

Easy read booklet



Spectrum 10K consultation

What was said about how to plan a good consultation





Who we are and what this booklet is about



We are **Hopkins Van Mil.** We help people and organisations talk to each other.



We are helping with a **consultation** about the **Spectrum 10K study**. A **consultation** is a way to get peoples views and thoughts about something.



The **Spectrum 10K study** is to learn more about **autism**. **Autism** affects how people act, communicate, learn and behave.



This consultation is in 3 parts called Phase 1, 2 and 3. In this booklet we explain what happened in Phase 2 and what will happen in Phase 3.

Background



The consultation is run by

- Hopkins Van Mil
- Leneh Buckle
- Spectrum 10K



Hopkins Van Mil will

- listen to what people with autism say in this consultation and find good ways to make the Spectrum 10K study better.
- work as an independent and impartial facilitators.





An **independent and impartial facilitator** means we help with the consultation, but we do not have a say or take sides.



Leneh Buckle will

- help plan the consultation.
- work with us to make sure autistic people have their say and can join in the consultation.





Leneh Buckle is autistic.



Spectrum 10K will

- help plan the consultation.
- look at what is said in this consultation and use it to make the Spectrum 10K study better.



The consultation phases



The consultation is in 3 parts called Phase 1, 2 and 3. We have finished Phase 1 and 2.



Phase 1

We decided who should take part in helping plan the consultation. We finished Phase 1 in March 2022.



Phase 2

We planned the consultation. Phase 2 happened between September and October 2022.



Phase 3

The consultation happens.
This will happen between January and March 2023.

What happened in Phase 2



Here we tell you who took part in Phase 2 and what we did.



 429 people asked to take part in Phase 2 and help plan the consultation.



• 130 people were chosen to take part. We call these people **co-designers**. About 110 of the people chosen were autistic.



 111 of the people chosen took part. About 95 of them were autistic.

 The people who took part were a mix of genders, ages, ethnicities and support needs. Ethnicity means your background.



We used **qualitative methods** to help us choose who could be co-designers.



Qualitative methods means we did not look at the number of times something was said, but how strongly the person felt about what they were saying instead.



To speak with the co-designers we had

- 4 online video calls with 22 to 24 people on the call.
- a place co-designers could talk online.



 person to person interviews with 9 of the co-designers. 8 by video call and 1 by email.



We had online surveys with multiple-choice questions.



What co-designers said about the consultation



Co-designers looked at a list of questions and worries about the consultation. They also added their own ideas about what should be looked at.



Here we tell you what co-designers said in Phase 2 about the consultation that will happen in Phase 3.



Most of the **consultees** in Phase 3 should be autistic.



A **consultee** is someone who is taking part and having their say in the consultation.





Consultees should have different **experiences** and views. **Experiences** are things you have done in your life.



The consultation plans should be **accessible** for any autistic person who wants to take part. **Accessible** is when something can be used or understood by anyone.



The consultation should think about the different needs each consultee might have so they can take part.



Consultees should have time to think about what they are being asked and what they have said.



Consultees should be sent emails to let them know what happens next. The consultation website should tell people what is happening.



Recommendations



We made 4 suggestions about what to do next after listening to the co-designers in Phase 2. We call these **recommendations**.



Recommendation 1

Make sure people trust the consultation.



Recommendation 2
Make good changes to the
Spectrum 10K study.



Recommendation 3
Show the consultation has been planned by autistic people.

Recommendation 4



Have a place where people can share their ideas and talk about the consultation and the **Spectrum 10K study**.

What happens in Phase 3



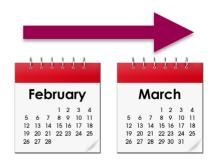
Phase 3 starts in the middle of January 2023.



We will tell people that the consultation has started and send out a survey to the consultees.



At the end of January 2023 we will look at what the consultees said in the survey.



Between February and March 2023 we will find out what consultees think by speaking to them in workshops and online.





At the end of March 2023 we will look at what people said and think of ways to make the **Spectrum 10K study** better.



After April will make changes to the **Spectrum 10K study** to make it better.



The co-designers said that we should take our time to make sure we do a good job but not take too long to finish the consultation.



What the consultees should know in Phase 3



Co-designers said that we should tell consultees more about the **Spectrum 10K study**.



They said that we should tell consultees any bad things about the **Spectrum 10K study**.



We should answer any questions consultees have as soon as possible.



Our information should be accessible using plain English, Easy Read or videos.

Who should take part in the consultation



Co-designers said that we should mainly think about the views of autistic people.



The consultees in Phase 3 should have similar interests and backgrounds as the co-designers in Phase 2.



We should listen to anyone who wants to share their thoughts and views.



Any number of people should be allowed to take part.



How the consultation will work



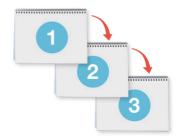
We thought about what the codesigners said when we planned how the consultation will work.



We will speak to people using different ways, like speech, text or pictures, to make sure anyone can take part.



Co-designers said the consultation should happen in **stages**.



When we break the consultation down into smaller parts, we call them **stages**.





There will be **2 parts** to the consultation.



Part 1 will be a large survey of consultees views on the **Spectrum** 10k study.



Part 2 will be a chance for consultees who want to to ask questions and talk with the researchers. A researcher works on the consultation and study.



The co-designers said that difficult things should be talked about at the start of the consultation in an open way.



How we will know if the consultation worked well



Here we tell you how we will know if the consultation worked well.



The consultation is **transparent**, and people know that it is. **Transparent** means people can see how it works and what has been done.



The information we give out in the consultation is correct, accessible and clear.



The consultation is a place where consultees thoughts and views are heard.



The consultation has good, bad and **neutral** views.



Neutral means views that are in the middle. They are not goo or bad.



People trust the consultation and the researchers.



The consultation is thought about in the **Spectrum 10K study**.



What is learn on the consultation is shared with other people and organisations.



Contact us



If you have any questions or want to know more about the **Spectrum 10K study**, please contact us.



Send an email to us at this address consultation@hopkinsvanmil.co.uk

Thank you to A2i for the words www.a2i.co.uk (reference 36289)



The full version of this document is called

What was said about how to design an effective consultation

Executive Summary

