Spectrum 10K Phase 1: Planning Phase 2 - The consultation co-design

1. Report methodology
2. What has happened in phase 1
    - Purpose of phase 1
    - Meetings held
3. Involvement in the co-design phase
4. Initial ideas for the co-design phase
5. Proposals for phase 2
    - Suggested timetable

Appendix: comments added after the meetings by phase 1 participants

Spectrum 10K Phase 1: Planning Phase 2 - The consultation co-design

1. Report methodology

Hopkins Van Mil (HVM) is a social research agency

We specialise in using qualitative research methods to listen to people's views and summarise what people have told us in reports.

At HVM we focus on facilitating engagement so that:
- voices are heard
- learning is shared
- understanding is achieved.

This means using a range of qualitative research tools to find the best way for people to explore their hopes, fears, challenges and aspirations for the future.

We create safe and trusted spaces for productive discussions.

Phase 1: Included small discussion groups

The HVM researcher spoke to the following groups:

- **Autistic people**
  - **5 participants in a group meeting**
  - **1 participant in a 1-2-1 interview**
  - **3 participants in a group meeting**
- **Autistic people conducting autism research:**
  - **6 participants**
- **Clinicians and charities**
  - **3 participants**
- **Spectrum 10K team**
  - **6 participants**
- **Spectrum 10K PPI Advisory Panel**
  - **6 participants**
- **Spectrum 10K Ambassadors**
  - **5 participants**

How this report was written

Participants to Phase 1 were recruited by open calls for people to join using, for example, NIHR's People in Research portal, and by sending requests to individuals and organisations as widely as possible. This included those who have been involved in Spectrum 10K previously and those who have not. This process is a stakeholder mapping exercise to understand who is interested in the consultation process.

This report summarises what the researcher from HVM heard whilst facilitating these discussions. The discussions were recorded and anonymised transcripts of what was said were used to create this report. The recordings have now been deleted and the report is drawn from the written transcripts and from the Chat which was saved during the discussions.

Standard qualitative research methods were used to review what was said. This means that we do not report on the number of times something was said, but rather the strength of feeling expressed across the discussion groups. We use grounded theory which means we read, and re-read, the transcripts many times, review what was said in groups and across the groups. We collate what was said into key themes (called codes) and from these draw out the meaning from the 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 occasionally used to reflect particular areas of agreement and difference
- Quotations are used to highlight points made by a number of participants and to underline points made by a range of participants across the discussion groups. These quotations are not edited so as not to distort the speaker's meaning
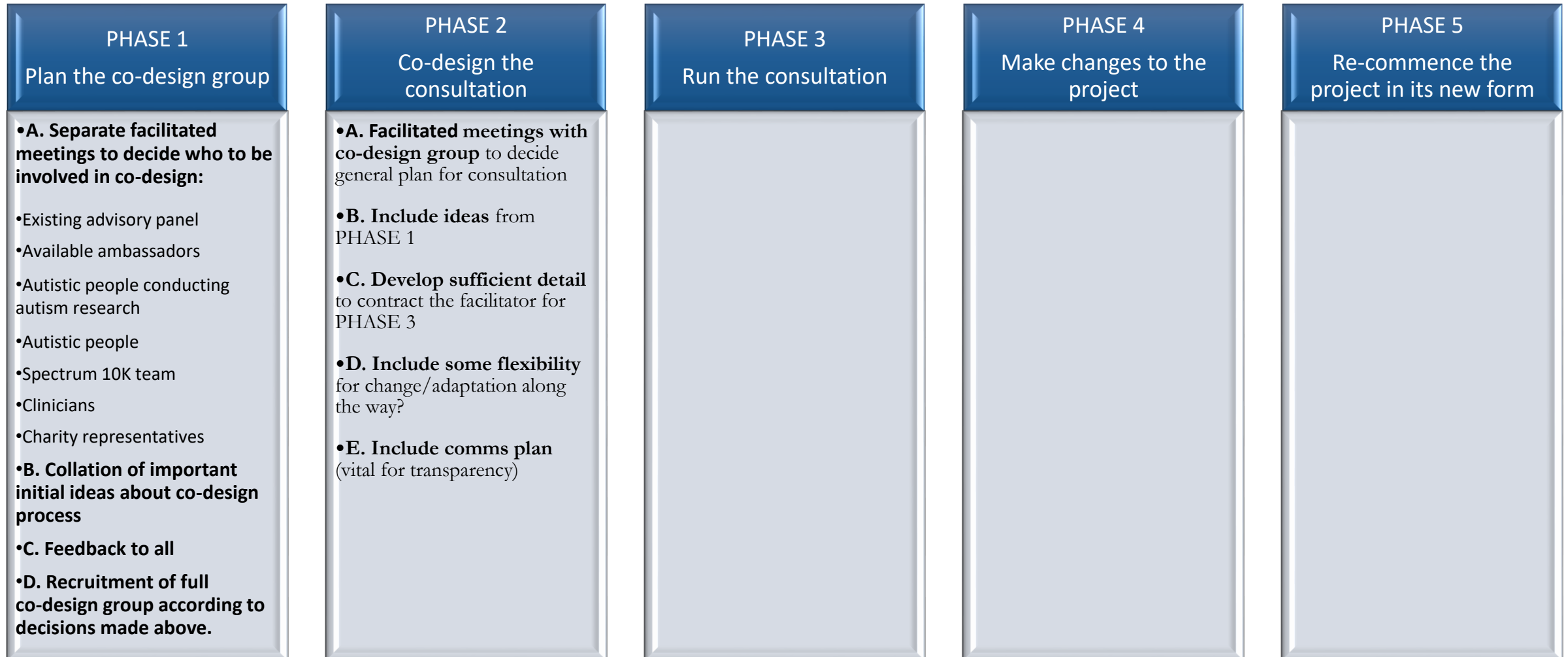
2. What has happened in phase 1

