**Guidelines on reading the summary**

# These are guidelines for reading the focus group summary you have been sent by email. If you have any more questions you can get in touch with Georgia at [gaitkenhead@turing.ac.uk](mailto:gaitkenhead@turing.ac.uk). She can also talk you through the summaries and take your feedback via. phone call or Skype if you would like.

The summaries are long because we wanted to make sure they represented the variety of views expressed in the focus groups. In recognition of this, we’ll pay all insight group members £30 for the extra time it takes to look through them.

You will be paid whether or not you ask us to make any changes.

# **What is the summary and how was it written?**

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On [date] you came to a focus group Fujitsu to talk about a project to design a platform to use for autism research.

The focus group was recorded.

The focus group was written down word-for-word apart from personally identifying information, which was taken out.

Personally identifying information includes:

* Names of individuals
* Precise ages
* Schools, workplaces, universities, and addresses

The recordings were then deleted.

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Quotations were taken from the document, shortened, and organised into groups based on common themes. These are the summaries you have been sent.

# **What Happens Next?**

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You will have a chance to review the summaries and make changes.

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The summaries will be openly published online at: <https://github.com/alan-turing-institute/AutisticaCitizenScience>

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Your suggestions will be turned into a to-do list for the project team of researchers, developers, and designers, and for the wider community.

They will be used to help build the citizen science platform. We can’t do everything, but we will try our best to follow your suggestions.

# **What now?**

You now have the opportunity to look through the summary and let us know if there is anything you would like changed. This is so that you can be sure we are using the information you give us in a way you know about and are comfortable with.

We will take out any of your own comments if you ask us to.

You can also ask us to change comments from you, or to include additional information. These will be included in the published summary, with a note to explain that they were changed from the original summary.

Please email Georgia at [gaitkenhead@turing.ac.uk](mailto:gaitkenhead@turing.ac.uk) with any changes you would like to be made to your comments. The summaries will be published in two weeks time.

It is up to you how you decide if anything needs to be changed or taken out, but here are some things you might want to think about:

**1.** Would you be happy for a stranger to read this comment?

**2**. Is there anything in this comment which would make it clear who you are to a stranger?

**3.** Is there anything in this comment which would make it clear to a family member, colleague, or friend that you are the speaker. If so, are you happy for them to read it?

**4.** Is there anything in the comment which would allow other people to know that they are being spoken about? If so, are you happy for them to read it?

**5.** If you are writing about someone else, would they be happy for the comment to be public? If you can, ask them directly.

# **About the Tagging System**

Every comment is tagged with letters. The tags were co-designed with autistic people in scoping sessions and meetings.

## Here is the complete key:

**Where From**

*A* = Autistica

*F* = Fujitsu

*T* = Turing

This tag is used to show which organisation the speaker is from. Autistica is an autism research charity which funds the project and recruits members for the Insight Group. Fujitsu is a tech company which has put together a development team to help the project and is offering free support. The Turing is the UK’s national institute for artificial intelligence and data science, and is funded to carry out the project.

**Specialist Role on Project**

R = Researcher

This tag shows that the comment comes from someone who is one of the core researchers of the project.

**Connection to Autism**

**A** = Autistic

**P** = Parent of someone Autistic

This shows the speaker’s connection to autism

**Connection to Experience**

d = direct: experience or opinion of speaker

i = indirect: witnessed, reported, or inferred on behalf of someone else by speaker

g = general comment

This gives some more information which might be needed to understand the comment. For example, in the comment “she can tell every different flower apart by its scent - delightful”, a parent of an autistic child might be speaking about their own delight that their child has such a skill (direct - d), or their child’s delight at smelling the flowers (indirect - i).

A comment which is not attached to a specific experience or applies to everyone is tagged as g, for example, ‘people want lots of options’.

If you would like any tags to be removed from your comments, for instance because you think it makes you too easy to identify, we will remove them if you ask us.

# **Thank You!**

We also always welcome general feedback.

Please email [gaitkenhead@turing.ac.uk](mailto:gaitkenhead@turing.ac.uk) with any feedback or requests for changes.