PRIMARY CARE
RESEARCH CENTRE

University of
Southampton

Creating Inclusive Research Recruitment: Guidelines from Lived Experience

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WHY WE CREATED THESE GUIDELINES

Creating clear, inclusive, and accessible research recruitment processes is essential to ethical research. But too often, standard documents are long, hard to understand, overly formal, or exclude people who process information differently, such as people who are autistic. If recruitment materials and processes aren't inclusive, research may miss valuable voices – meaning that its findings may not be generalisable or relevant to wider populations.

The guidelines are designed to be used by researchers inviting members of the public to take part in research. The aim is to make mainstream research more accessible to autistic people, who are often excluded even when the topic is directly relevant to their lives.

The Guidelines contain the following sections:

- **General design guidelines for inclusive recruitment materials**. These contain suggestions for layout, formatting and design that apply to all the materials.
- **Detailed guidance for adverts, patient information leaflets and receiving consent**. These have been ordered to help you design and write inclusive materials and processes by following these steps. This section also contains suggestions for **communication and follow-up** during the participation process.

WHO CO-CREATED THE GUIDELINES

This document was co-produced with autistic people, who shared their experiences of receiving and responding to recruitment materials in health research. Their insights included what made them feel excluded, overwhelmed, or welcomed. These directly shaped the recommendations in this guidance.

We ran ten "listening cafés" to gather wide perspectives (inclusive, safe group meetings where people share experiences and ideas). These included:

- **Five online sessions were conducted** with six autistic adults, representing a diverse range of ages, genders, ethnicities, and levels of prior engagement with health research. The sessions were held in a small-group format to facilitate reflection and discussion.
- **Five in-person sessions** hosted by a local community group affiliated with the National Autistic Society, with between 15 and 30 people attending each session. Participants included a diverse range of autistic adults, some people also had learning disabilities, and additional neurodivergent conditions such as ADHD and dyslexia. Most participants had no prior experience of engaging with health research or the University of Southampton.

These informal, participant-led sessions provided a rich understanding of how research invitations are experienced by people often excluded from traditional studies. **We warmly thank everyone who contributed to this project**, shared their insights, and helped shape this guidance. We hope it supports more inclusive, respectful, and effective research.

PROJECT TEAM

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WHERE TO FIND THESE GUIDELINES

The guidelines are available here: https://doi.org/10.5258/SOTON/P1288

The guidelines and example documents are also available on the Primary Care Research Centre, University of Southampton, Learning Disability and Neurodivergence Special Interest Group website (INCLUDE | University of Southampton)

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GENERAL DESIGN GUIDELINES

GENERAL DESIGN GUIDELINES FOR INCLUSIVE RECRUITMENT MATERIALS

The design of recruitment materials can either support or undermine inclusion. For autistic people and others with access needs, poor formatting, dense text, and overwhelming structure can create immediate barriers, regardless of how relevant or valuable the research may be.

These core design principles apply to all participant-facing materials: **adverts**, **information leaflets**, **consent forms**, and **emails**.

1. USE PLAIN ENGLISH

What to do: Use everyday words and short sentences.

Why it matters: Complex, formal, or academic language is often confusing, off-putting, or even intimidating.

How to do it:

- Replace jargon or acronyms with simple explanations
- Use a friendly conversational tone
- Use the active voice (e.g. “We are inviting you” rather than “Participants are being recruited”)
- Use short sentences, simple words, and a clear structure so everyone can understand.

2. BREAK UP TEXT

What to do: Use short paragraphs, bullet points, and lots of white space. Only include essential details.

Why it matters: Long blocks of text increase cognitive load and are harder to scan. This was particularly the case for people who also had ADHD, dyslexia, or sensory sensitivities. Autistic contributors described feeling anxious or disengaged when faced with too much detail.

How to do it:

- Keep paragraphs to 2–3 sentences
- Use bullet lists to present steps, options, or criteria
- Avoid underlining or italics, use bold sparingly for emphasis

3. USE ACCESSIBLE FONTS AND FORMATTING

What to do: Use fonts and layouts that are dyslexia-friendly and easy to read.

Why it matters: Serif fonts, small sizes, and cluttered designs make reading harder. Contributors strongly preferred clean, spacious documents.

How to do it:

- Use a sans-serif font (e.g. Arial, Calibri, Aptos)

- Font size: 12–14 pt for print or screen
- Use 1.5-line spacing.
- Use left-aligned text, avoid full justification
- Consider expanded font spacing.
- Provide electronic documents that can be re-formatted by individuals.

