

GARC

GLOBAL AUTISM RESEARCH CENTER

PRACTICAL TOOLKITS SERIES | NO. 08

AUTISM RESEARCH PARTICIPATION TOOLKIT

A Practical Evidence-Informed Guide for Ethical, Accessible, Participatory and Respectful Autism Research

For autistic people • families & supporters • researchers • institutions



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PUBLICATION

Publication Information

Scope, audience, evidence basis and use conditions for this toolkit.

Purpose and audience

This toolkit supports autistic adolescents and adults, parents and family members, supporters, researchers, research coordinators, universities, hospitals, charities, public bodies, sponsors, funders and other institutions involved in autism research. It is designed to make participation more ethical, understandable, accessible and genuinely collaborative from the first research question through the return of results.

Scope

The toolkit covers recruitment, informed consent, supported decision-making, accessibility, sensory and communication adjustments, privacy and data use, participant payment and expenses, co-production, research burden, safety, withdrawal, complaints, return of results, authorship and credit, and institutional quality improvement. It is relevant to surveys, interviews, observational studies, digital research, data studies and - with the applicable additional safeguards - clinical and interventional research.

Ethical and legal notice

This publication is an educational and institutional practice resource. It is not an ethics approval, protocol, legal opinion, data protection assessment, sponsor SOP, clinical trial authorization, consent form, safeguarding procedure or substitute for local law. Every actual human-participant study must follow the applicable ethics/research review, regulatory, sponsor, site, safeguarding, consent/capacity and data protection requirements in the jurisdiction(s) where it is conducted.

Research participation is not the same as public involvement

A person may take part as a research participant whose data are collected, as a public/lived-experience contributor who helps shape the study, as a community partner, or as a co-researcher with shared responsibilities. These roles can overlap, but they should not be blurred. The information, agreements, payment arrangements, confidentiality duties, training and ethics requirements may differ by role.

Language, dignity and agency

The toolkit generally uses identity-first language (for example, 'autistic person') while recognizing that individuals may prefer different terminology. Researchers should ask and respect communication preferences, pronouns, cultural context, support needs and the person's preferred level of family or supporter involvement.

Evidence approach

The guidance is informed by the 2024 World Medical Association Declaration of Helsinki, CIOMS ethical guidance, ICH Good Clinical Practice where applicable, the UN Convention on the Rights of Persons with Disabilities, autism participatory-research practice, UK public-involvement and co-production guidance, and current guidance on participant payment and return of results. Local requirements always take precedence where they impose additional protections.

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FOREWORD

Foreword

Research quality and participant respect are inseparable.

Autism research has the potential to improve understanding, policy, services and everyday life. Yet the value of a study depends not only on its analysis but also on how people are invited, informed, supported, heard and treated throughout the research process.

A study can be scientifically sophisticated and still create unnecessary barriers: information may be too abstract, recruitment may exclude people with different communication styles, consent may be rushed, payment may arrive months late, sensory needs may be ignored, data practices may be difficult to understand, or participants may never hear what the study found.

Respectful autism research starts from a different premise. Autistic people are not passive sources of data. They are people with rights, preferences, expertise and different ways of communicating and participating. Families and supporters can provide important knowledge, but their role should not automatically replace the autistic person's own voice. Researchers and institutions are responsible for designing systems that make informed and voluntary participation possible.

The 2024 Declaration of Helsinki strengthened the international emphasis on meaningful engagement with participants and communities before, during and after medical research. Participatory autism research goes further by asking who defines the problem, who holds decision-making power, whose knowledge counts, how contribution is recognized and whether findings are returned in ways that are useful.

This toolkit turns those principles into repeatable practice. It is deliberately useful to both sides of the research relationship: people deciding whether to join a study, and teams designing or governing that study. It should help everyone ask better questions, identify preventable barriers and build research participation that is transparent, accessible and worthy of trust.

**Global Autism Research Center (GARC)
Practical Toolkits Series**

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Quick navigation

Autistic people and families may wish to begin with Sections 3, 6, 8, 9, 10, 13 and 14. Researchers should use the full framework plus Tools A2-A19. Institutional leaders should focus on Sections 2, 12 and 15, the 90-day roadmap, and Tool A21.

USER GUIDE

How to Use This Toolkit

A shared resource for participants, research teams and institutions.

User	Use this toolkit to...
Autistic person / potential participant	Understand your rights, ask questions, request adjustments, decide whether participation is right for you, and know what should happen after a study.
Family member / supporter	Support communication and informed decision-making without replacing the autistic person's voice or choice.
Researcher / coordinator	Design recruitment, consent, data collection, payment, participation and results-sharing processes that are ethical and accessible.
Institution / sponsor / funder	Set minimum standards, review study readiness, resource accessibility and co-production, monitor participant experience and require accountable close-out.

Core principle

Do not ask, "How do we make autistic people fit our study?" Ask, "What barriers in our research design could prevent informed, voluntary and meaningful participation - and how do we remove them without weakening scientific integrity?"

Minimum conditions before recruitment begins

- ☐ Appropriate ethics/research review and site permissions are in place where required.
- ☐ The protocol explains who is eligible, why, and how inclusion/exclusion decisions are justified.
- ☐ Participant information and consent processes are understandable and accessible.
- ☐ Reasonable adjustments and alternative communication methods have been planned and resourced.
- ☐ Data collection, storage, sharing, retention and withdrawal consequences are clearly explained.
- ☐ Payment, expenses and reimbursement arrangements are transparent and operational.
- ☐ A distress, safeguarding, adverse-event or escalation pathway exists where relevant.
- ☐ A complaints/contact route independent of the immediate study interaction is available.
- ☐ A plan exists to return understandable study results to participants.
- ☐ Roles for autistic people and families in study design/governance are defined honestly - not described as co-production if they are only consulted.

SECTION 01

Why Participation Quality Matters

Ethical quality, scientific quality and accessibility reinforce one another.

Research participation is a relationship, not a transaction. A participant contributes time, attention, personal information and often emotional effort. Researchers carry the responsibility to make that contribution voluntary, understandable, proportionate and protected.

