Inclusion in the Practice of Genomic Medicine: Developing a Patient-Centered Counseling Approach

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Explicit vs. Implicit Bias

Explicit bias – have awareness of this attitude

Implicit bias – no awareness of this attitude and may be opposed to declared views

We all have implicit biases.
Healthcare providers manifest implicit biases to a similar degree as the general population.

Implicit Bias in Medicine

Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

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Genetics and Disability

Tay-Sachs Disease

Spinal muscular atrophy

Cri-du-Chat

Down Syndrome

Rett Syndrome

Deafness

Charcot-Marie-Tooth Disease

Huntington's Disease

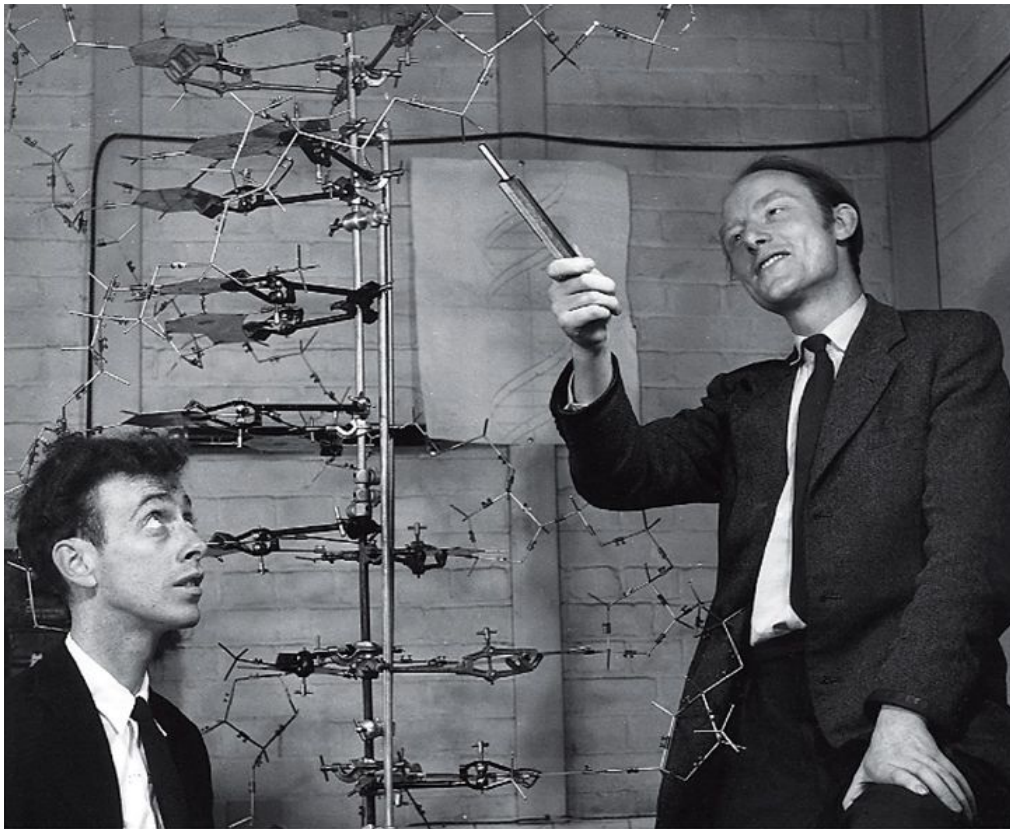
Fragile X Syndrome

Achondroplasia

Muscular Dystrophy

Many genetic diagnoses include physical or intellectual disabilities.

Evidence for Explicit Bias Against Disability in Genetics



"Seeing the bright side of being handicapped is like praising the virtues of extreme poverty."

- James Watson

Prenatal Testing and Disability

Does providing prenatal testing and opportunities for pregnancy termination for certain genetic conditions imply a belief that individuals with disabilities are defective?