4. CHOOSE COLOUR AND CONTRAST CAREFULLY

What to do: Avoid bright, highly saturated or visually intense colours and ensure high contrast between text and background.

Why it matters: Colour choices affect legibility and sensory comfort. Harsh colours may be overwhelming or difficult to read.

How to do it:

- Use high-contrast combinations (e.g. black text on pale background)
- Pastel yellow or pale green are often dyslexia friendly
- Avoid red text, flashing visuals, or bright/neon colours

5. PROVIDE MULTIPLE FORMATS

What to do: Offer materials in more than one format to meet different access needs.

Why it matters: Participants differ in how they process information; some prefer visual, some auditory, some written. Multiple formats offer choice and support autonomy.

How to do it:

- Offer:
  - Easy-read versions (with images and simplified text)
  - Audio versions (e.g. recorded voice read-aloud)
  - Brief summary videos with captions or avatars
  - Infographics for timelines or procedures
- Add a line such as:
  - ***If you'd like this in a different format, just let us know***

6. SUPPORT ASSISTIVE TECHNOLOGY

What to do: Make digital documents screen reader-compatible and mobile-friendly.

Why it matters: If materials aren't readable by assistive tech, people can't access them independently.

How to do it:

- Use Word or accessible PDFs (not image scans)
- Add *alt-text* to any images or diagrams
- Avoid relying solely on email, instead offer QR codes, SMS links, or web versions too

DETAILED GUIDANCE: RESEARCH ADVERTS

DETAILED GUIDANCE: RESEARCH ADVERTS

Adverts are often the first point of contact between a potential participant and your study. A well-designed advert communicates not just what the research is about, but who is welcome to take part. Autistic adults told us that many research adverts feel unwelcoming, overwhelming, or unclear, and that this first impression effects their decision to engage.

1. BE TRANSPARENT ABOUT THE STUDY

What to do: Clearly explain what the study is about, why it matters, and who is running it.

Why it matters: Contributors said they often felt sceptical about adverts with vague or overly polished language. Clarity builds trust and helps people quickly decide if the research is relevant to them. Trust and legitimacy were also recurring themes. People want to know that the study is genuine and ethical before engaging.

How to do it:
- Include the name of the university or organisation
- Explain the research in a short, plain English summary
- State why the study is being done/why it’s important
- Who has funded or approved the study (if relevant)
- Add a website link or QR code leading to the study page
- Say whether the research is for a degree, a clinical trial, etc

2. BE EXPLICITLY WELCOMING

What to do: Include a statement so that people know if they can take part.

Why it matters: Many contributors said they often assumed they were not the “intended” participant because of previous exclusion or lack of acknowledgment.

How to do it:
- Use friendly, affirming language and first-person plural or singular
- Add a sentence in bold or as a standalone line such as:
  - ***We welcome autistic people and anyone who has felt excluded from research in the past***
  - ***We welcome anyone and everyone who meets the inclusion criteria to take part***

3. DESCRIBE WHAT PARTICIPANTS WILL BE ASKED TO DO

What to do: Explain what participants will be asked to do, how the study will run, and how long it will take.

Why it matters: Uncertainty is a key barrier to participation. Contributors wanted to know exactly what they were committing to. Clear information helps people decide and prepare.

How to do it:

- Use bullet points or clear short sentences:
    - ***Online interview with you and someone from our research team***
    - ***Takes around 45 minutes***
    - ***We can arrange a time that is convenient for you***
    - ***Video or phone options available***
- Clarify if it's a single session or part of a series
- State that adjustments can be made to help them take part

4. MENTION INCENTIVES (IF APPLICABLE)

What to do: Say if participants will be paid or offered a voucher, and whether expenses are covered.

Why it matters: Some contributors valued recognition of their time and contribution. Others said too much emphasis on payment made the study feel transactional or exploitative.

How to do it:

- Be factual and low-pressure:
    - ***You'll receive a £20 voucher to thank you for your time***
- Avoid making the incentive the headline or focus

5. EXPLAIN WHAT HAPPENS NEXT

What to do: Make it easy for people to take the next step, whether that's reading more, signing up, or contacting someone.

Why it matters: Contributors wanted adverts to feel like an invitation not just a page of information. Ambiguous or missing instructions can stop people from acting, even if they're interested.

