

TITLE: DOING RESEARCH RIGHT: ETHICAL STANDARDS IN PRACTICE

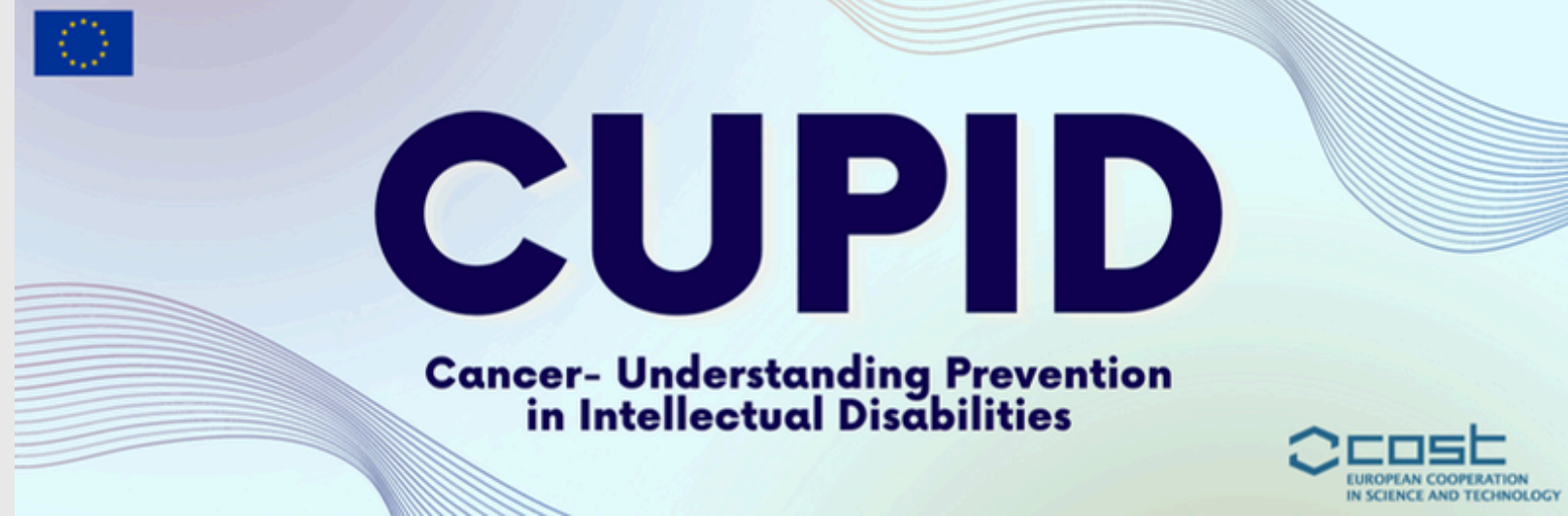
Cancer-screening and prevention for people with intellectual disability (CUPID)- Lunch and learn Webinar series

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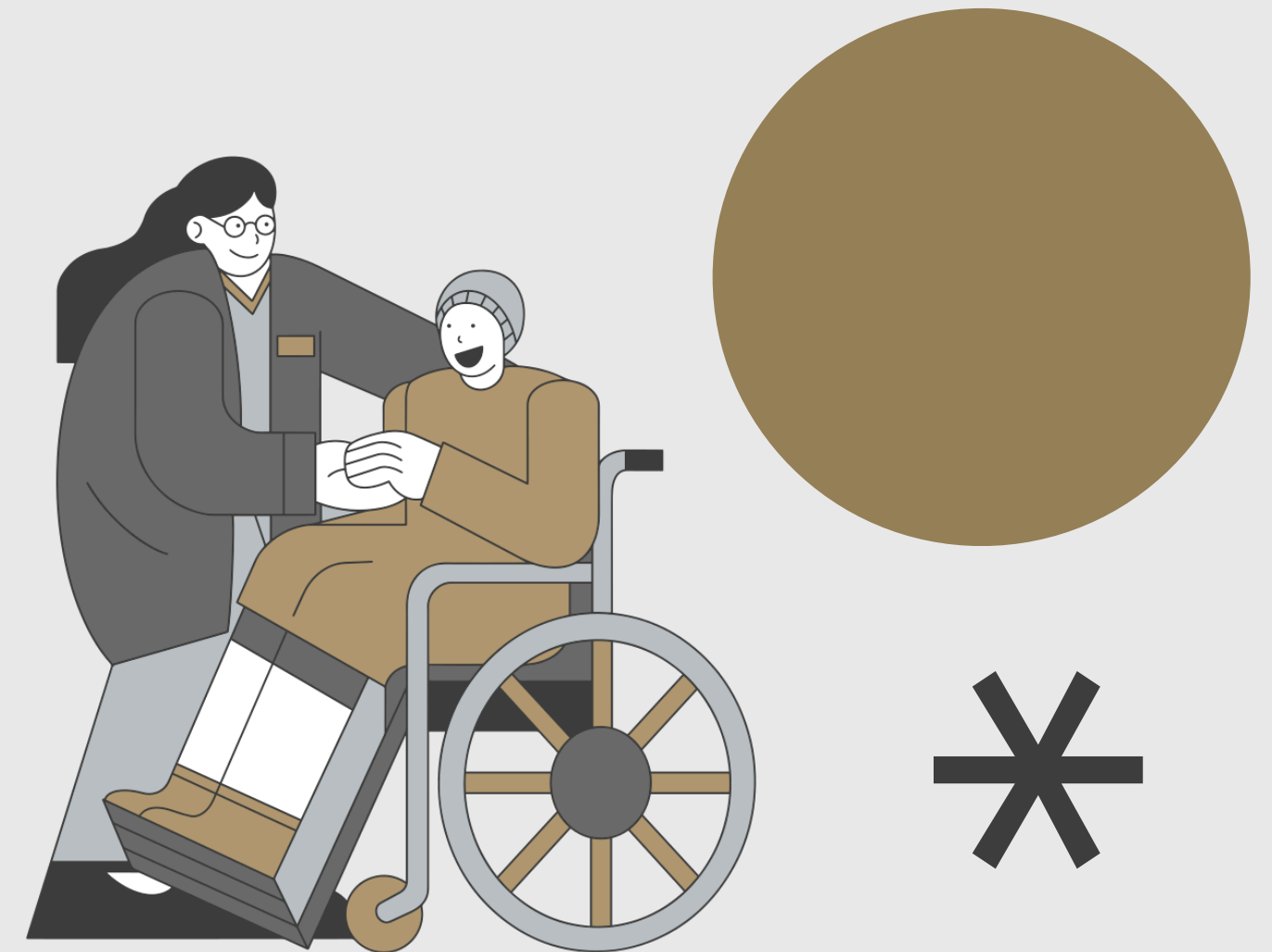