Poor participation design creates scientific risk

- Recruitment that depends on one communication style can distort who enters the sample.
- Long, ambiguous or sensory-demanding procedures can increase missing data, distress and dropout.
- Questions that autistic people interpret differently from researchers may reduce measurement validity.
- Failure to explain data reuse or privacy can damage trust and future willingness to participate.
- Excluding people who need adjustments can produce evidence that does not represent the population the study claims to address.

Respect is operational

Respect is visible in the details: the first email, the readability of the information sheet, whether a person can reply by text instead of phone, whether a supporter may attend, whether a break is allowed without penalty, whether expenses are paid promptly, whether withdrawal is uncomplicated, and whether the team later explains what the study learned.

Autism does not define one research-access profile

- Some people prefer written information before speaking; others prefer conversation, video or Easy Read.
- Some use speech fluently but need extra processing time or written follow-up.
- Some use AAC, typing, pictures, sign, gesture or communication partners.
- Some experience sensory overload, uncertainty or fatigue that changes across settings and days.
- Some want family involvement; others prefer privacy and independent communication.

For participants

You are allowed to ask how the study works, what data will be collected, what will happen if you stop, who can see your data, whether you will be paid, whether you can use your preferred communication method, and how results will be shared.

SECTION 02

GARC 10-Point Respectful Autism Research Participation Framework

A minimum practice standard for studies and institutions.

#	Domain	Practice standard
1	Relevant	Study questions respond to meaningful needs and are not defined only by researcher convenience.
2	Accessible	Recruitment, information, communication, environments and technology offer realistic access options.
3	Voluntary	Consent is informed, understandable, pressure-free and treated as an ongoing process.
4	Individualized	Communication, sensory and support needs are asked about rather than assumed.
5	Proportionate	Time, burden, risk and data collection are justified by the value of the research.
6	Private	Data are minimized, protected and used only as transparently described and lawfully approved.
7	Fair	Expenses are not shifted onto participants; payment and recognition are transparent and equitable.
8	Shared	Autistic people and families have meaningful opportunities to shape design, governance and interpretation.
9	Safe	Participants can pause, stop, complain or withdraw without reprisal; distress and safeguarding pathways are clear.
10	Accountable	Results are returned in accessible forms and institutions review what participants experienced and what changed.

Institutional standard

A study should not be described as autism-inclusive solely because autistic people are eligible to enroll. Inclusion is demonstrated by the design of information, communication, environments, decision-making, governance, data practices and follow-up.

SECTION 03

Participation Roles: Participant, Advisor, Partner and Co-Researcher

Name the role accurately so rights, expectations and responsibilities are clear.

Role	What it means	Minimum protections / clarity
Research participant	Takes part in a study and provides data, samples, observations or responses under an approved protocol.	Participant information, consent/assent where applicable, privacy, safety, withdrawal rights and study-specific compensation/expenses.
Lived-experience advisor / public contributor	Helps shape research priorities, materials, methods or dissemination but is not necessarily providing research data.	Role description, payment/expenses, confidentiality expectations, access needs, support and feedback on impact.
Community partner	Represents or works with a community/organization in recruitment, design, implementation or dissemination.	Partnership terms, responsibilities, data boundaries, conflicts, payment/resources, community feedback and attribution.
Co-researcher	Participates in substantive research work such as design, interviewing, analysis, governance or dissemination.	Clear decision rights, training, payment/contracting, confidentiality/data access, authorship/credit and supervision/accountability.
Family member / supporter	Supports communication, decision-making or participation according to the autistic person's preference and applicable law.	Role boundaries, privacy permissions, access needs and clarity about whose consent/voice governs each decision.

Avoid role inflation

Inviting one autistic person to comment on a finished information sheet is valuable consultation, but it is not the same as co-production. Co-production requires meaningful shared power, joint ownership of key decisions, respect for different forms of knowledge, reciprocity and sustained relationships.

Ask at the start

What role am I being invited to take? What decisions can I influence? What information or data will I access?
What will I be paid or reimbursed? How will my contribution be credited?

SECTION 04

Choosing Relevant Questions and Co-Producing Research

Participation can begin before a protocol exists.

Meaningful involvement starts with the question. Researchers should test whether the problem they plan to study reflects priorities that matter to autistic people, families and the communities affected by the findings.

A practical co-production cycle

1. Listen before defining - gather priorities from more than one type of stakeholder and make underrepresented perspectives visible.
2. Define the decision - be explicit about which research decisions can be shared and which are constrained by regulation, funding or scientific requirements.
3. Design access - budget for communication, support, accessible formats, interpreters, AAC access, travel, childcare where relevant and flexible meeting methods.
4. Share power - include autistic contributors in governance, not only focus groups.
5. Record impact - document what contributors changed, what could not be changed and why.
6. Review relationships - ask whether the process felt respectful, proportionate and worthwhile to contributors.
7. Share the output - return findings and credit contributions appropriately.

Questions worth asking before the protocol is finalized

- Who benefits if this study succeeds, and who carries the burden of participation?
- Could the research question unintentionally reinforce stigma or deficit-only assumptions?
- Whose outcomes are being measured - clinician, parent, institution or autistic person - and why?
- Are meaningful quality-of-life, autonomy, participation and lived-experience outcomes included when relevant?
- Will the design include people with different communication, intellectual, sensory and support profiles?
- Have we budgeted for accessibility and contributor payment as core research costs rather than optional extras?

Co-production is not a waiver of scientific accountability

Shared power does not remove the investigator's legal, ethical or scientific responsibilities. The goal is better decision-making, relevance and accountability - not the removal of roles that must remain accountable under law or regulation.

SECTION 05

Inclusive Recruitment and Fair Eligibility

Who gets invited shapes what the evidence can legitimately claim.

Recruitment principles

- Use multiple channels rather than relying only on specialist clinics, universities or one advocacy network.
- Offer more than one contact route such as email, web form, text or telephone where feasible.
- Write invitations in plain language and state the time commitment, tasks, payment/expenses, major eligibility criteria and main data types collected.
- Avoid deficit-framed or sensational language and do not imply that participation will provide treatment or diagnosis unless the protocol genuinely includes those elements.
- Do not require a family intermediary for an adult who can communicate and consent independently.
- Design eligibility criteria to answer the research question, not to simplify logistics at the expense of external validity.
- Monitor who is not being reached and whether accessibility barriers are creating hidden exclusion.