How to do it:

- Explain clearly what they need to do next if they are interested in taking part
- Include a QR code or short link to the Participant Information Leaflet

6. INCLUDE CONTACT DETAILS MAKING THE RESEARCH TEAM APPROACHABLE

What to do: Provide names of researcher(s) and multiple contact options, ideally email and phone. Include a name, photograph, and a brief introduction to the person who participants are likely to interact with.

Why it matters: Some people prefer speaking directly rather than writing, whilst others prefer email or written communication. In all cases, seeing who is behind the research makes it more human and approachable. Contributors said this reduced anxiety and helped them feel more confident engaging.

How to do it:

- Add a photo and brief bio with first names and some personal information:
  - ***I am Jamie, a researcher at the University of X. I have worked in public health for 10 years and enjoy cooking and walking in nature***
- Add clear contact details:
  - ***You can contact me at jamie@university.ac.uk or call 01234 567890 (Mon–Fri, 10am–4pm). If I am not available, please leave a message and I will call you back***

7. SHARE THE ADVERT THROUGH TRUSTED GROUPS AND NETWORKS

What to do: Advertise through autistic-led groups, neurodivergent-friendly communities, and local or national organisations.

Why it matters: Trust in the source of the advert influences whether people even read it. Seeing it shared by a familiar or respected group can increase credibility. Autistic adults told us they are more likely to engage with research when it comes through a group they recognise, even if the study is not specifically about autism. Being visible in these spaces signals that autistic people are genuinely welcome.

How to do it:

- Ask autistic contributors where they suggest advertising
- Use platforms that autistic people already use (forums, mailing lists, community newsletters)
- Where possible, include a short message of endorsement from the group/organisation or a peer

PARTICIPANT INFORMATION SHEETS

DETAILED GUIDANCE: PARTICIPANT INFORMATION SHEETS

Participant Information Sheets (PISs) are often the first detailed contact a person has with a research study. For many autistic participants, these documents are too long, impersonal, or overwhelming making it harder to decide whether to take part. A well-designed PIS should reduce uncertainty, build trust, and support informed decision-making.

1. START WITH A SUMMARY SECTION

What to do: Include a brief summary at the top of the leaflet or on the front page.

Why it matters: Many people don't read the full leaflet unless the opening feels clear and manageable. A summary helps people decide quickly whether the study might be relevant to them.

How to do it:

- Use a box or bullet list
- Include:
    - What the research is about and what it involves
    - Who can take part
    - Time commitment
    - What happens next

2. STRUCTURE THE REST OF THE LEAFLET

What to do: Provide essential information first, followed by more detailed content.

Why it matters: This reduces cognitive load and allows participants to engage at their own pace.

How to do it:

- Use clear section headings and subheadings
- Use bullet points and bolding to make scanning and understanding easier
- Use colour blocks and images to break up large chunks of text

3. EXPLAIN WHY THE RESEARCH MATTERS

What to do: Say clearly why the study is important and how it could make a difference.

Why it matters: Participants are more motivated when they understand the value of the research.

How to do it:

- If it addresses a national or global priority, explain it simply
- Link to the broader context:
    - ***This research helps us understand [X] to improve healthcare for more people***

4. EXPLAIN WHO CAN TAKE PART

What to do: Clearly state who is eligible, using bullet points. Also state who is excluded and consider explaining why.

Why it matters: Contributors said they often didn't know if they were "allowed" to take part. Clarity supports autonomy and avoids people excluding themselves unnecessarily.

How to do it:

- Use plain language like:
    - ***You can take part if you:***
        - ***Are 18 or over***
        - ***Have experience of [condition/topic]***
        - ***Live in the UK***
- State clearly if you would like people who don't have prior research experience

5. CLARIFY EXPECTATIONS

What to do: Say exactly what's involved in participation.

Why it matters: Ambiguity creates anxiety and can deter people from engaging.

How to do it:

- Include:
    - Number and format of sessions
    - Length and location
    - Whether someone can accompany them
    - Whether they will be asked to do anything afterwards
    - That reasonable adjustments are available on request

6. OFFER A PREVIEW OF PARTICIPATION

What to do: Include examples of the interview questions or discussion topics.

Why it matters: Knowing what will be asked reduces anxiety and helps people decide if they would like to take part. This is also likely to improve the quality of responses if they do decide to take part.

How to do it:

- Provide questions as a bullet list or attachment
- Say that participants can skip any question they don't want to answer

7. CONFIRM THAT PARTICIPATION IS VOLUNTARY

What to do: Remind people that they can say no or change their mind at any time.