Outline

- Why Ethics Matter in Research with People with Intellectual Disabilities
- Key Ethical Principles:
 - Informed Consent
 - Inclusion
 - Dignity
 - Confidentiality
 - Accessible Research Practices
- How Ethics Strengthen Research Quality
- Practical Tips and Resources

• Q&A

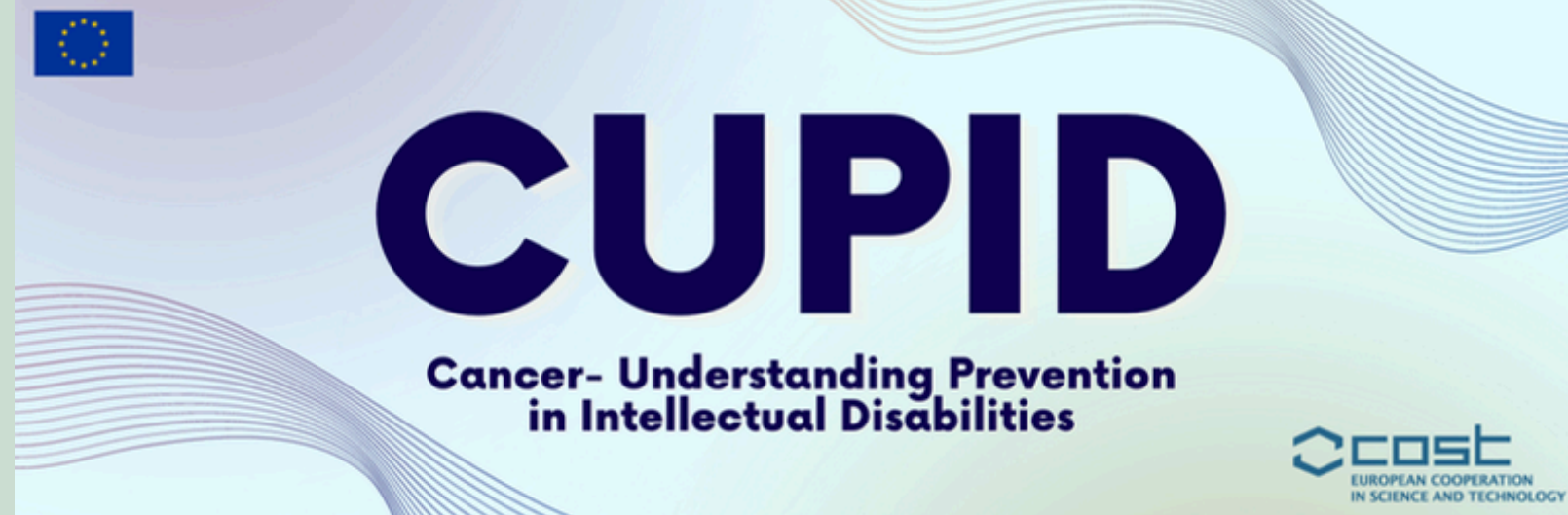




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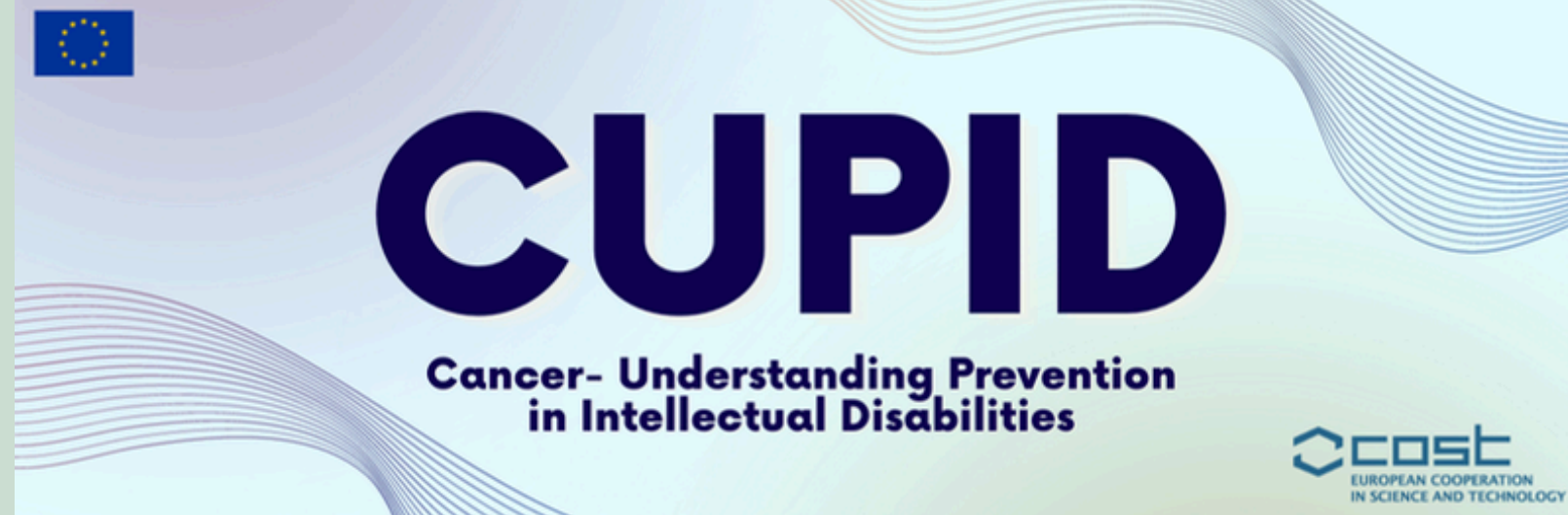
WEBINAR OBJECTIVES

OBJECTIVES

By the end of this webinar, participants will:

- Understand key ethical principles in disability-inclusive research
- Recognize barriers faced by people with intellectual disabilities in cancer research and care
- Explore practical approaches for accessible and inclusive research
- Learn how ethical practices improve research quality and participant protection
- Reflect on good practices and recommendations for future research



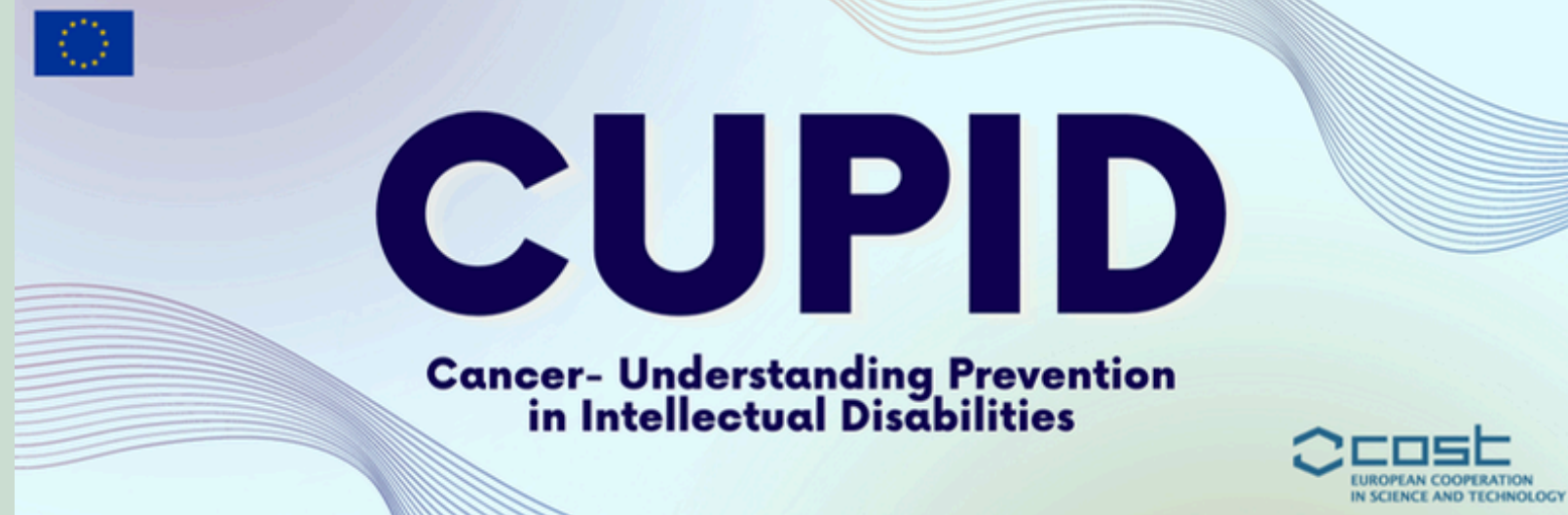


WHY ETHICAL RESEARCH MATTERS

PEOPLE WITH INTELLECTUAL DISABILITIES:

- EXPERIENCE SIGNIFICANT HEALTH INEQUALITIES
- FACE BARRIERS IN CANCER PREVENTION, SCREENING, DIAGNOSIS, AND TREATMENT
- ARE OFTEN UNDERREPRESENTED IN RESEARCH
- MAY EXPERIENCE COMMUNICATION AND ACCESSIBILITY CHALLENGES
- ETHICAL RESEARCH HELPS:
- ENSURE EQUAL PARTICIPATION
- IMPROVE EVIDENCE QUALITY
- REDUCE EXCLUSION AND DISCRIMINATION
- BUILD TRUST WITH COMMUNITIES



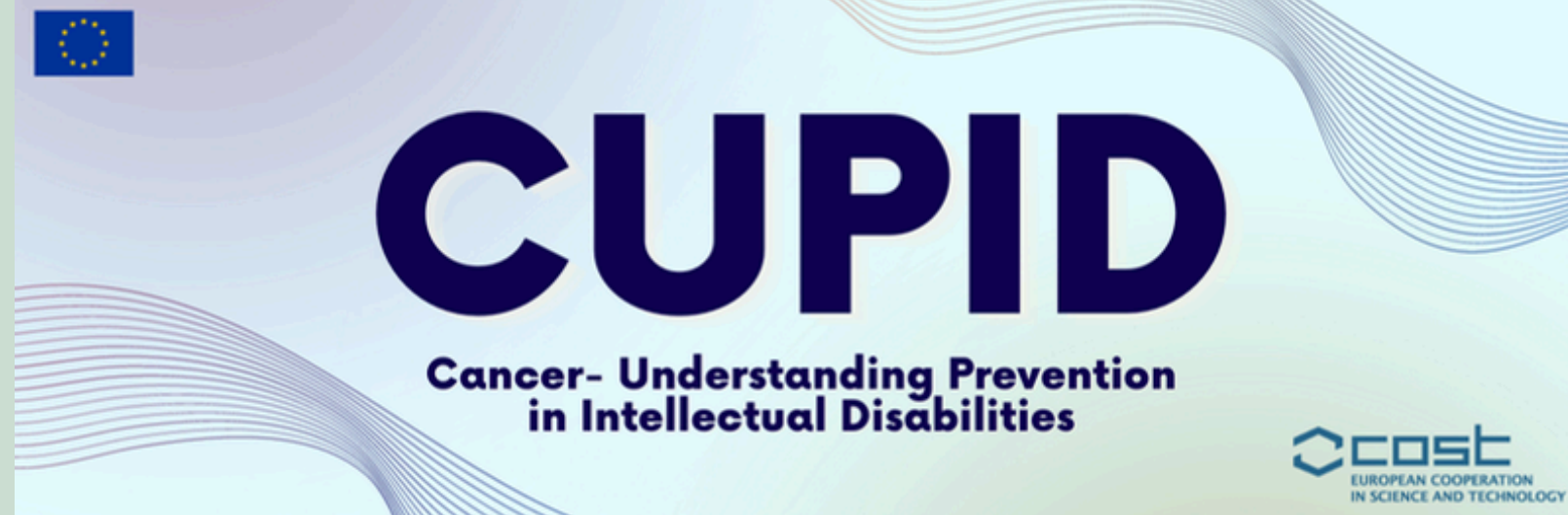


WHAT IS DISABILITY-INCLUSIVE RESEARCH?

- INVOLVING PEOPLE WITH DISABILITIES MEANINGFULLY
- REMOVING BARRIERS TO PARTICIPATION
- ADAPTING METHODS AND COMMUNICATION
- RESPECTING AUTONOMY AND DECISION-MAKING
- ENSURING ACCESSIBILITY THROUGHOUT THE RESEARCH PROCESS

KEY PRINCIPLE:

“NOTHING ABOUT US WITHOUT US.”



