## Red lines

“Use of the tool becomes unacceptable if...

- Data is shared with third parties **who are not going to use it for definite public health benefit** ~~without consent.~~

Figure 18: anonymised population tool group 3 edits

# Population tool (using anonymised data) conclusions

G3

## Principles

“Use of the tool is acceptable if....

- The use of the tool, and reasons for using it, are clearly communicated to the general public.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.
- The data is agile and able to adapt as new situations arise.
- The data is to ~~only~~ be used by Scottish Government and NHS Scotland **only** for the purpose of resource planning.
- There are data security protocols in place to ensure the tool is used appropriately (e.g. resource planning or ~~legitimate~~ **valid/justifiable** research **by verified third parties, e.g. non-profit research institutes**).

## Red lines

“Use of the tool becomes unacceptable if...

- Data is shared with **non-verified** third parties without consent (**e.g. for profit**).

Figure 19: anonymised population tool group 4 edits

# Population tool (using anonymised data) conclusions

G4

## Principles

“Use of the tool is acceptable if....

- The use of the tool, and reasons for using it, are clearly communicated to the general public .
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances (including in relation to the virus e.g. new variant)
- The data is agile and able to adapt as new situations arise (including change in profile of the population).
- The data is only be used by Scottish Government and NHS Scotland for the purpose of resource planning, research and informing the public.
- There are data security protocols in place to ensure the tool is developed and used appropriately (e.g. resource planning or legitimate research).

## Red lines

“Use of the tool becomes unacceptable if...

- Data is shared with third parties unless for relevant/approved research related to the pandemic. without consent.
- It is used to discriminate against certain groups

## Population tool (non-anonymised) – group edits

Figure 20: non-anonymised population tool group 1 edits

# Population tool (using non-anonymised data) conclusions

## Principles

“Use of the tool is acceptable if....

- There is sufficient support in place to help people understand their risk score.
- The use of the tool, and reasons for using it, are clearly communicated to the general public (as before)
- The score is held confidentially to minimise risk of stigma or discrimination.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.
- There are data security protocols in place to ensure the tool is used only Scottish Government and NHS Scotland for the purpose of identifying people at risk of Covid-19 or other serious viruses.
- **TO CONSIDER: IF a time of low-prevalence give an opt-out option for people so long as this doesn't impact anon data collection and data accuracy, or important behaviour that keeps prevalence low**

## Red lines

G1

“Use of the tool becomes unacceptable if...

- Data is shared with third parties without consent. (as before)
- There is not adequate ongoing support in place to help people who are identified as being at high risk.
- The data is not held securely.



Figure 21: non-anonymised population tool group 2 edits

# Population tool (using non-anonymised data) conclusions

## Principles

## Red lines

G2

“Use of the tool is acceptable if....

- There is sufficient support in place to help people **notified** understand their risk score.
- The use of the tool, and reasons for using it, **and what to do if you are notified as being at high risk**, are clearly communicated to the general public.
- The score is **confidential to the individual with no legal requirement to share held confidentially** to minimise risk of stigma or discrimination.
- The tool is kept up-to-date in case of people moving from low risk to high risk **(and vice versa)** based on new evidence or changing circumstances **and people are duly notified of changes to their risk level**.
- There are data security protocols in place to ensure the tool is used only **by the** Scottish Government and NHS Scotland for the purpose of identifying people at risk of Covid-19 or other serious viruses.

“Use of the tool becomes unacceptable if...

- Data is shared with third parties **without consent**.
- There is not adequate support in place to help people who are identified as being at high risk.
- The data is not held securely.
- **The risk to public health from Covid at the time is minimal.**

Figure 22: non-anonymised population tool group 3 edits

# Population tool (using non-anonymised data) conclusions

## Principles

“Use of the tool is acceptable if....