Why it matters: Some contributors feared that once they signed up, they couldn't back out. Reassurance supports autonomy.

How to do it:

- Say
  - ***Taking part is completely up to you. You can change your mind at any time, without giving a reason***
- Explain how people can let you know if they no longer wish to be involved in the study

8. DISCUSS INCENTIVES AND REIMBURSEMENT

What to do: Explain clearly whether participants will be paid, reimbursed, or given vouchers. Include whether expenses will be covered, costs for a carer if required, if a translator will be available.

Why it matters: People value knowing their time is respected but overemphasising payment can feel transactional. Clear information helps participants make informed decisions.

How to do it:

- Use a short, neutral sentence:
  - ***You'll receive a £20 voucher as a thank-you for your time***
- If travel costs or expenses are covered, say so:
  - ***We'll reimburse travel expenses so please keep your receipts***
- Acknowledge different values:
  - ***Some people take part to support research, and payment is not important to them. However, we appreciate your time and help and would like to thank you***

9. BUILD TRUST AND LEGITIMACY

What to do: Clearly state the research's funders, ethics approval, and what to do if something goes wrong.

Why it matters: Contributors said knowing the research was legitimate and knowing who to contact made them more confident in taking part. Trust is critical, especially for people who've been marginalised in previous healthcare experiences.

How to do it:

- Include:
- A section called 'Who is running this study?'
- Name of the funder (briefly)
- Include statement like:
  - ***This study has been reviewed by [name of ethics committee]***
  - ***If you have concerns or something goes wrong, you can speak to [contact person] or contact [institution]***
- Don't overload with institutional detail; stick to what's relevant to participants

10. EXPLAIN NEXT STEPS AND CONSENT

What to do: Clearly explain what someone should do if they want to take part, and what giving consent means.

Why it matters: Unclear instructions about what happens next can cause people to drop out, even if they're interested. Many contributors said they needed clarity on how to formally "join" the study.

How to do it:

- End with a simple "next steps" section:
  - ***If you're interested in taking part, you can contact us to ask questions or arrange a time. If you're happy to go ahead, we'll ask you to give consent either by signing a form or verbally***
- Explain that consent means:
  - ***You've had a chance to ask questions***
  - ***You understand what's involved***
  - ***You're choosing to take part voluntarily***

13. PROVIDE CLEAR CONTACT DETAILS

What to do: Include a real person's name and a phone number as well as email.

Why it matters: Contributors said it felt more reassuring to know who they'd be dealing with, and many preferred phone contact over email.

How to do it:

- Example:
  - ***You can contact me at jamie@university.ac.uk or call 01234 567890 (Mon–Fri, 10am–4pm). If I am not available, please leave a message and I will call you back***

14. BE CLEAR ABOUT DATA

What to do: Explain what happens to participants' data and what consent means.

Why it matters: Legalistic wording can cause confusion or mistrust. Transparency builds confidence.

How to do it:

- Use plain language:
  - What information is collected and who sees it.
  - How it is stored and for how long
  - What happens if someone withdraws
- Avoid vague statements like "may be used for training" say what, who, and how

RECEIVING CONSENT

DETAILED GUIDANCE: RECEIVING CONSENT

For autistic adults and others who process information differently, traditional consent forms can be difficult to navigate. Long, complex sentences, vague statements, and inflexible formats create barriers to understanding and trust. Inclusive consent forms reduce anxiety, promote autonomy, and make it easier for people to take part.

1. USE SHORT, CLEAR CONSENT STATEMENTS

What to do: Break consent into single, clearly worded statements, each with its own tick box.

Why it matters: Contributors told us that long, complex sentences were hard to process and made them unsure what they were agreeing to.

How to do it:

- One statement per line
- Examples:
  - ***I understand what the study is about***
  - ***I know what I'm being asked to do***
  - ***I know how my data will be used***

2. USE ACCESSIBLE FORMATTING

What to do: Present the form in a layout that is easy to follow and not overwhelming.

Why it matters: Poor layout increases cognitive load and can lead to mistakes or stress.

How to do it:

- Use 1.5 or double line spacing
- Left-align text and use bullet points or spacing to separate sections
- Place tick boxes clearly next to each statement
- If online, consider asking 1 or 2 questions per page

3. OFFER MULTIPLE CONSENT FORMATS

What to do: Let people choose how to give consent; written, verbal, or digital.

Why it matters: Some participants find signing forms stressful or inaccessible. Flexible formats make it easier for more people to take part.