Fair screening

Question	Good practice
Why is this criterion needed?	Link each inclusion/exclusion rule to safety, scientific validity or the defined research population.
Can adjustments enable participation?	Consider whether communication support, remote options, breaks or alternative response modes remove the barrier.
Is the screening itself accessible?	Avoid long phone-only screening or rapid verbal questioning as the sole route.
What happens if someone is ineligible?	Communicate respectfully, minimize unnecessary data retention and explain whether other opportunities may exist.

Do not confuse convenience with incapacity

Needing extra time, AAC, written communication, a supporter, sensory adjustments or a quiet setting does not by itself indicate inability to consent or participate.

SECTION 06

Accessible Information and Informed Consent

Consent is a process of understanding and choice - not a signature event.

The 2024 Declaration of Helsinki requires potential participants to receive plain-language information about the study, its methods, risks and burdens, privacy, incentives and other relevant matters, and to be free to refuse or withdraw without reprisal. It also emphasizes attention to individual information and communication needs.

Build consent for comprehension

- Provide the information before the decision whenever possible so the person can process it without time pressure.
- Use plain language, short sections and clear headings. Explain research terms such as randomization, placebo, data linkage, pseudonymization, future use and withdrawal consequences.
- Offer formats such as standard text, Easy Read, large print, audio, video, visual summary or supported conversation when appropriate.
- Allow questions through the person's preferred communication method.
- Use teach-back or another respectful way to check understanding instead of relying on "Do you understand?"
- Document accommodations used in the consent process.
- Re-consent or confirm ongoing willingness when the protocol, risk information or participation context materially changes as required.

Minimum information a participant should be able to find

Topic	The study should explain...
Purpose	Why the study is being done and how research differs from ordinary care or service provision.
What I will do	Tasks, visits, recordings, devices, samples, questionnaires, expected duration and total time.
Risks / burdens	Foreseeable discomfort, fatigue, distress, privacy risks, uncertainty and practical burden.
Benefits	Any realistic direct benefit, and the possibility that there may be no direct benefit.
Data	What is collected, who can access it, where it is stored, how long it is kept, sharing/reuse and data-transfer implications.
Payment / costs	Expenses, payment, timing and any conditions.
Choice	Right to say no, pause or withdraw without reprisal and what withdrawal can/cannot change once data are used.
Questions / complaints	Named study contact and independent or institutional route where available.
Results	Whether and how aggregate or individual results will be returned.

For potential participants

Ask for more time, another format or support where allowed. Participation should not depend on verbal fluency.

SECTION 07

Assent, Capacity, Supported Decision-Making and Minors

Use stronger safeguards without erasing the person's voice.

Consent and legal capacity rules vary between jurisdictions and study types. Autism alone should never be treated as proof that a person cannot decide. Decision-making ability must be approached in accordance with applicable law and the specific decision, with accessible information and support provided first.

Supported decision-making

- Reduce communication and sensory barriers before assessing understanding.
- Use the person's established communication method and allow adequate processing time.
- Break complex information into manageable parts and revisit it across more than one conversation if appropriate.
- Ask what support the person wants and what role a supporter should have.
- Distinguish difficulty expressing a decision from lack of a decision.
- Document who provided support and how the final decision was communicated.

Children and young people

Where minors are included, the study should follow the jurisdiction-specific rules for parental/legal-representative permission and the young person's assent or consent. Even where a legal representative provides authorization, the young person should receive age- and communication-appropriate information and should be involved in the decision to the fullest extent possible. A clear wish not to continue should trigger careful review under the approved protocol and local rules.

When a legally authorized representative is involved

- Explain the representative's role and the participant's own role separately.
- Consider the person's known preferences, values and present communication.
- Use only the minimum substitute decision-making necessary under applicable law.
- Continue to address the participant directly and seek assent/affirmation where appropriate.
- Revisit consent if the person's legal or decision-making status changes.

Human gate

Studies involving people who cannot provide free and informed consent require study-specific ethics review and the safeguards mandated by the relevant law and ethical framework. This toolkit does not determine legal capacity.

SECTION 08

Communication, Sensory and Accessibility Adjustments

Accessibility should be designed into the study, not negotiated as an exception.

Ask before assuming

A short accessibility preferences form can prevent repeated explanations and reduce uncertainty. Ask how the person wants to receive information, communicate answers, manage breaks, navigate the environment and involve supporters.

Potential barrier	Possible adjustment
Phone-only contact	Email, text, secure messaging or scheduled call with written follow-up.
Rapid verbal interview	Provide questions/themes in advance; allow typing, AAC, chat or written responses.
Bright/noisy setting	Quiet room, lower lighting, reduced waiting, remote option or participant-selected location.
Uncertain schedule	Visual agenda, clear start/end time, sequence of activities and updates if delayed.
Long session	Shorter visits, breaks, split sessions or asynchronous tasks where methodologically acceptable.
Unexpected touch/equipment	Explain before contact, demonstrate equipment and obtain permission for each step where appropriate.
Complex forms	Plain-language version, guided completion, compatible digital form and save-and-return function.
Travel burden	Remote participation, travel booking, reimbursement, accessible venue and supporter expenses where approved.

Communication access

- Do not remove or restrict access to AAC or other communication tools unless an immediate safety issue requires it.
- Use one clear question at a time and allow silence for processing.
- Avoid interpreting reduced eye contact, movement, delayed response or atypical prosody as disinterest or dishonesty.
- Confirm whether the participant wants a supporter to speak, clarify, observe or remain silent.
- For online platforms, check keyboard access, captions, readable contrast, screen-reader compatibility and the ability to pause/resume.

Universal design first

The strongest studies offer accessible options to everyone from the start, then add individualized adjustments when needed. This reduces stigma and administrative burden.

SECTION 09

Privacy, Confidentiality and Data Governance

Participants should understand what happens to their information beyond the interview room.

Autism research may involve highly sensitive information: health history, disability status, genetics, family information, school or employment records, audio/video, location, digital behavior or linked datasets. Good governance starts with collecting only what is needed and explaining data flows clearly.

