



Spectrum 10K consultation Phase 2: the Co-design

What was said about how to design an effective
consultation

Executive Summary

An independent report

Hopkins Van Mil & Karen Leneh Buckle



A note about analysing the findings of Phase 2

We have used mainly qualitative research techniques. In qualitative research we do not report on the number of times something was said, but rather the strength of feeling expressed across the methods used. We chose this approach in order to have a genuinely co-designed process from which new ideas can come from discussions. Throughout the report:

- Bullet points are used to summarise key points made, these mostly reflect areas of agreement and where points were made by many people across many of the groups
- Terms such as ‘a few’, ‘several’, ‘some’ or ‘many’ are used to reflect particular areas of agreement and difference
- Anonymised quotations are used to highlight points made by a number of co-designers
- We do not edit these quotations so as not to distort the speaker’s meaning
- In this report we describe those who took part in Phase 2 as ‘co-designers’ and those who will take part in Phase 3 as ‘consultees’.

Contents

1. Background (introduction)
2. What happened in Phase 2 (method)
3. What co-designers said about the consultation (results)
4. Recommendations (discussion)



1. Background

In this section of the report we explain who is leading the consultation. We describe the three phases of the consultation.

The consultation is jointly led by

- Hopkins Van Mil (HVM)
- Leneh Buckle
- Spectrum 10K

*Who is leading
the consultation?*

HVM's role:

- Co-lead the process
- Work as independent and impartial facilitators
- Listen to and explore the perspectives of the autism community to find constructive ways forward.

Leneh Buckle's role:

- Co-lead the process
- Work with HVM to facilitate communication and engagement with autistic people
- Ensure there is an autistic voice in the design and interpretation of the consultation.

Spectrum 10K's role:

- Co-lead the process
- Be part of the consultation co-design and the consultation
- Use the findings from the consultation to inform and adapt Spectrum 10K.

*The three phases of the
consultation process*

Spectrum 10K Consultation

Phase 1

Deciding who should be involved in co-designing the consultation

*Completed
March 2022*

Phase 2

Co-designing the consultation

*From
September to
October
2022*

Phase 3

The consultation

*From
January to
March 2023*



2. *What happened in phase 2*

In this section of the report we describe who was involved and what we did in Phase 2.



What happened in Phase 2

Who was involved?

- From a pool of 429 applicants, 130 people (85% autistic) were selected to be co-designers
- 111 people (85% autistic) were able to commit to taking part in Phase 2 from a range of genders, ages, ethnicities, support needs, views, and experiences.
- We used a variety of qualitative methods
- And three formats:
 - A series of 4 Zoom workshops with 22-24 people.
 - An online space for those involved in the workshops and 79 others
 - 1:1 interviews with 8 co-designers (7 on Zoom, 1 by email)
- Supplemented with online polls, prioritising and multiple-choice questions



3. What co-designers said about the consultation

In this section of the report we describe what was said in Phase 2 about how to design the consultation.



What co-designers discussed

Co-designers reviewed a list of questions and concerns that have been raised about the study and added further topics the consultation should cover.

Co-designers said:

- That autistic people must be a majority of the consultees
- Consultees should reflect diverse lived experiences and views
- Consultation design should be accessible for any autistic person who wants to take part
- The consultation should use a range of methods to suit different needs
- The consultation should adopt a staggered approach, giving people time to reflect and form their opinions
- Consultees need regular 'next steps' emails and updates are needed on HVM and Spectrum 10K websites to keep them informed.



2. Recommendations

In this section we explain the recommendations that have come from listening to what was said by the people who took part in Phase 2.