Evidence for Implicit Bias Against Disability in Healthcare

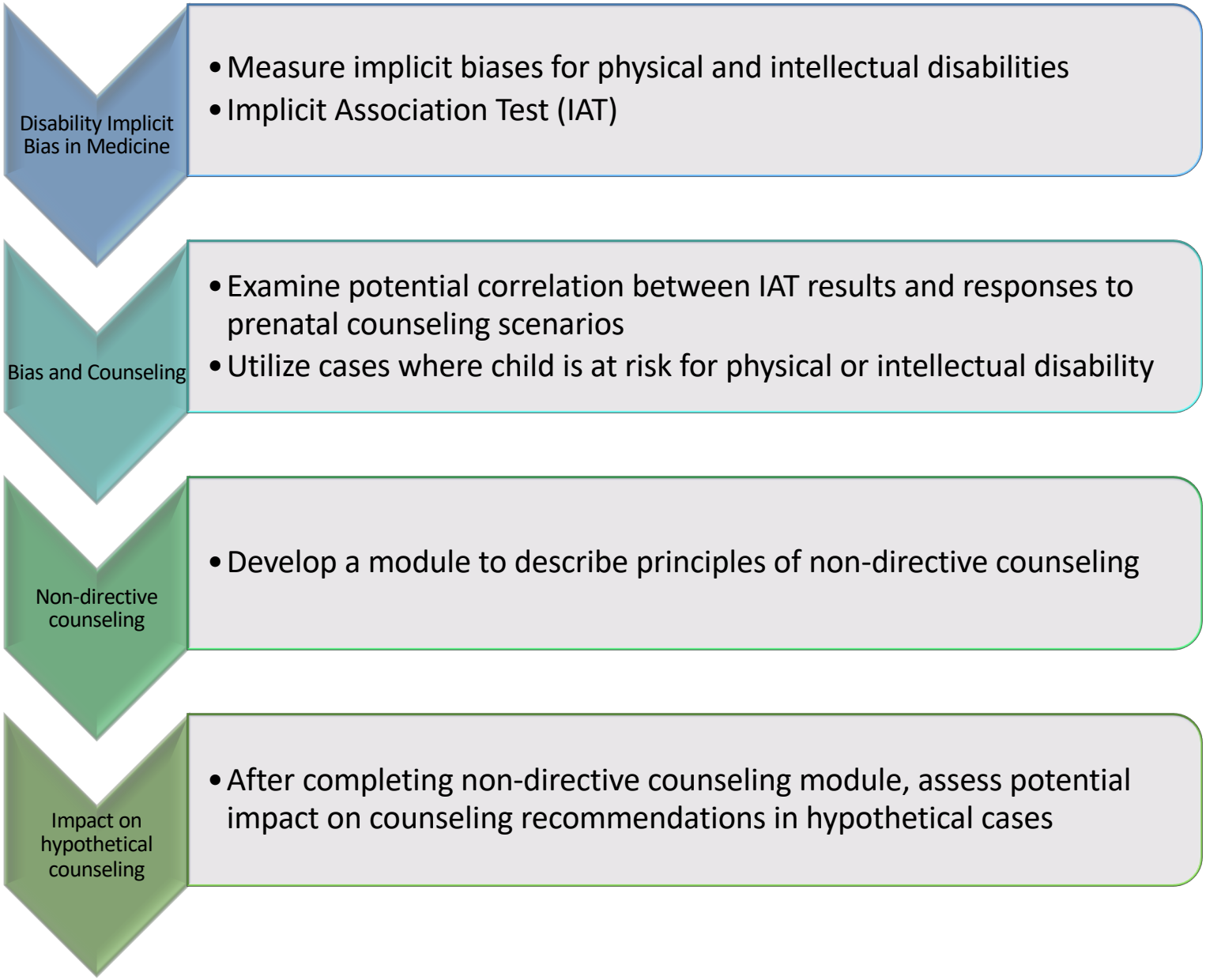
-Disconnect between personal views and understanding of role of physician in providing guidance to patients
-Misunderstanding of elements of non-directive counseling