CORE ETHICAL PRINCIPLES IN RESEARCH

1. RESPECT FOR PERSONS

AUTONOMY

INFORMED DECISION-MAKING

RESPECT FOR PREFERENCES AND DIGNITY

2. BENEFICENCE

MAXIMIZE BENEFITS

MINIMIZE HARM

3. NON-MALEFICENCE

AVOID PHYSICAL, PSYCHOLOGICAL, OR SOCIAL HARM

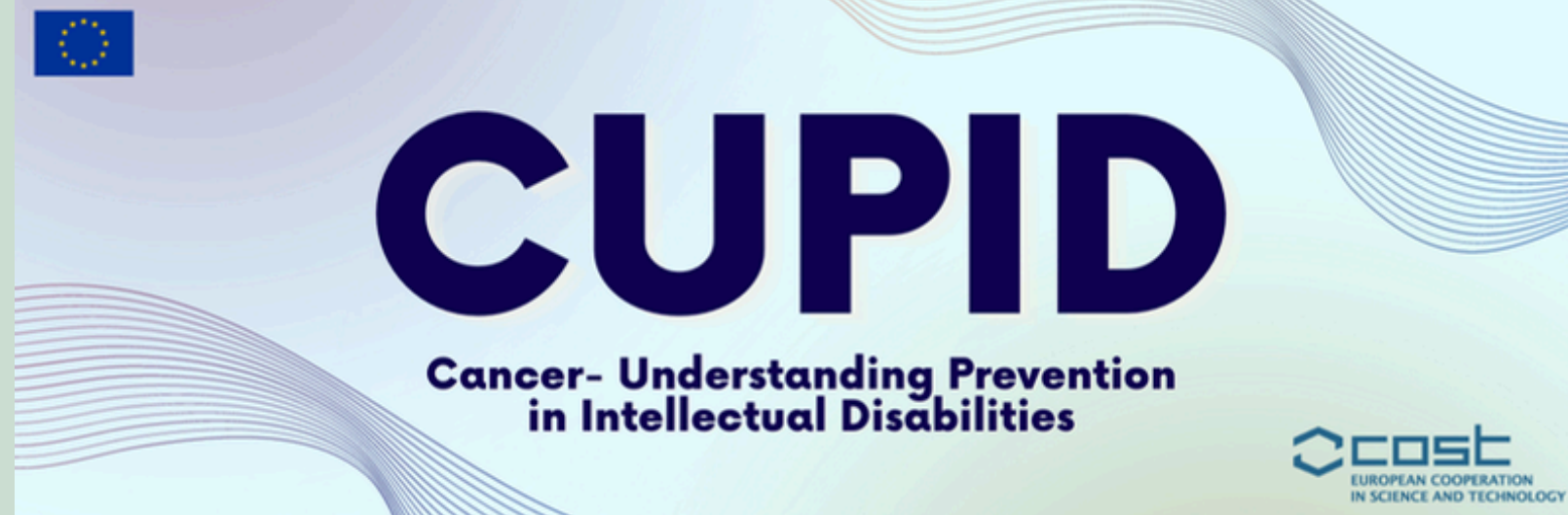
4. JUSTICE

FAIR INCLUSION AND EQUAL ACCESS

AVOID EXCLUSION FROM RESEARCH BENEFITS

5. CONFIDENTIALITY AND PRIVACY

PROTECT SENSITIVE PERSONAL AND HEALTH INFORMATION



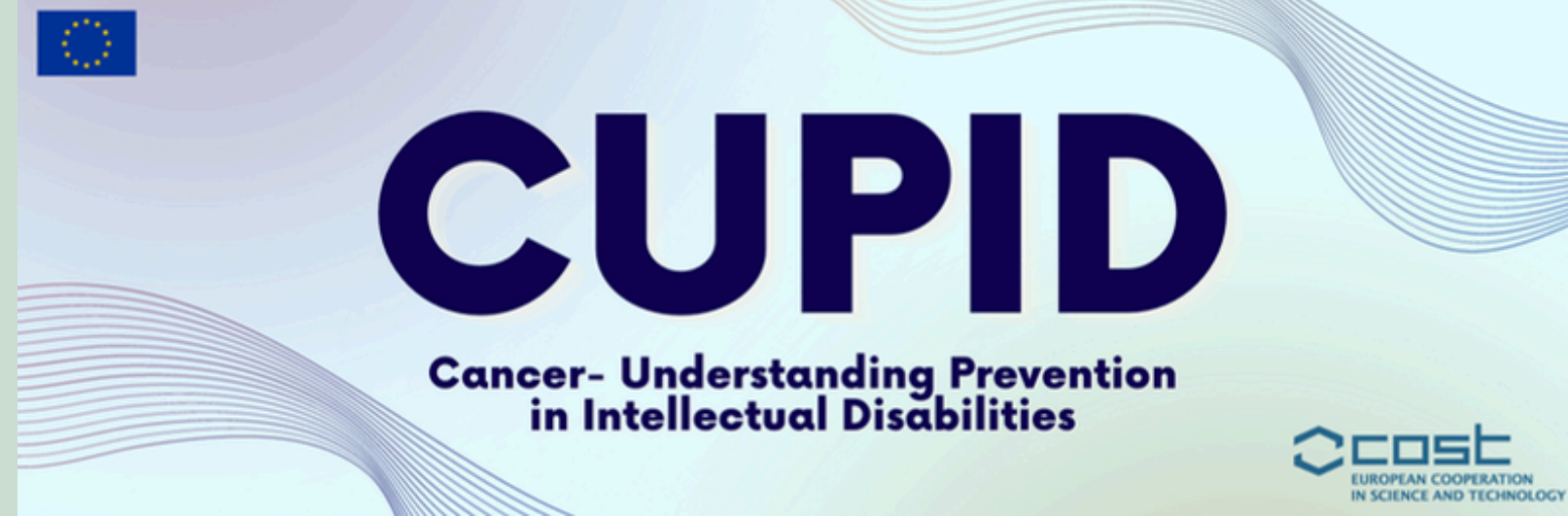
CONSENT- UNDERTAKING RESEARCH ON CANCER PREVENTION WITH PEOPLE WHO HAVE INTELLECTUAL DISABILITIES (PWIDD)

WHAT IS RESEARCH CONSENT?