Purpose of phase 1

Spectrum 10K statement 4th September: "We now want to co-design a wider consultation process with autistic people and their families to make sure that the views of the whole autistic community are gathered systematically, properly considered, and represented."

PHASE 1 Plan the co-design group	PHASE 2 Co-design the consultation	PHASE 3 Run the consultation	PHASE 4 Make changes to the project	PHASE 5 Re-commence the project in its new form
•**A. Separate facilitated meetings to decide who to be involved in co-design:** •Existing advisory panel •Available ambassadors •Autistic people conducting autism research •Autistic people •Spectrum 10K team •Clinicians •Charity representatives •**B. Collation of important initial ideas about co-design process** •**C. Feedback to all** •**D. Recruitment of full co-design group according to decisions made above.**	•**A. Facilitated** meetings with **co-design group** to decide general plan for consultation •**B. Include ideas** from PHASE 1 •**C. Develop sufficient detail** to contract the facilitator for PHASE 3 •**D. Include some flexibility** for change/adaptation along the way? •**E. Include comms plan** (vital for transparency)			

3. Involvement in the co-design phase

Involvement in the co-design

When discussing who should be involved in the co-design phase participants in all the discussion groups emphasise the need for an inclusive approach to enable the full range of people to inform the next steps for Spectrum 10K. They stress the importance of mapping those who have an interest in Spectrum 10K, and ensuring the co-design is representative including those who may be less inclined to be involved in planning the consultation. There is an understanding that the groups of people who might be interested in taking part in the research could be self-limiting. The following three quotations highlight these points:

"The first step is a stakeholder map. There isn't any point in this conversation until that has happened."

"I don't want to say something like 250 (people involved) but I think that the bigger the pre-consultation involvement you can have, the better, because you're going to get the voices and representation from the biggest group and that will then inform the actual consultation phase in a really powerful way in my opinion."

"You might get to saturation point quicker than you expect. But plan for larger numbers rather than smaller numbers, because there's so much diversity among autistic people and I think it's really important to take account of intersectionality and of co-occurring conditions and of the different profiles of autistic people."

Who needs to be represented?

Many participants in these discussions say that:

Autistic people are central to the co-design of the consultation
- A process led/ facilitated by autistic people who are experienced researchers
- A majority of autistic people involved in the co-design process
- Elevating the voices of autistic people to demonstrate that Spectrum 10K is listening
- This is seen as important in aiming to prevent miscommunication/ misunderstandings

Stakeholders – again majority autistic people
- The Spectrum 10K Advisory Panel
- Specialists in participatory design and research
- Charities - those representing autistic people and their families
- Clinicians
- The Spectrum 10K research team
- Researchers from other studies
- Mental health professionals
- The HRA providing guidance to inform the ethical review process

Who needs to be represented?