-Patients not receiving balanced information from counselors

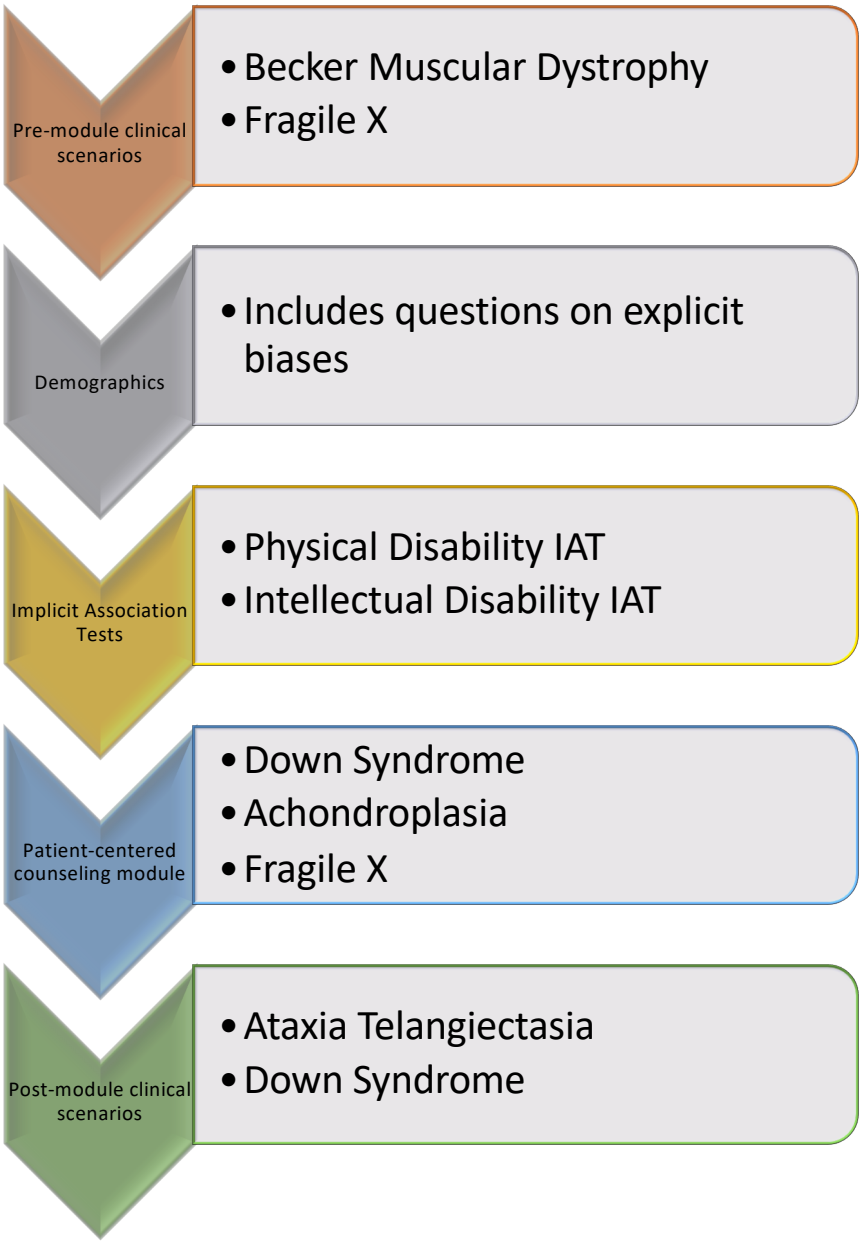
-PA students demonstrate preference for abled individuals