- There is sufficient support in place to help people understand their risk score.
- The use of the tool, and reasons for using it, are clearly communicated to the general public.
- The score is held confidentially to minimise risk of stigma or discrimination.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.
- **There is a mechanism to challenge or change the outcome.**
- There are data security protocols in place to ensure the tool is used only by Scottish Government and NHS Scotland for the purpose of identifying **and supporting** people at risk of Covid-19 or other serious viruses.

## Red lines

G3

“Use of the tool becomes unacceptable if...

- Data **about individuals** is shared with third parties without consent.
- There is not adequate support in place to help people who are identified as being at high risk.
- The data is not held securely.



Figure 23: non-anonymised population tool group 4 edits

# Population tool (using non-anonymised data) conclusions

## Principles

## Red lines

G4

“Use of the tool is acceptable if....

- There is sufficient **targeted** support in place to help people understand their risk score **and infrastructure in place for people (e.g. for essential items or services)**
- **There is a means of support for people to contact themselves and check what is available and if it is adequate**
- The use of the tool, and reasons for using it, are clearly communicated to the general public.
- The score is ~~held~~ **stored** confidentially to minimise risk of stigma or discrimination.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances **(including in relation to the virus e.g. new variant)**
- There are data security protocols in place to ensure the tool is used only by Scottish Government and NHS Scotland for the purpose of identifying people at risk of Covid-19 or other serious viruses.
- **There is clear communication about who might provide support for the individual and how they might access the information (with consent)**

“Use of the tool becomes unacceptable if...

- Data is shared with third parties without consent.
- There is not adequate support in place to help people who are identified as being at high risk.
- The data is not held securely.
- **It is used to discriminate against individuals**

## Clinical tool – group edits

Figure 24: clinical tool group 1 edits

G1

# Clinical tool conclusions

## Principles

- “Use of the tool is acceptable if....
- Information is provided to explain to patients what the tool is and how it will be used.
  - **Communicate why this tool is available (as before), inc. GPs/healthcare professionals flagging this is available when they're already there**
  - Support is provided to help patients understand their risk score.
  - GP resources are not placed under too much burden
  - Patients have the option to **ask for their score** ~~refuse~~.
  - The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.

## Red lines

- “Use of the tool become unacceptable if...
- It collects personal information which is not needed for the tool to work.
  - **The data was kept after you've received your score.**

Figure 25: clinical tool group 2 edits

G2

# Clinical tool conclusions

## Principles

“Use of the tool is acceptable if....

- Information is provided to explain to patients what the tool is and how it will be used.
- Support is provided to help patients understand their risk score.
- GP resources are not placed under too much burden\*
- Patients have the option to refuse.
- The tool is kept up-to-date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances.

## Red lines

“Use of the tool become unacceptable if...

- It collects personal information which is not needed for the tool to work.
- If it detracts from GPs' ability to address other health needs.
- If your score is shared with anyone other than your GP without your consent.

\* Might involve outsourcing use to relevantly trained other parties rather than GPs

Figure 26: clinical tool group 3 edits

G3

## Clinical tool conclusions

### Principles

“Use of the tool is acceptable if...

- Information is provided to explain to patients what the tool is and how it will be used.
- **Practical and emotional** support is provided to help patients understand **according to** their risk score.
- **GPs can help patients understand their risk score.**
- GP resources are not placed under too much burden
- Patients have the option to refuse.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.

### Red lines

“Use of the tool become unacceptable if...

- It collects personal information which is not needed for the tool to work.
- **It impacts on GPs ability to deliver other more critical services.**

Figure 27: clinical tool group 4 edits

G4

## Clinical tool conclusions

### Principles

“Use of the tool is acceptable if....

- Information is provided to explain to patients what the tool is and how it will be used.
- Support is provided to help patients understand their risk score.
- GP resources are not placed under too much burden
- **GPs are trained to use the tool and interpret and communicate the results effectively**
- Patients have the option to refuse.
- **Results are confidential**
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances. **(including in relation to the virus –e.g. a new variant)**

### Red lines

“Use of the tool become unacceptable if...