A range of perspectives

- An inclusive approach to co-design so that all those who wish to engage in Spectrum 10K can input into how the consultation process is designed
- A balanced representation from those who support, those who are critical, and those who are unaware or are neutral about the Spectrum 10K study
- A broader representation of the autistic population – many participants include here:
    - Non-speaking autistic people and/or those who communicate via AAC
    - Autistic people with intellectual or learning disabilities, including those whose needs and interests might require representation by proxies (advocates)
    - Autistic people with co-occurring conditions and/ or who are multiply disabled
    - Autistic parents of autistic children
    - A few participants also included non autistic parents of autistic children
- Ensuring a range of ages, racial and ethnic minorities, genders, LGBTQ+ representation

Participants stress that involvement mustn't be tokenistic, "Make sure that the people who do get involved, in whatever stage, are protected and actually have a bit of power so that it's not pointless and detrimental."

And that those who have been critical of the study should be involved in this process, "Critics are so important in order to ensure the highest standards are met. Criticism pushes research forward, improves processes and outcomes. The peer review process is a good example, and scepticism is different from constructive criticism."

4. Initial ideas for the co-design

Points raised about phase 2

Participants feel that it is critical that phase 2 is done well to ensure that it prepares everything that needs to be prepared for phase 3 – the consultation. One participant reflects the views of many of the participants in each of the groups by saying, "This is probably the place where we need to put as much detail and effort as possible."

Participants across all groups agreed that the **co-design process should:**
- Have very clear aims and objectives, there must be no ambiguity about:
    a. What the co-design aims to achieve
    b. What the consultation process aims to achieve
    c. What the Spectrum 10K research programme aims to achieve
- Demonstrate the "respect, empathy and humanity" due to all those involved

Many participants said that this process:
- Should build on a draft process framework, so those involved in the co-design will have something to amend, comment on and work wit
- Recognise that this phase is critical in gaining trust for the consultation process and what follows.

Options put forward by participants:
- **Take a thematic approach** to involving people e.g. people sign up to design the area of the consultation that most aligns with their interests and needs
- **Take a question based approach** to involving people e.g. people sign up to respond to a specific question posed during the co-design phase
- Design the consultation around the specific concerns raised about the study
- A multi-method process design which includes each of these elements

Co-design dilemmas raised by participants

1. Speed of the process

- Building momentum towards the consultation phase
- Whilst ensuring the co-design phase does not go so fast that people find it tokenistic
- And that the co-design phase is efficiently run because it is focused and managed well

2. Being effective

- Creating a co-design process which is inclusive
- Ensuring there are enough and a diverse range of people so that the process builds trust/ can be trusted
- Whilst not making the process so large it is impossible to hear people's views effectively, and is unmanageable and unfeasible

3. Recruitment and safeguarding

- Recruiting those who are concerned their involvement will harm the relationships within their personal and professional networks
- Involving a diverse and inclusive group of people in the co-design
- Whist protecting their anonymity
- And taking all steps to try not to increase risk of trauma and distress, a few participants suggest having sources of support available during the consultation if needed
- A few participants raised concerns about previous actions of some Spectrum 10K autistic ambassadors and want the consultation process to address those concerns.

Essential practicalities for phase 2

Those who joined the discussion groups highlight the need to:

- Create 'ways of working' agreements
- Build anonymity in to the process, protecting people's privacy and safeguarding against the jeopardy of feeling that taking part in the co-design might cause harm either to their sense of self and their place in their own networks and communities, and/ or professionally
- Ensure people can contribute outside work commitments e.g. evenings and week-ends
- Use a range of accessible consultation formats:
  - Small-scale workshops with full use of the 'chat' function and live transcription if held online
  - Which are independently facilitated and are very clearly timed and structured
  - Creating an environment whether on or off-line where people can feel safe and able to contribute
  - Sharing all questions/ information in advance
  - Follow up emails to ask further specific questions after having been involved in workshops
  - 1-2-1 interviews
  - In writing responses e.g. an online forum or platform or emailed in responses to specific questions
  - Surveys which can be part of a workshop e.g. zoom polls or separate from it e.g. survey monkey and equivalent online platforms
  - Enabling Augmentative and Alternative Communication (AAC) users to take part
- For all formats - give people opportunities to think about their responses
- Those involved in the co-design process should be paid for their time and the experience they bring

