

Letter of Information & Consent

Mindful streets: understanding neurodiverse transportation behaviours and the implications for complete streets planning.

Phase 2: Neurodiversity on the street: walk-alongs in Waterloo.

What is this letter about?

This letter is to help you make an informed decision regarding your participation in the research study *Mindful Streets*. This letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study.

Who is leading this study?

The lead researchers for this study are Samantha Leger, PhD Candidate for the School of Planning, University of Waterloo and Dr. Jennifer Dean, Associate Professor at the School of Planning, University of Waterloo.

What is the study about?

In recent years we have learnt more about neurodiversity, who it impacts, and how. Diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) are now better understood for how they can present in different populations, such as adults and women. As diagnoses became more accessible and less stigmatized the number of those who identify with ADHD and ASD has risen. Despite this emergence, very little research has explored how being neurodivergent can impact experiences and perceptions of everyday life in the public realm, including everyday travel. Many people who identify as neurodiverse are independently mobile, partaking in daily commuting and recreational trips around their communities. However, their unique needs and perceptions may not be accounted for in how the streets are planned and designed.

This is particularly pertinent for transportation planning given the rise of 'complete streets'; a growing planning effort that aims to comfortably accommodate a range of modes and users on the street through dedicated infrastructure, wayfinding, and streetscaping. Complete streets are often promised to be for 'all ages and abilities', with specific efforts that make streets more comfortable and accessible for vulnerable populations. Yet, in current complete streets planning practices, 'all ages and abilities' has narrowly considered age and some physical disabilities and is missing more fulsome consideration to different mental capabilities, and how these can influence access and comfort on the street.

To address this issue, this study aims to understand neurodiverse transportation experiences, and explore how these experiences can be better reflected in complete streets planning practices. Through sit-down and walk-along interviews with participants who identify as either Autistic or as having ADHD, this study will:

1. Assess route and mode choices of neurodiverse populations and examine the variables (in both the built and social environment) that can impact these choices.
2. Determine the types of streetscapes that are comfortable and accessible for neurodiverse populations (those with ADHD or who are on the autism-spectrum) and compare how these relate to complete streets planning practices.

This research is conducted as part of a PhD Dissertation.

What does participation involve?

Participation in the study will consist of a two-part one-on-one interview with the student researcher, Samantha Leger. The first portion of the interview (~20 minutes) will be conducted in-person, and will focus on questions regarding:

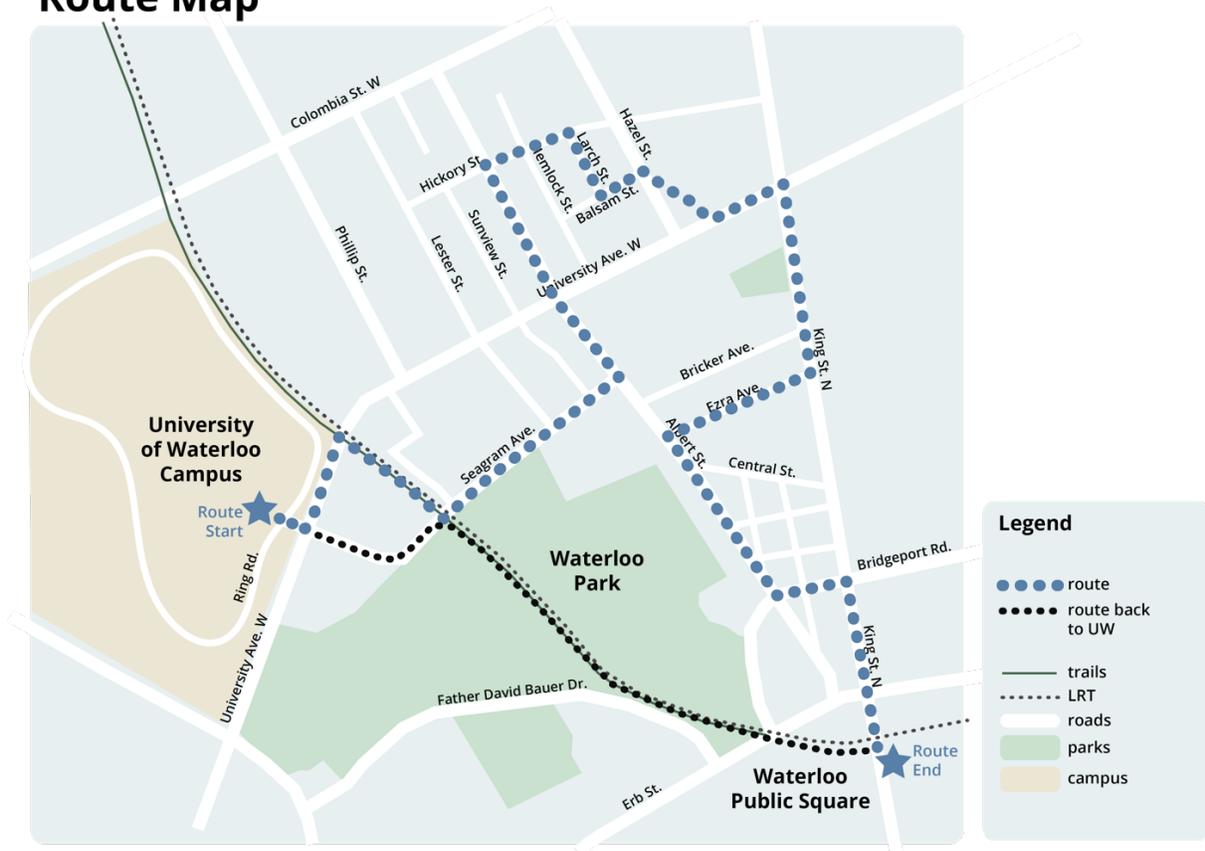
1. Your current transportation practices, and
2. Your preferred conditions for different modes.