Minimum data conversation

- What data or samples are collected and why?
- Which data are directly identifying, coded/pseudonymized or anonymized?
- Who can access identifiable information and under what authorization?
- Where data are stored and whether data may cross borders or be handled by external platforms/providers?
- How long data are retained and what determines deletion or archiving?
- Whether data may be shared with other researchers, deposited in repositories or used for future studies.
- Whether data may be used to train, test or evaluate AI/machine-learning systems.
- What withdrawal can still change after data have been de-identified, aggregated, shared or published?
- Whether audio, video, quotes or images could make re-identification more likely even if names are removed.

Do not overpromise anonymity

Removing names does not automatically make data anonymous. Rare combinations of characteristics, voice recordings, images, genomic data or linked records can remain identifiable or re-identifiable. Describe the actual safeguards rather than using absolute language the system cannot guarantee.

Secondary and future use

If foreseeable future uses, repositories, data linkage or secondary analysis are planned, those uses should be described in the consent and governance framework at an appropriate level of specificity. Unexpected secondary use may require additional ethics review or other authorization depending on law and the original consent.

Participant question

If I withdraw tomorrow, which information can still be deleted and which may already have been used, shared, anonymized or included in analysis?

SECTION 10

Payment, Expenses, Recognition and Undue Influence

Participation should not quietly transfer research costs onto participants.

Reimbursement, payment and recognition serve different purposes. Reimbursement prevents participants from being out of pocket. Payment may recognize time, inconvenience or contribution. Co-production and advisory work may be paid as expertise rather than as study participation. Local tax, benefit, employment, clinical-trial and ethics rules may apply.

Good payment practice

- Disclose payment and expenses before consent, including amount/rate, payment method, timing and what happens after withdrawal.
- Distinguish travel, childcare, parking, data/phone costs and supporter expenses from honoraria or participation payment.
- Use payment levels that are proportionate and ethically reviewed where required; payment should not obscure material risks or undermine voluntary choice.
- Where appropriate, use pro-rata payment for work already completed rather than making all payment depend on finishing the study.
- Do not link payment to giving certain answers, appearing compliant or remaining in a study against the person's wishes.
- Offer accessible payment routes and avoid avoidable delays, complex forms or systems that exclude people without specific bank/payment arrangements.
- For children, people who lack legal capacity, or regulated clinical trials, check specific jurisdiction and study-type restrictions before offering incentives.

Recognition in participatory research

Autistic advisors and co-researchers should not be expected to provide unpaid expertise by default while professional researchers are paid. Budget for time, preparation, training, accessibility, travel and administration. Discuss authorship, acknowledgements, presentation opportunities and ownership of outputs early rather than after publication.

Current example

UK Health Research Authority guidance updated in 2026 distinguishes reimbursement, payment, burden and undue inducement and recommends transparent, justified arrangements. Other jurisdictions may apply different rules; use local ethics and legal review.

SECTION 11

Study Visits, Remote Participation and Research Burden

A valid method should not create avoidable participation burden.

Before the session

- Confirm date, time zone, expected duration, location/link, who will attend and what will happen in order.
- Provide preparation requirements early, including fasting, medication restrictions or device setup only when the approved protocol requires them.
- Offer a named contact for accessibility questions.
- Confirm travel, expenses and supporter arrangements.
- Share interview topics or task examples in advance where this will not compromise the research method.

During the session

- State how long each part should take and warn before transitions.
- Remind the participant they can request a pause or stop.
- Watch for overload, fatigue or loss of communication without assuming the person wants to continue.
- Minimize repeated demographic questions when the information is already available and ethically usable.
- Document deviations or accommodations that may affect analysis rather than discouraging necessary adjustments.

Remote participation

Design issue	Minimum consideration
Platform	Privacy/security approval, browser/device compatibility, captions and accessible controls.
Digital exclusion	Offer non-digital or supported alternatives when scientifically and operationally feasible.
Environment	Allow camera-off or chat options where the protocol permits; clarify whether recording is required.
Support	Provide simple technical instructions and a contact if the link or device fails.
Privacy	Explain who may be heard/seen, how recordings are stored and how the participant can choose a private setting.
Fatigue	Shorter sessions, scheduled breaks and asynchronous completion where suitable.

Burden review

Scientific value does not justify collecting “everything that might be useful.” Every questionnaire, visit, sample, recording and follow-up request should have a clear purpose.

SECTION 12

Power, Governance, Co-Production, Authorship and Credit

Meaningful participation requires decision rights, not only invitations.

Shared-power practice

- Include autistic contributors early enough to change the research question, not only the wording of materials.
- Clarify which decisions are joint, advisory or investigator-accountable.
- Provide agendas/materials in advance and allow different ways to contribute.
- Use accessible facilitation so speed, confidence or academic vocabulary do not determine whose view is heard.
- Create a route for contributors to challenge assumptions, raise concerns and request changes without risking exclusion.
- Keep a decision log showing what input changed and why some recommendations could not be adopted.

Authorship and credit

Where autistic co-researchers make substantive intellectual contributions to study design, analysis, interpretation or writing, authorship should be considered under the same recognized authorship criteria used for other contributors. Where those criteria are not met, acknowledgement or other visible credit should still be meaningful and agreed. Do not use lived experience as invisible labor.

Governance roles

Level	Possible lived-experience role
Study design	Priority setting, outcome selection, accessibility testing, recruitment strategy.
Study governance	Steering group, advisory board, ethics-facing consultation, risk review.
Data collection	Co-interviewing, peer research, testing instruments, participant support design.
Analysis	Coding, interpretation, identifying alternative explanations and language.
Dissemination	Plain-language summaries, presentations, community briefings, policy translation.
Evaluation	Assessing whether participation was respectful, accessible and worthwhile.

Do not tokenize

One autistic contributor cannot represent all autistic people. Build diversity deliberately across communication, support needs, age, gender, culture, socioeconomic context and other characteristics relevant to the research question.

SECTION 13

Safety, Distress, Safeguarding and Withdrawal

Participants need a visible route to pause, stop and be heard.