Bouchard et al, 1995; Roberts et al, 2002; Archambault et al, 2008

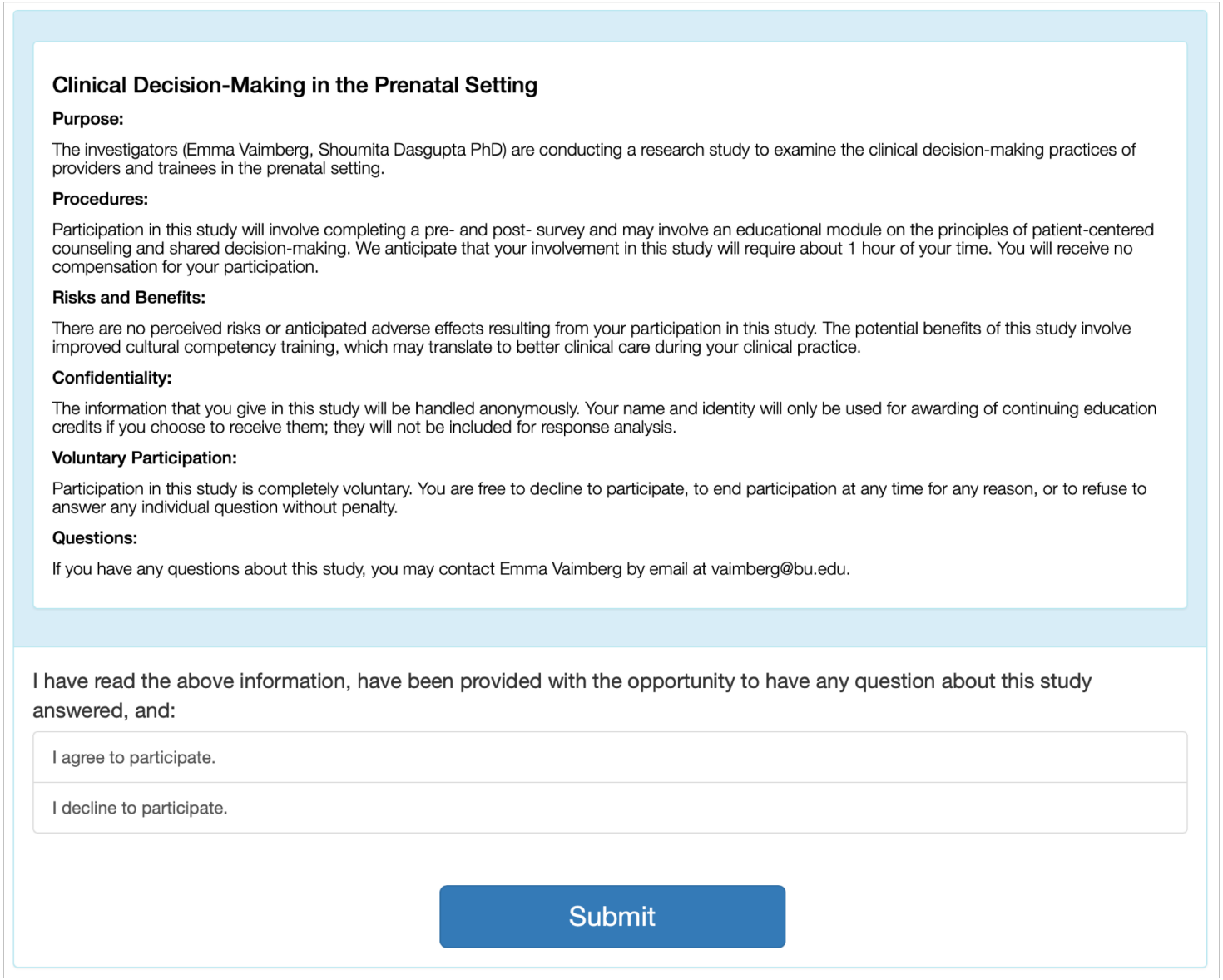
ISCC Project Inclusive Genetics



Clinical Decision-Making in the Prenatal Setting



1. Enter Module



Clinical Decision-Making in the Prenatal Setting

Purpose:

The investigators (Emma Vaimberg, Shoumita Dasgupta PhD) are conducting a research study to examine the clinical decision-making practices of providers and trainees in the prenatal setting.

Procedures:

Participation in this study will involve completing a pre- and post- survey and may involve an educational module on the principles of patient-centered counseling and shared decision-making. We anticipate that your involvement in this study will require about 1 hour of your time. You will receive no compensation for your participation.

Risks and Benefits:

There are no perceived risks or anticipated adverse effects resulting from your participation in this study. The potential benefits of this study involve improved cultural competency training, which may translate to better clinical care during your clinical practice.

Confidentiality:

The information that you give in this study will be handled anonymously. Your name and identity will only be used for awarding of continuing education credits if you choose to receive them; they will not be included for response analysis.

Voluntary Participation:

Participation in this study is completely voluntary. You are free to decline to participate, to end participation at any time for any reason, or to refuse to answer any individual question without penalty.

Questions:

If you have any questions about this study, you may contact Emma Vaimberg by email at vaimberg@bu.edu.

I have read the above information, have been provided with the opportunity to have any question about this study answered, and:

I agree to participate.

I decline to participate.

Submit

2. Clinical Scenarios

Clinical Scenario One

A couple, Mr. and Mrs. J, comes to you after learning that they are expecting a male child. Mrs. J tells you about her family history of Becker Muscular Dystrophy (BMD) and that she knows that she is a carrier for the disease. BMD is an X-linked condition that causes progressive skeletal muscle weakness and cardiomyopathy. BMD typically presents in childhood or adolescence and has an average lifespan in the 40–50s. The phenotype typically presents only with physical aspects to the condition. Your patient is concerned about her risk for passing on BMD, and she asks you to perform genetic testing to determine if the fetus has Becker Muscular Dystrophy.