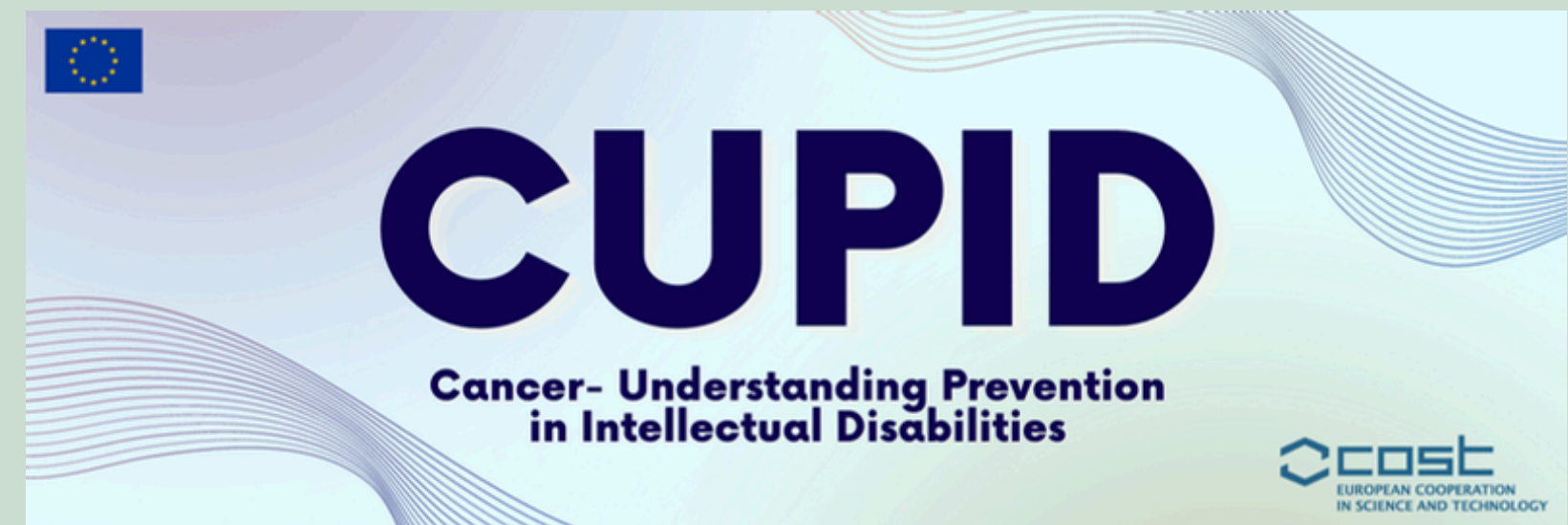
Research consent is the informed, voluntary, and explicit agreement of a competent person to participate in a research study after being fully informed about its purpose, procedures, risks, benefits, and their rights, including the right to withdraw at any time without penalty.



It is a fundamental ethical principle ensuring participants understand what their involvement entails and are not coerced into participating.



The rules around consent to participate in research for people with intellectual disabilities vary significantly across countries. They reflect differences in legal frameworks, ethical traditions, disability rights movements, and interpretations of international conventions such as the UN Convention on the Rights of Persons with Disabilities (CRPD).



CAPACITY VS. COMPETENCE



- **MOST COUNTRIES ASSESS WHETHER A PERSON CAN PROVIDE INFORMED CONSENT BASED ON DECISION-MAKING CAPACITY (UNDERSTANDING, APPRECIATION, REASONING, AND COMMUNICATION).**
- **IF DEEMED INCAPABLE, ALTERNATIVE PATHWAYS (PROXY CONSENT, ASSENT, SUPPORTED DECISION-MAKING) COME INTO PLAY.**



ROLE OF GUARDIANS OR PROXIES

- **SOME COUNTRIES ALLOW LEGAL GUARDIANS TO CONSENT ON BEHALF OF AN INDIVIDUAL.**
- **OTHERS REQUIRE BOTH THE PARTICIPANT'S ASSENT AND GUARDIAN'S CONSENT.**
- **A GROWING TREND IS TOWARD SUPPORTED DECISION-MAKING RATHER THAN SUBSTITUTED DECISION-MAKING.**





MARIA'S STORY

- Maria is a 42-year-old woman with a mild intellectual disability who lives semi-independently with support from a visiting caregiver. She was invited to take part in the research study on cancer screening.
- **THE CONSENT ENCOUNTER**
- When presented with the standard consent form, Maria struggled:
- She became anxious at words like “confidentiality,” “data storage,” and “withdrawal of consent.”
- She initially said, “I don’t know... I don’t want to sign something I don’t understand.”

- WHAT WOULD YOU DO?





AISHA'S STORY

- AISHA IS A 36-YEAR-OLD WOMAN WITH MODERATE INTELLECTUAL DISABILITY WHO LIVES IN A SUPPORTED GROUP HOME.
- THE CONSENT ENCOUNTER
- WHEN THE RESEARCH TEAM INTRODUCED THE STUDY, AISHA BECAME DISTRACTED AND REPEATEDLY CHANGED TOPICS.
- EVEN WITH AN EASY READ SHEET AND PICTORIAL AIDS, SHE COULD NOT DEMONSTRATE AN UNDERSTANDING OF WHAT PARTICIPATION WOULD INVOLVE OR THAT SHE HAD A CHOICE TO DECLINE.
- WHEN ASKED IF SHE WANTED TO BE PART OF THE STUDY, AISHA NODDED BUT THEN IMMEDIATELY ASKED ABOUT GOING SHOPPING, SUGGESTING SHE DID NOT FULLY GRASP THE CONTEXT.



SOPHIE'S STORY?

- **SOPHIE IS A 29-YEAR-OLD WOMAN WITH MILD ID WHO WORKS PART-TIME AND LIVES INDEPENDENTLY WITH MINIMAL SUPPORT.**
- THE CONSENT ENCOUNTER
- **AT FIRST, SOPHIE WAS NERVOUS: "I DON'T LIKE SIGNING THINGS. WHAT IF I DO IT WRONG?"**



MARIA’S STORY- POSSIBLE RESEARCHER RESPONSES?

