Study 1:
Deep Dive Into Adapted Consent Procedures

Study Lead:

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Study 1 Aim 2

Find out whether using the My Health and Well Being Survey in a doctor's office can help with patient-provider communication.

Promoting Agency and Self-Determination within the Study

Challenge 1:

Finding a balance between promoting agency in decision-making about the study and ensuring that we follow legal and ethical regulations about legal consent documents.

Challenge 2:

Creating a cognitively accessible consent process that is understandable and includes all the required components of consent per research regulations.

How do we find a balance between…

Empowering adults with intellectual disabilities to make their own decisions about research participation.

Making sure to respect legal and ethical guidelines for consent processes so we do not get ourselves or our participants in trouble!

Last year at the Summit, we tried out our adapted consent process with the DEEP…

It needed work…

Accessible Consent Process

3 brief videos (2 minutes or less) giving multi-modal information (voice, text, images) about key parts of the study

- Part 1: What is the study about and it is your choice whether or not to participate
- Part 2: Possible risks and benefits of the study.
- Part 3: Choice about whether to allow videotaping (only for those who are interested in participating)

Accessible Consent Process

After each video…

- Pause for questions about that section
- Ask a few follow-up questions to make sure the person understands the most important parts

Options for Who Provides Consent

Multiple options for consent and assent have been approved by our Institutional Review Board (IRB)

For People Who Are Their Own Legal Guardian

- Provide consent for themselves using our adapted, accessible consent process

- If they have a hard time understanding the study or want help deciding, we can help with contacting a person of their choice to use a supported decision making framework

For People Who Have a Legal Guardian

- We first contact the legal guardian to let them know about the study and they can opt in or out
  - If they opt in, the adult with intellectual disability still needs to assent to be involved

- If the legal guardian doesn't respond either way, the adult with intellectual disability can decide for themselves whether to participate

Next Steps

Start recruiting participants!

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