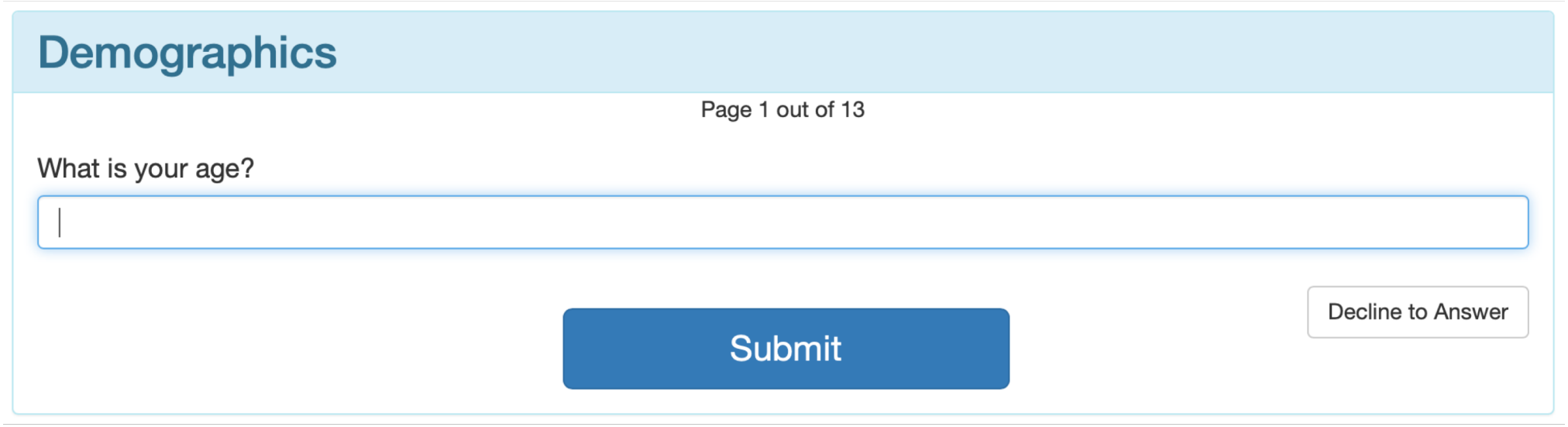
Click Here to Proceed

Clinical Scenario Two

A 30-year-old woman, Ms. N, comes to you because she recently learned she is a premutation carrier of Fragile X syndrome and is pregnant with a male fetus. Fragile X syndrome is an X-linked condition characterized by cognitive impairment, developmental delays and autism. She understands that she has a 50% risk to have a baby with Fragile X syndrome and is interested in learning more about her testing options.