How to do it:

- Include a range of consent options in your ethics application
- Consider using WhatsApp voice notes or messages, video or phone recordings, or typed responses where appropriate

- State clearly that different consent options are available

4. ALLOW PARTICIPANTS TO CHOOSE WHICH ELEMENTS THEY CONSENT TO

What to do: Use a flexible consent structure that allows participants to opt in to different parts of the study.

Why it matters: People may want to contribute in some ways but not others, for example, participating in an interview but not having their data reused.

How to do it:

- Include multiple optional items:
  - ***I consent to my interview being audio recorded***
  - ***I consent to anonymous quotes being used in publications***
  - ***I consent to my data being used in future related studies***
- Make it clear that people can say no to some items and still take part

5. EXPLAIN WHY PERSONAL INFORMATION IS BEING COLLECTED

What to do: If you are collecting additional information to purposively sample, explain why you're collecting it in plain English
Why it matters: Vague or academic explanations create mistrust. Clear explanations help participants feel respected and in control.

How to do it:

- Instead of stating: We will collect demographic data for analysis, say:
  - ***We are asking your age and gender so that we can make sure we talk with a wide range of different people.***

COMMUNICATION AND FOLLOW-UP

DETAILED GUIDANCE: COMMUNICATION AND FOLLOW-UP

Inclusive research doesn't end with recruitment. For many autistic participants, **unclear communication during and after the study** can cause anxiety, confusion, or disengagement. Small changes to the way interviews, focus groups or meetings are organised, reminders are given, and follow-up is managed can make participation feel more predictable, safe, and respectful.

1. USE CLEAR WRITTEN COMMUNICATION

What to do: Keep emails short and structured, with clearly highlighted questions or actions.

Why it matters: Long, ambiguous emails make it hard to understand what's needed, especially for people who process information differently.

How to do it:

- Use bold or bullet points to highlight:
    - What we need from you
    - When to reply by
    - Next steps
- Keep messages brief, with simple language and plenty of white space

2. SHARE TOPIC GUIDES/INTERVIEW QUESTIONS/AGENDAS ONE WEEK IN ADVANCE

What to do: Share the discussion questions or agenda at least one week ahead and attach it to any online calendar invites.

Why it matters: Many autistic contributors said they prefer time to prepare their responses in advance to reduce anxiety and improve communication.

How to do it:

- Include:
    - What the session will cover
    - Who will be there
    - How long the session will last
    - Whether preparation is expected and how long preparation it will take
    - What payment will be offered (including for prep time)
- Clarify that all questions are optional and whether participants can bring notes
- Attach the agenda to any Zoom, Teams, or calendar invites so it's easy to find later

3. SET EXPECTATIONS FOR SESSION

What to do: Let participants know in advance how the session will be run and how they can contribute.

Why it matters: Unclear expectations can make group meetings inaccessible. Participants said that knowing the “rules” in advance made them feel more confident.

How to do it:

- Clarify in the agenda:
    - Whether people can have cameras off
    - How to ask a question or contribute (e.g. raise hand, use chat)
    - If there will be breakout rooms
    - That it’s OK not to speak or just to listen
    - That breaks will be offered and people can step away.

5. OFFER ON THE DAY REMINDERS

What to do: Offer a reminder on the day of the session via text or email, depending on the participant’s preference.

Why it matters: Some people struggle with time management or memory, especially when anxious. Reminders reduce the risk of missed sessions.

How to do it:

- Ask during recruitment: Would you like a reminder on the day of the session?
- Send a short message like:
    - ***Just a reminder that we’re meeting at 2pm today. Looking forward to talking with you***

6. OFFER FLEXIBLE FEEDBACK OPTIONS

What to do: Let participants give feedback after a session, in whatever way works best for them.

Why it matters: Some people find it difficult to contribute in group settings or need time to process. Offering alternative formats supports inclusion and captures more honest feedback.

How to do it:

- At the end of the session, suggest that participants may provide follow-up by:
    - Email
    - A one-to-one phone or video meeting
    - Anonymous feedback form

7. PROVIDE A SUMMARY AFTERWARDS (IF APPROPRIATE)

What to do: Offer a written summary of what was discussed, including next steps.

Why it matters: Not all participants retain verbal information, especially if the session was emotional or fast-paced. Summaries help people feel reassured and included.

How to do it:

- Send a follow-up email with:
    - Key points or decisions
    - Any agreed actions
    - What will happen next and when
- Ask whether participants want a copy of their own contributions (e.g. transcript, anonymised notes)