After this interview is complete, you will then go on a walk-along with the student researcher to discuss your experiences of different street typologies. During the interview, you will be asked questions such as *How does this street make you feel? What features of the street are most noticeable to you and in what way? Would this be a street you typically travel on? What modes would you feel comfortable using on this street?* The route will start from the University of Waterloo campus and walk into Uptown Waterloo, a map of the route is included below. If a part of the pre-planned route becomes uncomfortable at any given time during the interview, an alternate route will be sought. You will not be taken anywhere that does not feel safe or comfortable to you.

The route will take 1 hour, and then the student researcher will walk with you back to campus (1.5 hour walk overall). A summary of your interview will be sent to you at the conclusion of this phase of research.

In total the time expected of you to participate in this interview will be approximately 2 hours. By talking about your experiences, you will help urban planners design more inclusive streets which accommodate for the needs of those who are neurodiverse.

Route Map



After your interview, the student researcher will follow up with a summary of key findings from your interview to review.

Who can participate in the study?

In order to participate in this study, you must be at least 18 years of age and self-identify as either Autistic or with ADHD. Both those who have self-diagnosed and been professional diagnosed are eligible to participate. You must also actively walk, cycle, take transit, or drive around your community and be a current student at the University of Waterloo

This phase of the study will involve up to 15 participants.

Is my participation voluntary?

Yes, this study is completely voluntary.

Are there risks to participating?

As this research involves walking in community, there are some risks to participating. Firstly, participants will be required to walk along various types of streets for 1.5 hours and make crossings at intersections between the University of Waterloo and Uptown Waterloo. To mitigate risks to the walk, a series of precautions will be followed: crossings will only occur

when prompted by the signalized intersection, and participants will only walk on the dedicated pedestrian infrastructure during the walk. If at any time a portion of the pre-planned route feels unsafe or uncomfortable to a participant, the interview will be stopped, and an alternative route will be sought. If you become tired, or feel fatigue, the interview will be stopped. The researcher will come equipped with water bottles for any participant who needs hydration during the walk. The researcher will also have a cellphone on hand in case of any emergencies.

You will not be identified by name in any publications or presentations that arise from this research. However, when out in the community, there is some risk to being identified. The researcher cannot control who hears/sees participants partaking in the study whilst out on the walk-along interview.

Finally, as this research will be focused on your personal mobility experiences, there is some risk to the questions evoking negative emotions and/or memories. If a question, or the discussion, makes you uncomfortable, you can choose not to answer. You can stop participating in the interview at any time. If you choose to withdraw, your data will be deleted.

Will I receive anything for participating?

Yes. For your time and effort participating in the study you will receive a VISA pre-loaded gift card of \$40. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

What are the benefits to participating?

Participation in this study will not provide any personal benefit to you. The findings of this research will enhance our knowledge on transportation behaviors of neurodiverse populations, and how to plan more inclusive streetscapes and mobility options. Findings of this work will be shared to both academic researchers and practicing urban planning professionals.

Will my identity be known?

Only the researcher will know which data is from your participation. The interviews will be audio-recorded and transcribed verbatim. Excerpts from the interview discussion may be quoted in publications and/or presentations that arise from this research. These quotes will be anonymous and not be attributed to identifying information from any individual participant.

Will my information be kept confidential?

Only the researchers will have access to the names of the participants. Your identity will be kept confidential by assigning ID codes to the transcriptions, so they do not contain any identifying information. Audio files will be deleted once transcribed. The list of names will be deleted upon study completion when they are no longer required to authenticate the results. For the duration of this study, all interview transcripts will be securely stored on team members' password-protected computers and in an encrypted cloud-based data management platform. After seven years, all information collected from the study will be deleted.



Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #45403). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

Who should I contact if I have questions regarding my participation in the study?

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact Samantha Leger by email at sjleger@uwaterloo.ca or Dr. Jennifer Dean at 519-888-4567 ext. 49107 or by email at jennifer.dean@uwaterloo.ca

Thank you for your interest in this research study,

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Consent

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Prior to the interview you will be asked if you have read and understood the Letter of Information and provide your consent to the following questions:

1. Do you agree to participate in this research study?
2. Do you agree that the interview can be audio-recorded?
3. Do you agree that anonymous quotations can be used in reports, be used in publications and/or presentations that arise from this research. These quotes will be anonymous and not be attributed to identifying information from any individual participant.