Plan for distress before it happens

- Identify research procedures that could trigger sensory overload, emotional distress, fatigue, pain, trauma-related responses or disclosure of risk.
- Agree a stop/pause signal for interviews or procedures.
- Train staff to respond without punishment, argument or pressure to continue.
- Distinguish research support from clinical care. Researchers should not imply that the study team provides treatment unless the protocol and service authorization genuinely do so.
- Have escalation routes for medical emergencies, adverse events, safeguarding concerns and crisis disclosures where relevant to the study.
- Document and report events according to the approved protocol, sponsor requirements and applicable law.

Withdrawal

Participants should be told how to withdraw, whom to contact, whether withdrawal can be partial, whether future contact can stop, and what happens to data or samples already collected. Withdrawal should not require a confrontational explanation and should not affect ordinary care, education, services or other entitlements except where the participant is specifically told of a lawful consequence tied to the study.

Complaints and concerns

- Provide the study-team contact and an institutional/independent route where available.
- Explain how confidentiality will be handled and any limits where safeguarding duties apply.
- Do not require participants to complain only to the person whose conduct concerns them.
- Review patterns in complaints, withdrawals and missed visits for accessibility or conduct failures.

Safety principle

The participant is not responsible for managing the study team's ethical obligations. Consent does not transfer responsibility for safety, privacy or respectful conduct from the researchers to the participant.

SECTION 14

Returning Results and Closing the Loop

People who made the research possible should not be the last to hear what it found.

The 2024 Declaration of Helsinki states that medical research participants should be given the option to be informed about the general outcome and results of the research. Returning understandable results also supports transparency, trust and reciprocity.

Aggregate study results

- Plan the return-of-results method, budget and contact permissions at the start of the study.
- Use plain language and explain what the study can and cannot conclude.
- Include negative, null or inconclusive findings - not only positive results.
- Offer more than one accessible format where feasible, such as a 1-2 page summary, infographic, video/webinar or accessible web page.
- Explain publication status, next steps and where fuller outputs can be found.
- Protect privacy when presenting quotes, small subgroups or rare characteristics.

Individual results and incidental findings

Returning individual research findings is different from returning aggregate results. The study should predefine whether individual findings will be returned, which types, under what validation and clinical-interpretation conditions, by whom, and with what support. Unvalidated research findings should not be presented as a clinical diagnosis. The approved protocol, ethics review and local regulatory requirements should govern this process.

Close the involvement loop

- Tell contributors what changed because of their input - “You said / we did / what happened.”
- Credit lived-experience contributors and community partners according to agreed terms.
- Invite feedback on the participation process, not only the scientific outcomes.
- Retain contact information for results only with the necessary permissions and data safeguards.

Emerging practice

As of September 2026, the U.S. NIH is consulting on a draft policy to make sharing plain-language summary-level results with participants standard practice in NIH-funded clinical research. This is a developing policy, not yet a final universal requirement.

SECTION 15

Institutional Quality, Accountability and Continuous Improvement

Turn respectful participation into a system rather than individual goodwill.

Institutional minimum standard

- ☐ A participant-accessibility policy or study standard exists and has an accountable owner.
- ☐ Plain-language and accessible participant-information templates are available.
- ☐ Accessibility needs can be recorded without over-collecting sensitive information.
- ☐ Payment/expense processes have target timelines and alternatives for access barriers.
- ☐ Co-production roles, payment and authorship/credit are governed consistently.
- ☐ Data governance covers sharing, repositories, cross-border transfer, future use and AI use where relevant.
- ☐ Research staff receive training in accessible communication, consent, distress response and supported decision-making.
- ☐ Participants have a visible complaints/feedback route.
- ☐ Every study has a results-return plan or a justified, ethics-approved alternative.
- ☐ Participant experience is reviewed across studies and reported to research leadership.

Suggested metrics

Domain	Measure
Accessibility	% of studies using an accessibility checklist before recruitment; % of participants offered an adjustment/preferences route.
Consent	% of studies with plain-language review; number of consent-process deviations/complaints.
Equity	Recruitment reach across groups relevant to the research question; reasons for screen failure and withdrawal.
Payment	Median days from participation to expense reimbursement/payment; % completed within target.
Experience	Participant-reported clarity, respect, burden, accessibility and willingness to participate again.
Co-production	% of major studies with lived-experience input before protocol finalization; documented changes arising from input.
Results	% of completed studies returning aggregate results; time from primary analysis/publication to participant summary.
Governance	Number/type of complaints, safeguarding events, privacy incidents and corrective actions.

Quality question

Would a participant experience the same minimum standard of respect and accessibility across different GARC-supported or partner studies, or does quality depend on which individual researcher happens to run the project?

PART A

Practical Tools and Templates

Ready-to-adapt tools for participants, researchers and institutions.

These tools are templates, not completed ethics documents. Study teams should adapt them to the approved protocol, local law, sponsor policies and population. Institutions may integrate them into SOPs, study-startup checklists, participant packs or quality dashboards.

Tool	Title
A1	Participant Rights at a Glance
A2	Accessible Research Invitation Checklist
A3	Participant Information Sheet Quality Checklist
A4	Accessible Consent Conversation Guide
A5	Communication & Accessibility Preferences Form
A6	Consent / Assent / Supported Decision-Making Plan
A7	Recruitment Equity Audit
A8	Sensory & Environmental Planning Checklist
A9	Remote Participation Accessibility Checklist
A10	Participant Burden Review
A11	Payment & Expenses Transparency Checklist
A12	Data & Privacy Explanation Template
A13	Co-Production Role Agreement
A14	Lived-Experience Contributor Terms of Reference
A15	Accessible Meeting Checklist
A16	Risk / Distress / Stop Plan
A17	Withdrawal Handling Checklist
A18	Return-of-Results Plan
A19	Plain-Language Results Summary Template
A20	Participant Experience Feedback Survey
A21	Institutional Self-Assessment Scorecard

TOOL A1

Participant Rights at a Glance

A one-page orientation for people considering or taking part in a study.

- ☐ To receive understandable information about what the study is and what participation involves.
- ☐ To ask questions and request information in an accessible format.
- ☐ To decide freely whether to participate, subject to the study's eligibility criteria.
- ☐ To know the foreseeable risks, burdens, privacy implications and any realistic direct benefits.
- ☐ To know whether you will be paid or reimbursed and how this works.
- ☐ To ask for reasonable communication or sensory adjustments where they can be provided within the approved study.
- ☐ To know who will access your data and how sharing/future use works.
- ☐ To pause or withdraw according to the consent and applicable rules without reprisal.
- ☐ To raise concerns or complaints through the routes provided.
- ☐ To be offered information about the general results where the ethical framework/study provides for this.