5. Proposals for phase 2

Participants in most of the discussion groups speak of the need to ensure that the process is meaningful and rewarding for all those concerned. Clarity on what the expected outcomes of Spectrum 10K are needed was a point made by many across most of the discussion groups. These two quotations highlight the points made by many:

"This must have reciprocity, so if people are giving you their time, energy, emotions and they're getting nothing in return, it's not a co-design relationship. It's more like opinion harvesting. So make it an ongoing and mean it."

"If you look at what the researcher's aims were for the study, they look good. The issue has always been that the ethics and the actual research methods. And then its snowballed because the longer the researchers haven't explained it and giving the information that's needed. I mean I still don't know if I had given my DNA what they would have done with it."

An inclusive *and* manageable process

Three proposals made by participants in the discussion groups on the number of people are:

- **A large panel of people** – up to 250 who are invited to form a co-design panel
  - People join the process in the ways in which they can best make their contribution
  - At points where they feel they have a contribution to make
  - There are small-scale workshops (no more than 6 people)
  - With ways of contributing in writing, via video/ audio recording **without attending workshops**
  - With ways of contributing in writing, via video/ audio recording **to supplement contributions made at workshops**

- **A core co-design group of circa 24-36 people**
  - Who meet in small-scale workshops (no more than 6 people)
  - With ways of contributing in writing (e.g. email responses to specific questions), via surveys, via video/ audio recording **without attending workshops**
  - With ways of contributing in writing (e.g. email responses to specific questions), via surveys, via video/ audio recording **to supplement contributions made at workshops**
- Including 1-2-1 interviews for those who prefer to work in this way

- **Combining these two options** so there is a large-scale panel and a core co-design group

The content of the co-design phase

Proposals discussed by participants on the content of the co-design phase are:

- **Take a thematic approach** to involving people e.g. people sign up to design the area of the consultation that most aligns with their interests and needs
- **Take a question based approach** to involving people e.g. people sign up to respond to a specific question posed during the co-design phase
- **Create the co-design phase around the specific concerns** raised about the study, using a definitive list drawn from what has been said in blogs, social media and in protests about the study to create a series of key questions which are used in the co-design phase to create the framework for the consultation itself. As a result the co-design will be based on:
  - Specific questions e.g. 'How can we create a consultation which responds to this specific issue?'
  - Key themes e.g. DNA consent; autistic representation within the study design; clarity on what the DNA samples collected will be used for; security of genetic data
- Allow **sufficient flexibility** to ensure that the co-design phase creates a consultation framework which allows people to raise concerns which are not yet known yet: bringing in new thinking, demonstrating that the study is listening to people's views and hearing all concerns, whether known about yet or not.
- Use the co-design process **to embed trust** in the whole process, ensuring anxieties are not compounded by taking part, answering questions as openly as possible

6. Co-design principles proposed

Participants in many of the discussion groups spoke of who should facilitate phase two. They also shared the view that there are autistic people who will not wish to be involved in the co-design or the consultation, but might be more inclined to do so if an autistic person is facilitating the process.

"You've heard of the double empathy problem, where non-autistic people and autistic people find it difficult to understand each other. I think, if you've got an autistic facilitator and autistic people leading the co-design, you're reducing the chances of misunderstandings, you're reducing the chances of bias. You are also addressing that issue of the power imbalance, where autistic people are done to, are done on, are just offering their opinion when actually if autistic people are given some of the power to be running and facilitating this that would say a lot about how much researchers are listening."

"I know a lot of autistic people that wouldn't come anywhere near a consultation like this with a barge pole. If they knew that autistic people were running and leading it, they might be more likely to. This could mitigate a lot of the trust issues that autistic people have in being involved."