Click Here to Proceed

3. Demographics



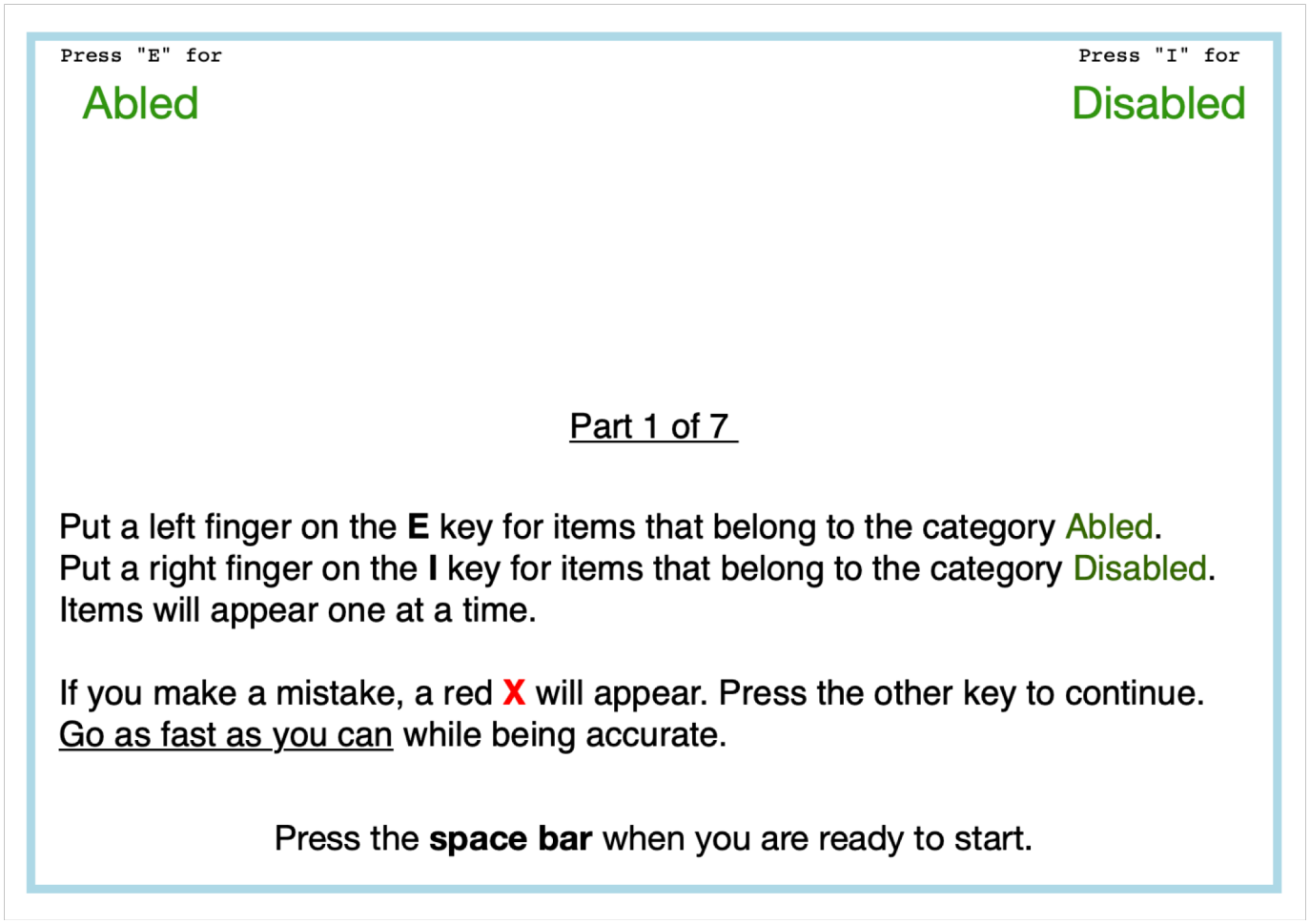
4. Two Implicit Association Tests

The next task is the **IAT**. In this task, you will see words, presented one at a time at the center of the screen. The categories will be presented at the top-right and top-left corners of the screen. For each word, if it belongs to a category on the right, hit the key **i**, and if it belongs to a category on the left, hit the key **e**.

For instance, in the illustration below, because the image belongs to the category 'Dogs' that appears on the right, the correct response is **i**.

Click here to proceed

4. Two Implicit Association Tests



*Will add functionality of returning results to learner.

5. Patient-Centered Counseling Module

An Introduction to Patient-Centered Counseling: An Educational Web Module

Introduction & Goals

As a healthcare provider, you will be responsible for helping patients make important decisions about their healthcare. It is not only your responsibility to discuss potential risks and benefits related to medical decisions, but it is also critical for you to understand your patients' goals. Understanding your patients' values can help you advise them on decisions that are consistent with their own wishes and beliefs. Some of the decisions your patients may face can be challenging and may even bring up ethical challenges for both you and your patient. Situations in which you may encounter these challenges could involve risk assessment for hereditary cancer, discussing preconception and reproductive health, or prenatal diagnoses, to name a few.

In prenatal and preconception counseling, there are many important counseling aspects to consider, especially as they relate to prenatal genetic diagnoses and pregnancy management options. In this module, you will learn about patient-centered counseling, patient autonomy and shared decision-making, and will apply these concepts to clinical cases in the prenatal setting.

Goals:

1. Describe a patient-centered model for genetic counseling
2. Outline how to facilitate autonomous decision making
3. Apply knowledge of patient-centered genetic counseling techniques to clinical case scenarios

Click Here to Proceed

6. Final Clinical Scenarios

Clinical Scenario Three

A couple, Mr. and Mrs. H, was referred to you for a prenatal counseling session at 12 weeks gestation because they were both found to be carriers of ataxia telangiectasia (AT) through expanded carrier screening ordered by Mrs. H's obstetrician. AT is a condition characterized by childhood onset movement problems called ataxia. They can have difficulty walking and with balance, chorea and neuropathy. The movement problems typically cause people to require wheelchair assistance by adolescence. They can also have a weakened immune system and an increased risk for cancer. The phenotype typically presents only with physical aspects to the condition. The lifespan varies greatly but individuals typically survive into early adulthood. When both parents are carriers, each pregnancy has a 25% risk to be affected.