To support her decision-making:

- The researchers use an Easy Read consent sheet with short sentences, symbols, and pictures (for example, a lock to represent privacy).
- They explain each step in plain language, e.g., “We want to ask you some questions about going to the doctor for check-ups. You can say yes or no. If you say yes now, you can change your mind later.”
- Her caregiver to stay with her but was asked not to answer on her behalf, only to help explain if Maria requested it.

- **ANYTHING ELSE?**





POSSIBLE FOLLOW ON...

- Maria signed the Easy Read form herself, with her caregiver co-signing to acknowledge support. Throughout the study, researchers checked back with Maria to make sure she was still comfortable. On one occasion she said she was too tired to do an interview that day, and the session was postponed – respecting her process consent.

WHAT HER STORY SHOWS



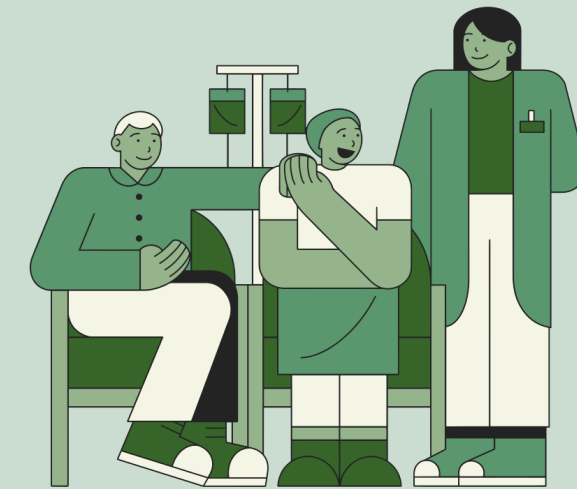
- **MARIA'S EXAMPLE HIGHLIGHTS THAT:**
- **WITH THE RIGHT ADJUSTMENTS, WOMEN WITH ID CAN EXERCISE AGENCY IN DECIDING TO PARTICIPATE.**
- **TRADITIONAL CONSENT FORMS AND PROCESSES OFTEN EXCLUDE PEOPLE.**
- **RESPECTING SMALL BUT IMPORTANT CHOICES (LIKE POSTPONING AN INTERVIEW) STRENGTHENS ETHICAL PARTICIPATION.**



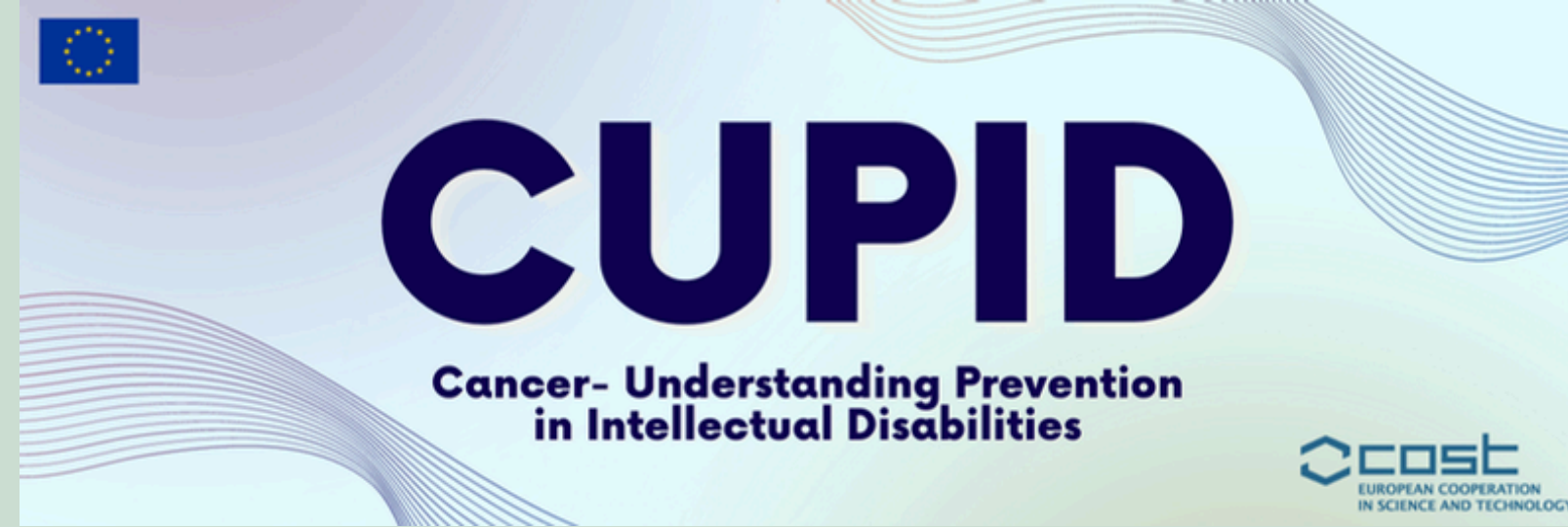
PARTICIPANT EXAMPLE 2: AISHA'S STORY



BEST OUTCOME?