Co-design principles proposed

- Autistic people are the majority voice in the co-design process
- Autistic people lead and facilitate the co-design process
- Independent facilitation is important
- The co-design will be a transparent process well communicated to all those who have a stake in it
- Ensure this is truly 'co-design' not something being 'done to' the group
- Do not use "demeaning, de-humanising, pathologising and/ or deficit based language"
- Safeguarding all those involved: the process will not create distress. It will support people to contribute safely
- Enabling people's engagement in co-design to be completely anonymous
- Trust remaining front of mind at all times
- There will be clearly stated aims and objectives for each of the phases 2-5
- The first co-design meetings will refine and confirm the aims and objectives of the co-design/ consultation phases
- The potential outcomes of Spectrum 10K will be clear so that people can understand how their involvement in the consultation will work in relation to the study
- Part of the process must be that the study will change in response to what happens in the consultation

Co-design principles proposed

- Meeting agreements will be embedded into all co-design approaches
- These will include an agreement that if you are involved in the co-design you will not prevent the process moving forward to the consultation phase
- The co-design process will be created around clearly defined questions and themes
- It will take a multi-modal fully accessible approach which enables people to be involved in the co-design in the ways in which they can best contribute including workshops, polls during workshops, the chat during workshops, surveys, email responses to specific questions,
- Workshops will be held at times that people are available, more likely evenings and week-ends than on weekdays
- It will be clear that there is a difference between the Phase 2 co-design and the Phase 3 consultation
- Participants in Phase 2 can continue into Phase 3
- Participants are paid for their contribution in recognition of their time and experience

A suggested framework for co-design

Recruit mainly from the autistic community – conduct stakeholder mapping to ensure the process is inclusive

Engage an autistic person with participatory research experience to lead facilitate the process

Enable anonymous contributions ensuring safeguarding is front of mind at all times

A core co-design working group of 24-36 people meeting in a series of workshops – no more than six people attending any one workshop

A wider co-design panel who contribute asynchronously to the process: surveys, email responses to key questions, audio and video file submissions

Each member of the core co-design group attends two workshops one week apart. Workshops are no longer than 2 hours and include workshop polls and use of the chat & assistive technologies

The core co-design group can also contribute asynchronously outside of workshops should they wish to provide supplementary information

Specific questions/ themes, and a framework for phase 3, shared in advance and addressed in the workshops and in the asynchronous process

Keep a momentum to the process. Co-design concluded in April.

Appendix: comments added after the Phase 1 meetings

The following additional comments were made by Phase 1 participants after the meetings, they are summarised using the words shared by participants:

- Consultation should use relevant guidance on participatory research as a point of reference, e.g. the NICE guidelines
- Include visioning and scenario planning to identify what good looks like and build process evaluation into the design
- Be clear about what the team will do if the research findings are inconclusive
- The larger the stakeholder list, the bigger the expectations
- Missing from the stakeholder list currently are educators, employers, criminal justice and social workers - i.e. the autistic person in their social context. These professionals are also important stakeholders to engage in understanding a holistic picture of how to improve Autistic people's lives.
- A suggestion would be to hold an open day to answer any questions, concerns there may be around this study
- A statement describing the end goal of the consultation process should be included. For example; (1) to drive participant acquisition in S10K and thereby achieve the programme's main goal, (2) to maximise legitimacy and acceptance of the outcomes from S10K, (3) lay down a marker for future ARC research projects in representing the needs of the UK autistic community in the research it undertakes.
- I would like to see every participant asked to frame their objective(s) from being involved in the consultation - 'before' participating. These should then be used to guide phases 3 & 4 and provide a framework for communication at the end of the consultation and throughout the lifetime of S10K. This will be critical to show that the expectations of most participants are seen to be met, and that the consultation process has an end.
- There's got to be something positive that the project can yield from this momentary hiatus. I would like to see this explicitly built into Phase 2, perhaps designed as a breakout with a smaller group of autistic participants who help the project identify priority areas where research could better inform treatment and care.

Appendix: comments added after the Phase 1 meetings

Additional comments continued:

- The report does not clarify why some autistic people were invited and not others into specific groups such as autistic autism researchers. It would build trust to clarify the decision-making process into who gets invited.
- Similarly, it does not clarify who is on the Spectrum 10K advisory panel and how they were chosen.
- The emphasis on an autistic-led process and autistic-majority process is accurate to our meeting, but why is there a discrepancy between Spectrum 10K saying the study aims to recruit autistic people "and their families" and yet families (of those adults who cannot directly represent themselves) are never mentioned in the report?
- The core co-design group should have the option of having access to (a summary of at least) all the group communication discussed in the other workshops (which should have mostly autistic people).