Overarching principles

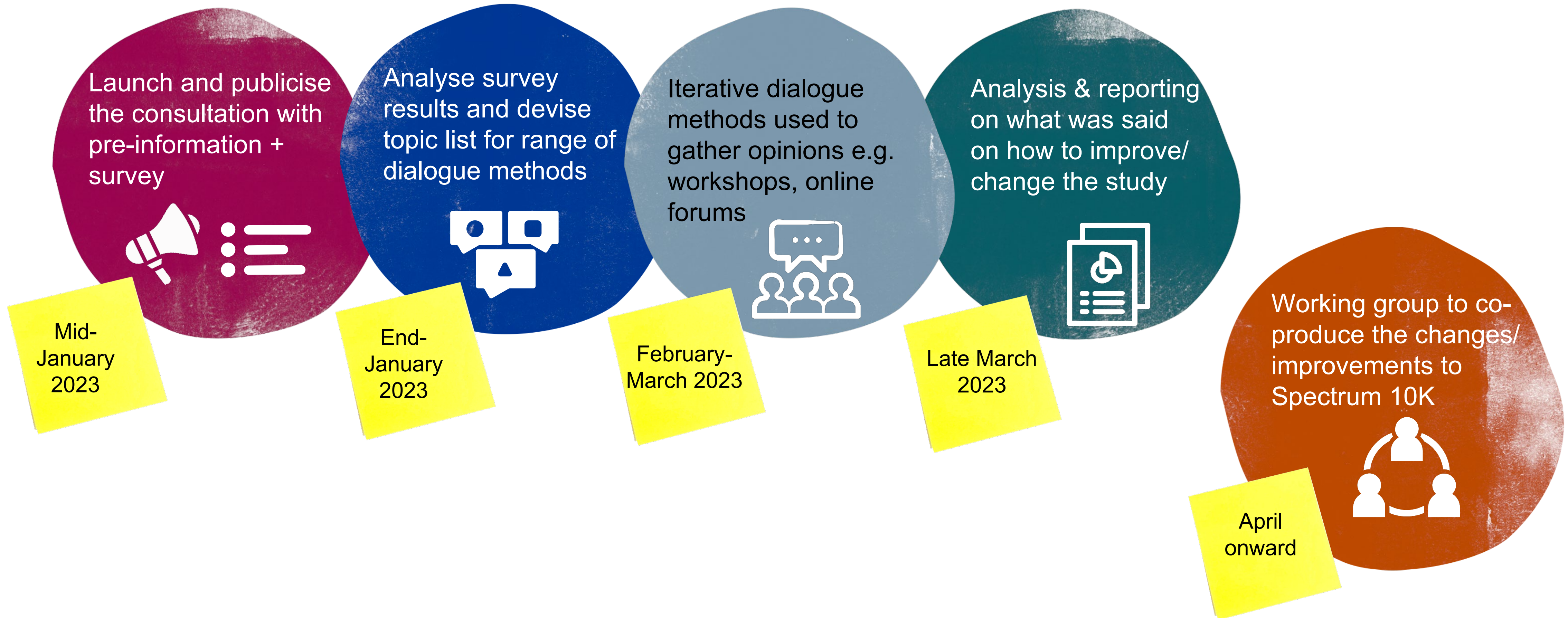
1. Build trust in the process
2. Make real change to the study
3. Show the consultation is designed by autistic people
4. Create a space for constructive discussion



Take time, but not too long, to conduct the consultation

Consultation timetable

Phase 3 Consultation





Information for consultees

Co-designers said that the following information would be useful for consultees:

- Information about the Spectrum 10K project
- Information about criticisms
- Response to straightforward factual questions in advance
- As much as possible, provide materials and topics in multiple formats for maximum access (e.g. plain English, Easy Read, video).



Who should be involved

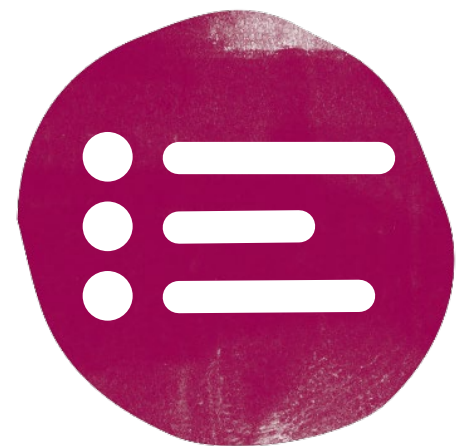
Phase 2 co-designers said that the consultation should:

- Primarily focus on the views of autistic people.
- Include a similar range of backgrounds and interests as in Phase 2.
- Be open to anyone who wishes to share their views
- Not have a restriction on the number of people who can take part

Consultation format

Phase 2 co-designers said that the consultation should:

- Take a staggered approach where one stage feeds into the next and topics are revisited as necessary.
- Include multiple means of engagement (e.g. speech, text, pictures).
- Have two stages:










- A wide survey of views on all topics related to the Spectrum 10K study



- Opportunities for in-depth discussion and engagement with researchers. Confront contentious topics openly and early.

How success should be measured

The consultation is successful if:

-  It is – and is seen to be – transparent
-  Information provided is accurate, accessible and clear
-  It provides a constructive space where consultees' opinions are heard
-  It includes a balance of positive, negative and neutral aspects of autism
-  It builds trust in the study and the research team
-  It has influence on the study
-  It shares learning

Co-design of the Spectrum 10K consultation

For further information on the Spectrum 10K
consultation contact:

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