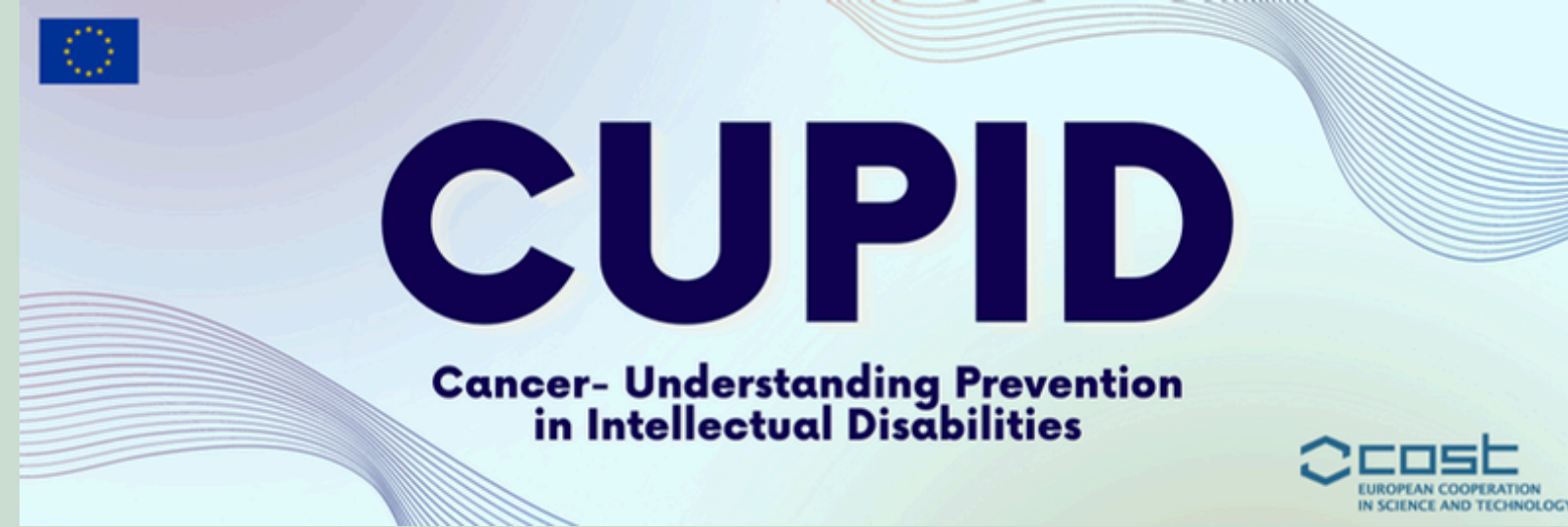


- **BECAUSE AISHA COULD NOT SHOW COMPREHENSION OR PROVIDE ASSENT, THE RESEARCHERS ETHICALLY DECIDED NOT TO ENROL HER — EVEN THOUGH HER LEGAL GUARDIAN HAD OFFERED PROXY CONSENT.**
- **KEY LEARNING: RESPECTING THE PARTICIPANT'S AUTONOMY SOMETIMES MEANS RECOGNISING WHEN CONSENT (AND ASSENT) CANNOT BE MEANINGFULLY OBTAINED.**



SOPHIE'S STORY?

- SOPHIE IS A 29-YEAR-OLD WOMAN WITH MILD ID WHO WORKS PART-TIME AND LIVES INDEPENDENTLY WITH MINIMAL SUPPORT.
- THE CONSENT ENCOUNTER
- AT FIRST, SOPHIE WAS NERVOUS: “I DON’T LIKE SIGNING THINGS. WHAT IF I DO IT WRONG?”
- THE RESEARCHERS EXPLAINED THAT SIGNING MEANT SHE AGREED TO TALK ABOUT HER EXPERIENCES, AND THAT SHE COULD STOP AT ANY TIME.
- They used role-play (acting out “saying stop” or “changing your mind”) so Sophie felt confident she had control



KEY LEARNING FROM SOPHIE'S STORY?

- **PROCESS CONSENT AND ROLE-PLAY STRATEGIES CAN EMPOWER PARTICIPANTS WITH ID TO ENGAGE MEANINGFULLY, BUILDING TRUST AND SAFEGUARDING AUTONOMY.**



Question to Consider?

SHOULD PROXY CONSENT BE ALLOWED IN RESEARCH FOCUSED ON PERSONAL EXPERIENCES SUCH AS CANCER SCREENING?

RESEARCHERS FACE AN ETHICAL DILEMMA: HOW TO RESPECT AUTONOMY WHILE ENSURING PROTECTION?





HAVE WE CONSIDERED?

- Accessible Information: Development of Easy Read consent forms with simplified text, symbols, and pictorial aids.
- Supported Decision-Making: Participants encouraged to have a trusted support person (family member, caregiver, or advocate) present during the consent process?
- Process Consent: Instead of a one-time signature, researchers revisit consent at multiple points during the study to ensure ongoing understanding and willingness?
- Assent plus Proxy Consent: Where women were unable to give fully informed consent, assent can be sought from the participant alongside proxy consent from a legally authorised representative (Country specific!!)
- You must know the legal situation in your country when undertaking research!



CREDIT TO:

**DR SUZANNE DENIEFFE, ACTION CHAIR, CUPID COST PROJECT
HEAD OF FACULTY OF ARTS AND HUMANITIES (WATERFORD), IRELAND**

Thank you!