Remember

You can be eligible for a study and still decide not to join. You can also ask for more time before deciding.

TOOL A2

Accessible Research Invitation Checklist

Use before publishing recruitment ads, emails, flyers, social posts or registry notices.

- ☐ The study purpose is described in 1-2 plain-language sentences.
- ☐ Who can take part is clear without requiring people to decode technical inclusion criteria.
- ☐ Expected time, tasks, location/online method and number of contacts are stated.
- ☐ Payment/expenses are stated or a clear route to details is given.
- ☐ Major recording, specimen, data-linkage or sensitive-data elements are disclosed early.
- ☐ There is more than one contact method where feasible.
- ☐ The text avoids promises of benefit, diagnosis or treatment that the study does not provide.
- ☐ The invitation states that adjustments can be discussed.
- ☐ Images and language avoid stereotypes, infantilization or deficit-only framing.
- ☐ An autistic/lived-experience reviewer has tested the invitation for clarity where possible.

TOOL A3**Participant Information Sheet Quality Checklist**

A pre-submission / pre-use review for clarity and accessibility.

- ☐ Purpose and research question are clear.
- ☐ What the participant will do is described in chronological order.
- ☐ Risks and burdens are separated from possible benefits.
- ☐ Data use, storage, sharing, reuse and withdrawal implications are understandable.
- ☐ Payment/expenses and timing are explicit.
- ☐ Voluntary participation and withdrawal are easy to find.
- ☐ Contacts for questions, concerns and complaints are clearly distinguished.
- ☐ Results-return arrangements are stated.
- ☐ Jargon and unexplained acronyms have been removed.
- ☐ The document has usable headings, spacing, contrast and readable font size.
- ☐ Alternative accessible formats can be provided where needed.
- ☐ Version/date and approval-controlled identifiers are present as required by the study system.

TOOL A4**Accessible Consent Conversation Guide**

A structured conversation that supports understanding without becoming a test.

1. Ask how the person prefers to receive information and communicate.
2. Explain the study in short sections: purpose, activities, risks/burdens, data, payment, choice, results.
3. Pause after each section and invite questions through the preferred communication method.
4. Check understanding with open prompts such as “Can you tell me what you expect would happen if you joined?” rather than a yes/no question.
5. Correct misunderstandings without criticism and revisit information in another format if needed.
6. Confirm that the choice is voluntary and that saying no will not cause reprisal.
7. Document the consent method and any accommodations required by the approved process.
8. Provide a copy of the information/consent record in the accessible format agreed.

TOOL A5

Communication & Accessibility Preferences Form

A practical form to complete with - not about - the participant.

Preference area	Participant preference / notes
Best contact method	_____
Best way to receive study information	_____
How I prefer to answer questions	_____
Processing time / pace	_____
AAC / communication tools	_____
Support person and desired role	_____
Sensory needs	_____
Breaks / session length	_____
Remote / in-person preference	_____
Anything that makes participation harder	_____
Anything that helps	_____
Permission to share these adjustments with relevant study staff	☐ Yes ☐ No ☐ Ask me each time

Do not use this form to collect diagnostic or health information that is not needed for research access or the approved study.

TOOL A6

Consent / Assent / Supported Decision-Making Plan

Use for studies where participants may need decision support or where minors are enrolled.

- ☐ Applicable legal/ethics requirements identified for the participant group and study type.
- ☐ Accessible information format(s) prepared.
- ☐ Person responsible for consent is trained and appropriately independent where required.
- ☐ Supporter / legally authorized representative role is defined.
- ☐ Participant assent, preferences and signs of unwillingness are considered in the approved process.
- ☐ Re-consent triggers are defined (age transition, protocol change, new risk information, status change).
- ☐ Documentation requirements are clear.
- ☐ Escalation route exists if the team is uncertain about consent/capacity requirements.

TOOL A7

Recruitment Equity Audit

Check whether the recruitment pathway itself is excluding people.

Question	Yes / No / Action
Are recruitment channels broader than one clinic, university or online community?	_____
Can people contact the team without telephone-only communication?	_____
Are eligibility rules scientifically justified?	_____
Can adjustments remove some participation barriers without invalidating the method?	_____
Are people with higher support needs automatically excluded? If yes, is there a defensible reason?	_____
Are language, geography, cost, transport or digital access creating hidden exclusion?	_____
Are screen failures and non-response patterns monitored?	_____

TOOL A8

Sensory & Environmental Planning Checklist

For labs, clinics, interview rooms, community venues and events.

- ☐ Quiet waiting option or minimal waiting plan.
- ☐ Adjustable lighting or permission for participant aids where safe.
- ☐ Noise reduction where possible.
- ☐ Predictable room/route and clear signage.
- ☐ Advance description or photos of the location when useful.
- ☐ Permission for headphones, sunglasses, movement or comfort items where compatible with procedures.
- ☐ Private space for breaks.
- ☐ Clear touch/equipment explanation before procedures.
- ☐ Accessible toilets and physical access.
- ☐ Plan for supporter seating and role.

TOOL A9

Remote Participation Accessibility Checklist

For video interviews, online surveys, e-consent and digital studies.

- ☐ Platform approved for required privacy/security level.
- ☐ Captions/transcripts available where appropriate.
- ☐ Keyboard and screen-reader access checked.
- ☐ Camera requirement justified rather than assumed.
- ☐ Chat or typed response option available where method permits.
- ☐ Survey can save progress and resume.
- ☐ Time limits are generous or removable where method permits.
- ☐ Technical support/contact provided.
- ☐ Alternative route available for participants with limited connectivity where feasible.
- ☐ Recording requirements are disclosed and consented.

TOOL A10

Participant Burden Review

Complete before ethics submission and again after pilot testing.