Continue

Clinical Scenario Four

A 38-year-old female, Ms. F, is referred to you at 18 weeks gestation because she had a prenatal blood test that evaluates DNA from the pregnancy in maternal blood (cell-free DNA screening) and the test has come back indicating the pregnancy has an increased risk to be affected with Down syndrome. Down syndrome is characterized by a wide range of developmental and physical disabilities, including mild to moderate intellectual disabilities developmental delay, characteristic facial features, congenital heart defects and other congenital anomalies, and an increased risk for several health concerns, most of which are treatable. You counsel the patient that while the blood test results show an increased chance that the fetus has Down Syndrome (approximately 90% chance), it is not definitive and an amniocentesis is necessary to rule out or diagnose the condition.

Continue

Implicit Bias Study design

Does implicit bias for both physical and intellectual disability exist among healthcare providers?

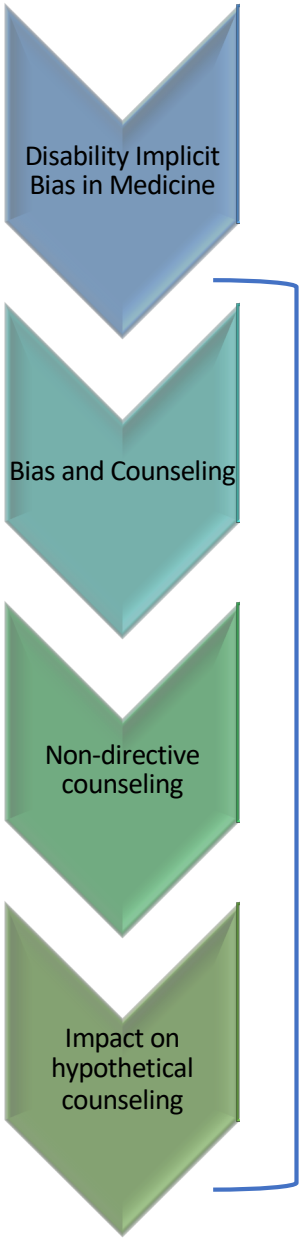
- Does it vary by demographics of provider vs. the general public?
- Do measures differ between the two disabled communities?
- Does it vary by specialty of provider or stage of training?

Implicit Bias Study design

Is there a correlation between implicit bias against disabled community and hypothetical prenatal genetic counseling of patients?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?

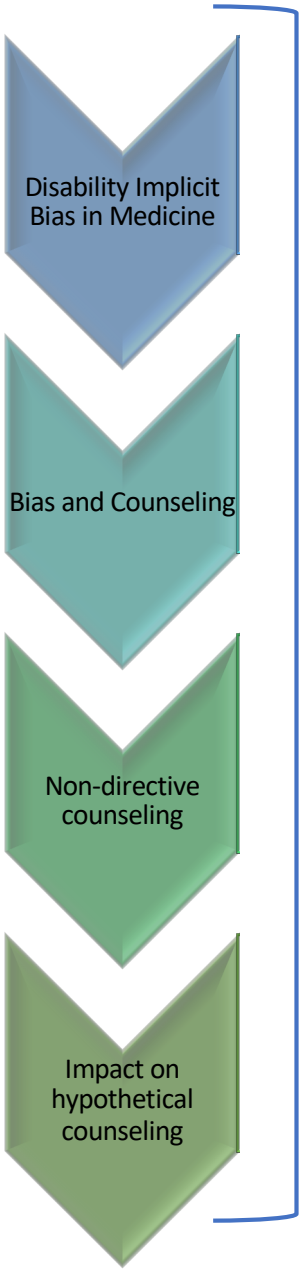
Implicit Bias Study design



Are providers able to appropriately apply principles of non-directive counseling to hypothetical prenatal clinical scenarios?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?
- Is the educational module effective at mitigating any potential deficiencies in this skill?

Implicit Bias Study design



Does implicit bias impact healthcare providers' ability to appropriately counsel patients in a prenatal setting, and can this be improved by training in non-directive counseling?

Acknowledgements

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- You!

https://goo.gl/forms/MIRZLnIWqW3gFFsG3