- It collects personal information which is not needed for the tool to work.
- **Other parties can access the information**

## Public-facing tool – group edits

Figure 28: public-facing tool group 1 edits

G1

# Public facing tool conclusions

## Principles

“Use of the tool is acceptable if....

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, braille).
- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is guidance for using the tool to reduce the risk of misuse.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.
- **Re-work premise e.g. using the score from a clinician to input onto a public-facing tool that tells you about what actions you should be taking / how to access support**

## Red lines

“Use of the tool becomes unacceptable if...

- There is not adequate support in place to help people understand their score.
- There is no alternative for people excluded from using an online tool.
- The data can be accessed by anyone else.
- **It doesn't reach everyone who needs it i.e. exacerbates inequalities**
- **It can guaranteed that the data put in is accurate**

Figure 29: public-facing tool group 2 edits

G2

## Public facing tool conclusions

### Principles

“Use of the tool is acceptable if...

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, braille, **and simple language**).
- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is **clear, simple** guidance for using the tool to reduce the risk of misuse.
- The tool is kept up-to-date in case of people moving from low risk to high risk (**and vice versa**) based on new evidence or changing circumstances.

### Red lines

“Use of the tool becomes unacceptable if...

- There is not adequate support in place to help people understand their score.
- **If it is introduced on its own (without the clinical tool being available)**
- There is no alternative for people excluded from using an online tool.
- ~~The data can be accessed by anyone else~~ **Identifiable information is requested and/or stored.**

Figure 30: public-facing tool group 3 edits

G3

## Public facing tool conclusions

### Principles

“Use of the tool is acceptable if....

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, **braille or text to speech**).
- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is guidance for using the tool to reduce the risk of misuse, **and there are consequences for misuse. There should be a way to report suspected misuse.**
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances.

### Red lines

“Use of the tool becomes unacceptable if...

- There is not adequate support in place to help people understand their score.
- There is no alternative for people excluded from using an online tool.
- The data can be accessed by anyone else.
- **There is any obligation for people to pass on information about their risk.**

Figure 31: public-facing tool group 4 edits

G4

## Public facing tool conclusions

### Principles

“Use of the tool is acceptable if....

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, braille).
- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is guidance for using the tool to reduce the risk of misuse.
- The tool is kept up-to-date in case of people moving from low risk to high risk based on new evidence or changing circumstances. (including in relation to the virus –e.g. a new variant)

### Red lines

“Use of the tool becomes unacceptable if...

- There is not adequate support in place to help people understand their score.
- There is no alternative for people excluded from using an online tool.
- The **data information an individual inputs** can be **accessed used** by anyone else.

## **Summary of jury's principles and red lines for each tool**

### **Clinical tool**

#### **Use of the tool is acceptable if:**

- Information is provided to explain to patients what the tool is and how it will be used.
- It is communicated why this tool is available, including via GPs (or other healthcare professionals) to flag that it is available when with a patient.
- Practical and emotional support is provided to help patients according to their risk score.
- GPs (or other healthcare professionals) can help patients understand their risk score.
- GP resources are not placed under too much burden (which may involve outsourcing to relevantly trained health professionals rather than GPs).
- GPs (or other healthcare professionals) are trained to use the tool and interpret and communicate the results effectively.
- Patients have the option to ask for their score (and to refuse the option to discover their score).
- Results are confidential.
- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. a new variant).

#### **Use of the tool becomes unacceptable if:**

- It collects personal information which is not needed for the tool to work.
- The data is kept after you've received your score.
- If it detracts from GPs' ability to address other, more critical, health needs.
- If your score is shared with other parties (i.e. anyone other than your GP) without your consent.

### **Public-facing tool**

#### **Use of the tool is acceptable if:**

- There is sufficient support in place to help people understand their risk score.
- It is accessible (e.g. alternative formats – language translations, large print, braille or text to speech, and simple language).