Burden	Estimate	Can it be reduced?
Total participant time	_____	_____
Number of visits / contacts	_____	_____
Travel / waiting	_____	_____
Questionnaire length	_____	_____
Sensory / communication load	_____	_____
Emotional sensitivity	_____	_____
Samples / procedures	_____	_____
Technology / data costs	_____	_____
Follow-up period	_____	_____
Supporter / family burden	_____	_____

TOOL A11

Payment & Expenses Transparency Checklist

Use before recruitment so participants are not surprised by costs or conditions.

- ☐ Payment vs reimbursement clearly distinguished.
- ☐ Amount/rate and payment schedule stated.
- ☐ Eligible expenses listed.
- ☐ Supporter expenses addressed where approved.
- ☐ Payment method is accessible.
- ☐ Expected processing time stated.
- ☐ Pro-rata rules after withdrawal stated.
- ☐ Any tax/benefit implications are signposted where relevant.
- ☐ No payment is conditional on giving certain answers.
- ☐ Special restrictions for the participant group/study type have been checked.

TOOL A12

Data & Privacy Explanation Template

Use in participant-facing materials and consent conversations.

Complete each line in plain language:

Prompt	Study-specific explanation
We will collect...	_____ _____
We need this because...	_____ _____
Your directly identifying information will be seen by...	_____ _____
Your study data will be stored...	_____ _____
We will keep it for...	_____ _____
We may share data with...	_____ _____
Future / secondary use...	_____ _____
AI / automated analysis use, if any...	_____ _____
If you withdraw...	_____ _____
Questions about privacy can be sent to...	_____ _____

TOOL A13

Co-Production Role Agreement

Create this before the first substantive co-production meeting.

Topic	Agreement
Purpose and scope	_____
Decisions shared	_____
Decisions retained by accountable investigator/sponsor	_____
Time commitment	_____
Payment and expenses	_____
Accessibility / support	_____
Confidentiality / data access	_____
Training needed	_____
Authorship / credit	_____
How disagreements are handled	_____
How impact will be reported back	_____
Review date	_____

TOOL A14

Lived-Experience Contributor Terms of Reference

Minimum headings for an advisory or steering role.

- Role purpose and what success looks like.
- Membership and diversity approach.
- Decision rights and voting/advisory status.
- Meeting frequency and preparation expectations.
- Payment, expenses and payment timeline.
- Accessibility and support.
- Confidentiality, conflicts of interest and data boundaries.
- Behavior / respect expectations.
- How members can raise concerns or leave the role.
- Authorship, acknowledgement and external representation.
- Review cycle and who owns updates.

TOOL A15

Accessible Meeting Checklist

For advisory boards, focus groups, steering committees and co-production sessions.

- ☐ Agenda and papers sent early.
- ☐ Plain language used; acronyms explained.
- ☐ Start/end time and breaks clear.
- ☐ Online/in-person access confirmed.
- ☐ Captions / communication support arranged where requested.
- ☐ One speaker at a time.
- ☐ People can contribute by voice, chat, writing or after the meeting.
- ☐ No requirement for eye contact or camera-on participation unless necessary.
- ☐ Facilitator monitors dominance and makes space for quieter communication styles.
- ☐ Actions and decisions circulated in an accessible summary.

TOOL A16

Risk / Distress / Stop Plan

A study-level plan and participant-specific option where relevant.

Element	Plan
Potential sources of distress	_____
Early signs / participant-specific indicators	_____
Pause / stop signal	_____
Immediate response	_____
Who decides whether to continue	_____
Medical / safeguarding escalation	_____
Support information provided	_____
Adverse event / incident documentation	_____
Follow-up after distress	_____

TOOL A17

Withdrawal Handling Checklist

Make withdrawal respectful, fast and consistent.

- ☐ Confirm what the participant wants to stop: procedures, follow-up contact, data use where possible, or all future participation.
- ☐ Explain what data/samples can still be deleted and what cannot be reversed under the approved protocol/law.
- ☐ Process any payment or expenses already earned.
- ☐ Stop unnecessary reminders/contact.
- ☐ Record the withdrawal accurately without requiring the person to justify the decision.
- ☐ Offer a route to provide a reason voluntarily if useful for quality improvement.
- ☐ Complete any safety follow-up that remains ethically/legally required and was disclosed.
- ☐ Update study systems and relevant sites/teams promptly.

TOOL A18

Return-of-Results Plan

Plan before recruitment - not after the paper is published.

Question	Plan
Which results will be returned?	_____
Who will receive them?	_____
Preferred formats	_____
Accessibility review	_____
Timing trigger	_____
Who writes and approves summary	_____
How negative/inconclusive findings are explained	_____
Individual results policy	_____
Contact permissions retained	_____
Budget / owner	_____

TOOL A19

Plain-Language Results Summary Template

A concise participant-facing structure for aggregate findings.

Suggested 1-2 page structure

1. What question did we ask?
2. Who took part? (without compromising privacy)
3. What did participants do?
4. What did we find?
5. What did we not find / what remains uncertain?
6. What do the findings mean - and what do they not mean?
7. What happens next?
8. How autistic people / families contributed to the study design or interpretation.
9. Where can I find the full publication or more information?
10. Who can I contact with questions?

Plain-language rule

Do not turn a research association into a personal prediction. Avoid implying that group-level findings diagnose, explain or forecast what will happen to an individual participant.

TOOL A20

Participant Experience Feedback Survey

A short post-participation tool for continuous improvement.

Statement	Strongly disagree -> Strongly agree
I understood what the study involved before I agreed.	1 2 3 4 5
I could ask questions in a way that worked for me.	1 2 3 4 5
The study respected my communication and accessibility needs.	1 2 3 4 5
I felt able to pause or stop without pressure.	1 2 3 4 5
The time and effort asked of me were reasonable.	1 2 3 4 5
Payment/expenses were clear and handled as described.	1 2 3 4 5 / N/A
I understood how my data would be used.	1 2 3 4 5
I was treated with respect.	1 2 3 4 5
I would consider taking part in research again.	1 2 3 4 5

What should we keep doing? _____

What should we change? _____

Was there an adjustment you needed but could not access? _____

TOOL A21

Institutional Self-Assessment Scorecard

Score each domain 0-2: 0 = absent, 1 = partial/inconsistent, 2 = embedded and monitored.

