TO PARTICIPATE, OR NOT TO PARTICIPATE?

Many of you will have heard about the exciting research studies going on in BPK. Perhaps some of you have seen posters or e-adverts for opportunities to get involved in research in BPK – sometimes as a student researcher, but sometimes as a participant. Volunteering to be a participant in a research study can be a wonderful opportunity to contribute to understanding of how our bodies work, and how researchers might better help people living with health concerns. So, if you’re thinking about taking part in a research study, what can you expect as a participant?

YOU CAN EXPECT TO PROVIDE INFORMED CONSENT

This means that you will have the chance to learn all about what the study involves before making a decision to take part – why it is being done, everything you will be asked to do as a participant, and whether there are any expected risks to you, or benefits to you, from taking part. Typically, you will be given an informed consent document that outlines the study in lay terms. You will have time to read this, take it away, and be able to ask your family, friends or doctor what they think about the study, and then make a decision about whether you want to do the research. If you do not understand what the study involves, or the possible risks or benefits to you if you choose to take part, then it is not informed consent. Ask the research team to explain anything you are not sure about.

YOU CAN EXPECT TO SAY “NO” WITHOUT ANY CONSEQUENCES TO YOU

Whether you decide to take part in a research study is up to you. You can decide not to do the study without fear of a negative consequence. If you decide to say no you do not have to give a reason for your decision, and the research team should not ask you for one.

You can start the study and change your mind later, without any negative consequences, and without giving a reason. No one should pressure you into doing the study.

YOU CAN EXPECT TO BE TREATED WITH DIGNITY AND RESPECT

The researchers should explain all the study procedures to you. If the researchers need to touch your body to do testing (for example to place measurement devices on you) the researchers should explain who will do this, where and when they will touch you, how the device will be fitted and for how long, what you can expect it to do, and whether it will be uncomfortable. If the research involves asking you personal or difficult questions this should be made clear before you start the study, and you can choose not to answer them. If you feel unwell or upset as a consequence of taking part in a research study, the researchers should help you access appropriate care.

YOU CAN EXPECT TO KNOW WHAT WILL HAPPEN TO THE INFORMATION COLLECTED ABOUT YOU

You have the right to know what will happen to your data – how it will be stored, who will have access to it, how it will be reported, how long it will be kept for, and how your confidentiality will be respected. You can expect to be told how you can obtain a copy of the findings of the research study when the study is finished if you want to learn more.

YOU CAN EXPECT TO BE SUPPORTED IN THE EVENT THAT YOU HAVE CONCERNS ABOUT YOUR EXPERIENCE AS A RESEARCH PARTICIPANT

If you have concerns about your rights as a research participant and/or your experiences while participating in an SFU research study, please contact Dr. Jeffrey Toward, Director, SFU Research Ethics:

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So, if all this talk of research has left you with an urge to take part in a study, click here to learn more about research participation opportunities in BPK. And if not, then don’t. It’s up to you.