

00:00 Hello, my name is Emma Stallwood and I am a research assistant at the Hospital for

00:04 Sick Children. Thanks so much for taking a few minutes to hear about our research

00:09 project that could be of interest to you and really needs your input.

00:13 This project is called IN-ROADS. The goal of the IN-ROADS project is to get your feedback on

00:18 what aspects of your life do you want to see most improved after receiving treatment for depression.

00:24 Depression is a medical condition that can affect many areas of one's life. Around the world,

00:30 one in five young people experience depression at some point during their teenage years. Currently,

00:36 there is a need for more research to identify the best treatments for teenagers with depression.

00:41 In research looking at treatments for teenagers with depression, different researchers are

00:46 measuring different aspects of teenagers' lives to determine if a treatment works.

00:51 For example, one researcher who is assessing a new treatment for teenagers with depression

00:57 may look to see if the teenager improves in: how well they do in school,

01:02 their response to treatment, and how well the teenager is getting along with their family.

01:07 But, another researcher who is assessing a different new treatment for teenagers with

01:12 depression may measure aspects such as depression severity, tiredness, and how the teenager

01:19 functions in social situations such as organized activities, to determine if a treatment works.

01:26 If both researchers found their treatment to be effective based on what they were measuring in

01:31 teenagers' lives, we cannot determine which treatment is better because different aspects

01:36 of the teenagers' lives were measured. This means that we cannot compare the effects of

01:42 these treatments. In research, these aspects are called 'outcomes' because they are the outcome

01:48 or effect of a treatment that a researcher is measuring to determine if a treatment works well.

01:54 So, what outcome do you believe should be measured in research for teenagers with depression?

02:00 This is where you come in. You have what we call lived experience,

02:04 which means that you are an expert in what it is like to live with depression.

02:08 We need to know which outcomes are important to you when you receive treatment. In other words,

02:14 what do you want researchers to be measuring to determine if a treatment is effective?

02:19 Our research project wants your input on what outcomes mean the most to you.

02:24 We are developing what is called a 'core outcome set' to collect this information.

02:29 A core outcome set is a small list of outcomes that are agreed to be measured

02:34 in all studies of a particular condition, such as depression. It is important to note

02:39 that a core outcome set does not restrict researchers from measuring other outcomes,

02:44 but it provides a list of outcomes that at minimum, a study should measure.

02:49 These core outcomes would allow researchers to make comparisons about treatments,

02:54 and, very importantly, since the core outcomes will be developed with your input,

03:00 these core outcomes provide researchers with a list of outcomes to measure in

03:04 their studies that are important to teenagers with depression.

03:09 So, how do you get involved? We need your help to identify which outcomes

03:13 of treatment are the most important to you. In other words, what aspects of

03:18 your life do you want to see being measured and improved after treatment for depression?

03:23 We invite you to attend one of our workshops for teenagers with depression

03:27 so that we can learn what is important to you.

03:30 After the workshop, we will combine these lists of outcomes from teenagers and the outcomes

03:35 caregivers gave us in their own workshop, with outcomes that doctors, psychologists and other

03:41 health care providers who work with teenagers with depression think are important to be measured in

03:46 research studies. This list of combined outcomes will be put in a survey called a “Delphi survey”.

03:53 At this point, you will already have contributed enormously to the project,

03:57 by sharing which outcomes are important to you and it will be up to you if you want to

04:02 continue with the next phase of the IN-ROADS project. If you are interested, there is a

04:07 short video on the Delphi survey phase of the project, that you can listen to at any time.

04:12 Thank you so much for taking the time to watch this video.

04:15 I really hope you will consider sharing your lived experience.

04:19 If you would like to learn more about the project, please email inroads.initiative@sickkids.ca.