Domain	Score	Priority action
1. Study relevance / lived-experience input	0 1 2	
2. Accessible recruitment	0 1 2	
3. Plain-language information	0 1 2	
4. Consent / supported decision-making	0 1 2	
5. Communication & sensory access	0 1 2	
6. Data privacy / future use clarity	0 1 2	
7. Payment & expenses	0 1 2	
8. Co-production / governance	0 1 2	
9. Safety / withdrawal / complaints	0 1 2	
10. Return of results	0 1 2	
11. Staff capability / training	0 1 2	
12. Metrics & continuous improvement	0 1 2	

Maximum score: 24. Use the score as a quality-improvement baseline, not as an accreditation or certification label.

Range	Interpretation
0-8	Foundational controls missing - prioritize participant protection and accessibility basics before scaling.
9-16	Core elements exist but are inconsistent - standardize templates, ownership and monitoring.
17-24	Strong system maturity - verify performance with participant feedback and study-level evidence, then improve gaps.

PART B

90-Day Implementation Roadmap

A practical institutional sequence for adopting the toolkit.

Period	Actions
Days 1-30 - Baseline	Assign an accountable research-participation lead; map current ethics/data/payment/accessibility processes; adopt standard participant information and accessibility checklists; define minimum payment/expense targets; create a results-return requirement; identify 1-2 studies for pilot review.
Days 31-60 - Build	Train research staff; establish a lived-experience contributor pool with role/payment terms; create accessibility-preferences and burden-review tools; align data/privacy language; test consent materials with autistic reviewers; set complaint and feedback routes; build dashboard fields.
Days 61-90 - Pilot & verify	Apply the standard to pilot studies; collect participant experience feedback; measure payment timing, adjustment delivery and results-return readiness; review incidents/withdrawals; correct gaps; approve the institutional standard for wider use; schedule quarterly review.

Suggested accountable owners

Function	Owner role (example)
Ethics / participant rights	Research governance / ethics lead
Accessibility	Study PI + participant-access coordinator
Data privacy	Data protection / information governance lead
Payments	Research operations / finance
Co-production	Public involvement / lived-experience lead
Results return	PI + knowledge translation / communications
Quality dashboard	Research operations / quality lead

Important

GARC may use this toolkit as an internal or partner quality standard, but it should not claim that applying the toolkit constitutes ethics approval, clinical-trial compliance, regulatory authorization or accreditation.

PART C

References and Further Reading

Core international ethics, disability-rights, participatory-research and implementation sources.

1. **World Medical Association (WMA).** Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Participants. Current official revision: October 2024. <https://www.wma.net/policies-post/wma-declaration-of-helsinki/>
2. **Council for International Organizations of Medical Sciences (CIOMS).** International Ethical Guidelines for Health-related Research Involving Humans. Fourth Edition, 2016; republished under Creative Commons in 2025. <https://cioms.ch/publications/product/international-ethical-guidelines-for-health-related-research-involving-humans/>
3. **International Council for Harmonisation (ICH).** E6(R3) Guideline for Good Clinical Practice. Principles and Annex 1 final Step 4 guideline, January 2025; Annex 2 adopted and published subsequently. Applicable specifically to clinical trials within its scope. <https://www.ich.org/>
4. **United Nations.** Convention on the Rights of Persons with Disabilities, including Article 9 (Accessibility), Article 22 (Privacy) and Article 31 (Statistics and Data Collection). <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
5. **UN Committee on the Rights of Persons with Disabilities.** General Comment No. 7 (2018) on the participation of persons with disabilities through their representative organizations, including meaningful and accessible involvement.
6. **Academic Autism Spectrum Partnership in Research and Education (AASPIRE).** Community Based Participatory Research model and autism research resources. <https://aaspire.org/>
7. **National Autistic Society.** Research principles and partnership approach emphasizing respectful, ethical research that centers autistic people and meaningful co-production. <https://www.autism.org.uk/what-we-do/who-we-are/research>
8. **National Institute for Health and Care Research (NIHR) / Learning for Involvement.** Guidance on co-producing a research project; principles include sharing power, including all perspectives, respecting all forms of knowledge, reciprocity and relationship building. <https://www.learningforinvolvement.org.uk/>
9. **UK Standards for Public Involvement.** Inclusive Opportunities; Working Together; Support and Learning; Communications; Impact; Governance. NIHR and UK partner resources.
10. **Health Research Authority (UK).** Payments and Incentives in Research. Updated 18 May 2026. <https://www.hra.nhs.uk/about-us/committees-and-services/nreap/payments-and-incentives-research/>
11. **National Institutes of Health (NIH), Office of Science Policy.** Return of Research Results. Current roadmap and draft policy activity for summary-level results; page updated September 2026. <https://osp.od.nih.gov/policies/return-of-research-results/>
12. **World Health Organization.** Autism spectrum disorders: research priorities and evidence needs; includes the importance of local community roles in research and dissemination.
13. **National Academies of Sciences, Engineering, and Medicine.** Returning Individual Research Results to Participants: Guidance for a New Research Paradigm. 2018. Washington, DC: The National Academies Press.
14. **Sgro GM, Maurer M, Nguyen B, Siegel JE.** Return of aggregate results to study participants: facilitators, barriers, and recommendations. Contemporary Clinical Trials Communications. 2023;33:101136.
15. **GARC practice note.** Local law, ethics-review requirements, sponsor policies and study-specific approvals should always be checked before implementation. References in this toolkit are not an exhaustive legal or regulatory list.

ABOUT GARC

About GARC

Global Autism Research Center - research, evidence, knowledge and institutional capacity.

Global Autism Research Center (GARC) develops research, evidence resources, practical toolkits, frameworks, partnerships and knowledge products intended to strengthen autism-related policy, practice and institutional capacity internationally.

GARC Practical Toolkits Series

The series translates evidence and rights-based principles into practical resources for schools, families, educators, early-years settings, universities, workplaces, healthcare systems, research participants and institutions.

Series publications completed

- 01 - School Community Autism Toolkit
- 02 - Family & Caregiver Autism Toolkit
- 03 - Educator Autism Toolkit
- 04 - Early Years Autism Toolkit
- 05 - University & Higher Education Autism Toolkit
- 06 - Workplace & Employer Autism Toolkit
- 07 - Healthcare Professional Autism Toolkit
- 08 - Autism Research Participation Toolkit

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