- There are alternative ways of accessing the score for those who are not online or who require additional support.
- There is clear, simple guidance for using the tool to reduce the risk of misuse, and there are consequences for misuse along with a way to report suspected misuse.
- The tool is kept up to date in case of people moving low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. a new variant).

**Use of the tool becomes unacceptable if:**

- There is not adequate support in place to help people understand their score.
- It is introduced on its own (without the clinical tool being available).
- There is no alternative for people excluded from using an online tool.
- The information an individual inputs can be accessed and/or used by anyone else.
- Identifiable information is requested and/or stored.
- It doesn't reach everyone who needs it i.e. exacerbates inequalities.
- There is any obligation for people to pass on information about their risk score.
- It can be guaranteed that the data put in is accurate.
  - Note that the group who deliberated this final “red line” recognised this would not be plausible without a medical professional present, at which point it becomes the clinical tool. They therefore suggested changing the intended use of the public-facing tool to maintain intentions of empowerment but reduce the risk e.g. using the score from a clinician, provided using the clinical tool, to input onto a public-facing tool that provides information about actions that should be taken and how to access support.

**Population tool (using non-anonymised data)**

**Use of the tool is acceptable if:**

- There is sufficient targeted support in place to help people notified understand their risk score and infrastructure in place for people (e.g. for essential items or services).
- There is a way for people to access further support if needed.

- Information about the use of the tool, and reasons for using it, and what to do if you are notified as being at high risk, is available and clearly communicated to the general public i.e. without jargon.
- The score is stored confidentially to the individual, with no legal requirement to share, to minimise risk of stigma or discrimination.
- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. new variant), and people are duly notified of changes to their risk level.
- There is a mechanism to challenge or change the outcome.
- There are data security protocols in place to ensure the tool is used only by the Scottish Government and NHS Scotland. In the case of QCovid®, this would be for the purpose of identifying and supporting people at risk of Covid-19 or other serious viruses.
- There is clear communication about who might provide support for the individual and how they might access the information (with consent).
  - Note that, while this was included as a principle, one group deliberated (without reaching consensus) the potential for including an opt-out option for people, as choice is important in terms of rights and building trust, so long as this doesn't impact anonymous data collection and data accuracy or important behaviours that keeps prevalence low.

#### **Use of the tool becomes unacceptable if:**

- Data about individuals is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.
- There is not adequate ongoing support in place to help people who are identified as being at high risk.
- The data is not held securely.
- The risk to public health from Covid-19, or another virus, at the time is minimal.
- It is used to discriminate against individuals (e.g. in the workplace or in accessing services such as insurance).

#### **Population tool (using anonymised data)**

##### **Use of the tool is acceptable if:**

- Information about the use of the tool, and reasons for using it, is available and clearly communicated to the general public i.e. without jargon.

- Note that some felt the information should be available where others felt it should be presented i.e. during a public briefing by a medical professional. Some also felt medical professionals should be kept up to date in order to keep their patients up to date.
- The tool is kept up to date in case of people moving from low risk to high risk (and vice versa) based on new evidence or changing circumstances (including in relation to the virus e.g. new variant).
- The data is agile and able to adapt as new situations arise (including change in profile of the population).
- The data is to be used by Scottish Government and NHS Scotland only for the purpose of resource planning, research and informing the public.
- There are data security protocols in place to ensure the tool is developed and used appropriately (e.g. resource planning or valid/justifiable research by verified third parties e.g. non-profit research institutes).

**Use of the tool becomes unacceptable if:**

- Data is shared with third parties for purposes that do not align with healthcare-related public benefits relating to the pandemic.
- Data is not protected from commercial companies accessing it.
- There is any collaboration with data farm companies.
- It is used to discriminate against certain groups (e.g. being denied access to certain services based on age or ethnicity).



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