Service User Consent Policy

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Last Reviewed:

Next Review: February 2027 (or sooner if significant changes in legislation, guidance, or organisational activities occur)

Reviewed by:

Responsible Officer: CEO

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1. Introduction and Commitment

Pathways Associates CIC is a disabled-led Community Interest Company dedicated to enabling people with learning disabilities, autistic people, and their families to live the lives they choose as equals in their local communities.

We are committed to ensuring that Experts by Experience, self-advocates, participants, and families provide informed, voluntary consent for their involvement in our activities. Consent is fundamental to respecting autonomy, promoting empowerment, and building trust. This policy ensures consent processes are accessible, ethical, and aligned with best practice.

It draws on UK GDPR/Data Protection Act 2018 for data-related consent, Mental Capacity Act 2005 for decision-making support, and guidance from the ICO, CQC, and NHS on inclusive consent. This policy supports our Co-production Policy (emphasising shared decision-making), Information Governance and Data Protection Policy (data consent), Equality and Diversity Policy (inclusive practices), and Patient Safety Incident Response Policy (consent in reviews), embedding consent into our values:

- **Led by lived experience** — Involving disabled people and families in designing consent processes that reflect their needs
- **Partnership** — Collaborating with service users, advocates, and professionals to obtain and respect consent
- **Inclusion and respect** — Ensuring consent is accessible, free from coercion, and sensitive to diverse needs
- **Innovation** — Using creative, user-friendly methods (e.g., easy-read forms, visual aids) to facilitate consent
- **Integrity** — Acting transparently and accountably, with clear records and easy withdrawal options

We commit to obtaining meaningful consent, supporting capacity where needed, and reviewing processes to uphold rights and dignity.

2. Scope

This policy applies to all interactions where consent is required, including:

- Participation in training, events, co-production, or Expert Hub activities
- Sharing personal stories, data, or images (e.g., for resources, evaluations, or marketing)
- Data processing (as per our Information Governance Policy)
- Involvement in safety incident reviews or quality improvements

It covers:

- Service users, including people with learning disabilities, autistic people, families, and carers
- Colleagues, associates, volunteers, and partners handling consent

It does not cover clinical consent in regulated activities; refer to partner organisations if applicable.

3. Key Objectives We aim to:

- Ensure consent is informed, specific, and freely given, with easy withdrawal
- Support decision-making capacity through accessible information and advocacy
- Protect individuals from coercion or undue influence
- Maintain accurate records of consent to demonstrate compliance
- Integrate consent into co-production and data handling for ethical practice
- Learn from feedback to improve consent processes continuously

4. Core Principles Our consent practices are guided by:

- **Informed and voluntary** — Provide clear, accessible information on what is involved, risks, benefits, and alternatives
- **Capacity-focused** — Assume capacity unless assessed otherwise; use supported decision-making under the Mental Capacity Act
- **Accessibility** — Use easy-read, visual, verbal, or signed formats; offer interpreters or advocates

- **Specific and granular** — Consent for distinct purposes (e.g., data sharing vs. photo use)
- **Withdrawable** — Allow withdrawal at any time without detriment
- **Transparent** — Document and share how consent is obtained, used, and stored
- **Proportional** — Tailor processes to our small CIC's low-risk activities, avoiding unnecessary complexity

5. Roles and Responsibilities

- **CEO / Senior Leadership**
  - Oversee policy implementation and ensure resources for accessible consent tools
  - Appoint a Consent Lead (e.g., integrated with DPO role)
  - Review consent-related incidents or feedback
- **Consent Lead / DPO**
  - Advise on consent processes, especially for data
  - Monitor compliance, conduct audits, and handle withdrawal requests
  - Provide training and support
- **Managers / Event Leads**
  - Obtain and record consent for activities
  - Ensure accessible methods and support for capacity assessments
  - Report issues to the Consent Lead
- **All Colleagues, Associates, and Volunteers**
  - Follow consent procedures and respect service user choices
  - Report concerns about capacity or coercion
  - Use approved tools (e.g., consent forms)
- **Service Users and Advocates**
  - Provide or withhold consent freely
  - Raise questions or withdraw consent via info@pathwaysassociates.co.uk

If consent involves safety incidents, align with our Patient Safety Incident Response Policy.

6. Procedures

We follow clear steps for consent:

- **Obtaining Consent**
  - Provide information in accessible formats (e.g., easy-read privacy notices, verbal explanations)
  - Confirm understanding and voluntariness; use checklists for complex cases
  - For data: Base on consent or legitimate interest, with opt-out options (as per Information Governance Policy)
- **Capacity and Support**
  - Assess capacity if doubts arise (e.g., using MCA principles)
  - Involve advocates, family, or independent supporters
  - Document best-interest decisions if capacity is lacking
- **Recording and Storage**
  - Use secure forms/templates; store in encrypted systems
  - Note date, purpose, method, and any withdrawals
  - Retain as per data retention schedules
- **Withdrawal and Review**
  - Process withdrawals promptly (e.g., stop data use, remove images)
  - Review consent periodically (e.g., annually for ongoing involvement)
- **Specific Contexts**
  - Co-production: Obtain consent for sharing lived experiences
  - Events/Photos: Separate consent for media use
  - BYOD: Ensure devices comply with security for consent records

Breaches: Report to DPO; notify affected individuals/ICO if required.

7. Training, Awareness, and Support

We commit to:

- Annual consent training for all (covering GDPR, MCA, accessibility)
- Induction for new joiners, with resources like ICO guides
- Awareness campaigns via meetings and easy-read materials
- Support for service users (e.g., advocacy referrals)

8. Monitoring, Review, and Continuous Improvement

- This policy is reviewed annually or following changes/feedback
- Monitor via audits, consent logs, and service user surveys
- Learning co-produced with Experts by Experience
- Feedback welcomed; annual summaries in CIC report for transparency

9. Conclusion

Pathways Associates CIC is dedicated to ethical, inclusive consent practices that empower self advocates and uphold their rights. By obtaining informed consent respectfully, supporting decision-making, and learning together, we honour our disabled-led values and foster trust for better outcomes for people with learning disabilities, autistic people, and their families.