PARTICIPANT INFORMATION SHEET

Title of Project: *Photovoice study of biographical disruption of persons living with Autoimmune conditions and their interaction with urban settings*

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Name and Contact Details of Supervisor (if relevant): Dr Graham Ford. Graham.ford@port.ac.uk

Ethics Committee Reference Number: CCI-FEthC 2025-021

1. Invitation

I would like to invite you to take part in my research study. Joining the study is entirely up to you, before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. I would suggest this should take about 10 minutes. Please feel free to talk to others about the study if you wish. Do ask if anything is unclear.

To introduce myself, I am Lucie Dick, a fully qualified Architect and PhD researcher at the University of Portsmouth. I live with a number of health conditions which affect various parts of my body. None of my conditions have a cure, meaning my health is about managing symptoms and trying to find a better quality of life. I go in and out of flares regularly and often can feel overwhelmed by it. Why am I telling you this? To help you understand that I am part of the chronic illness community and what you say/ share with me is reaching understanding ears. My health conditions were the leading cause for me studying architecture, as I was often left unaccommodated in the built environment, and wanted to see this change. The reason I started a PhD was that I found myself stuck by legislation which only did the bare minimum and which looked at disability from a one dimension wheelchair/ mobility perspective, leaving out many other adjustments needed by the chronically ill.

2. Study Summary

This study is concerned with understanding the interaction of the built environment and Autoimmune Conditions. It is particularly looking at how we can accommodate symptoms of autoimmune conditions better in urban settings.

Participant requirements:

- Diagnosis of a minimum of one autoimmune condition
- AND Live within the South of the U.K.
- AND Be aged 18+
- AND Live with fatigue
- AND Live with a minimum of one of the following symptoms: brain fog, light sensitivity, allergic type conditions
- AND Be able to leave the home a number of times during a 14 day period

Study requirements:

- Stage 1: Engage with an online presentation, which should take approximately 45 minutes
- Stage 2: Photograph and narration collection period. Carry on about your usual day and take images when your health impacts any decision you make when leaving your home. Lasts 14 days, with the aim of the participant to take 1no photograph a day with accompanying text. You may find that you are symptomatic/ pass baseline for a number of days and are unable to leave the home, that is fine, please do not push yourself if you are unwell/ in a flare. Some days you may exit your home and find your health impacts your decision-making a lot, or certain spaces are inaccessible, on these occasions please take as many images as you find fit. Each image and accompanying text should take around 5 minutes.
- Stage 3: Semi-structured interview and debrief. This will be an online meeting. Approximately 1 hour long.

Any of the stages can be adjusted around your health. If you are unable to meet because you have woken up in a flare, please contact the Lead Investigator (Lucie Dick) and we will easily accommodate a reschedule.

3. What is the purpose of the study?

The purpose of this study is to contribute to a larger piece of work for my PhD study, which aims to question urban policy and how to create an inclusive environment for those living with Autoimmune Disorders. From the information you share during this study, I will analyse key themes and identify; what prevents persons living with Autoimmune Conditions from entering areas within the built environment, key barriers they are facing when leaving the home, and the additional thoughts you may have to consider compared to persons living without these health conditions.

Once you have been able to provide insight on the aforementioned areas, the next stage of the PhD will see the creation of a series of "personas" based on a number of participants. These personas will be under pseudonyms, and no more than two items will be based on one individual. For example if you are called: Jane Smith, aged 45, living with MS, symptoms including brain fog, the pseudonym may be "Becky Johnson, aged 45, living with IBD, symptom brain fog", images will then be shown from the study, however, images from another participant will be used. These "personas" will be taken to a series of professionals, where I aim to conduct a workshop to see how they would address the barriers you face. This will later inform a series of design "rules" or "principles" to cater for more inclusive spaces for people living with autoimmune disorders.

4. Why have I been invited?

A charity which deals with autoimmune conditions, has deemed it appropriate to send on details of this study to you as a potentially viable candidate. OR you have seen one of the posters either online or in person. This study aims to recruit between 11-20 people to engage with the full study. You are invited on a personal basis and not in association with any organisation who forwarded you details of this study or any establishments where you may have seen the posters.

5. Do I have to take part?

No, taking part in this research is entirely voluntary. It is up to you to decide if you want to volunteer for the study. I will describe the study in this information sheet. If you agree to take part, I will then ask you to sign the attached consent form, dated 22.07.2025, version number, 01.

6. What will happen to me if I take part?

The study you are participating in is called a Photovoice study, which is often used for social research, and community building.

Once you agree to participate and sign the relevant consent forms we will meet (refer to Stage 1 in section 2). Stage 1: The Lead Investigator will do a one to one presentation with you, to provide more details about the study. Here you can raise any concerns, queries and ask questions to help you better understand the process of engaging in this study. During this stage the Lead Investigator will take notes if applicable. This will take around 45 minutes.

Stage 2: You will be taking images when you leave the house about areas that affect your physical wellbeing, where you are travelling and what considerations you have regarding your health. What transportation you use and why. Where do you avoid and why? What issues you encounter to reach your destination. You should aim to take around 1 photograph a day with accompanying narration, this is estimated to take around 5 minutes each time. Therefore in total over the 14 day period, will be around 1 hour and 10 minutes. You may find this takes you less or more time, and you are welcome to submit multiple images from each day. Please do note that images should not be taken outside of your normal daily routine.

Stage 3: Semi-structured interview. Here you will give an overview of how you found the study, what images you particularly felt captured your experience the most. You will also be asked a series of open ended questions about your experience with Photovoice, your health conditions and the urban environment. This should take approximately an hour (1hr).

At the end of Stage 3 your study is complete.

It is important to note, that you will not engage with any other participant during this study.

7. Expenses and payments

As a thank you for your time and contribution to the study, you will be given a £50 shopping voucher at the courtesy of the Leo Lion Foundation.

The study should not require any out of pocket expenses, as you should just continue with your daily routine.

8. Anything else I will have to do?

During the photo collection period (Stage 2 as highlighted in Section 2 of this document), you will have to make sure that all images are sent to the Lead Investigator, Lucie Dick. This can be either on a shared google drive or via an encrypted email. You have the choice to send these images and accompanying narrative as you see fit, for example, this could be daily, weekly, or at the end of the study.

9. What data will be collected and / or measurements taken?

Stage 1:

Data: Notes.

Why? This will be of any further information or requests to other studies you may have asked for at the end of the presentation.

General: At this stage you will disclose what Autoimmune Condition you have, duration of condition, symptoms you experience.

What will happen with this data? Any information collected during this stage regarding your condition and symptoms, will be stored and analysed at the end of stages 2 and 3.

Stage 2:

Data: the photographs and accompanying narration you document.

Why? To enable you to tell your story, and have the opportunity to allow others to gain a better understanding of the experience of living with an autoimmune condition.

What will happen with this data? The data collected during Stage 2, will be reviewed and used to guide questions in Stage 3.

Stage 3:

Data: audio transcripts of semi-structured interviews.

Why? To enable the identification of themes in comparison with other participants, and use direct quotations (under pseudonyms) in papers. Find out your restrictions on images to be used in publications, at workshops, conferences and the like.

What will happen with this data? At the completion of the study, the data you share with us, will be anonymised and shared in publications, workshops, conferences etc. Any information which you wish to be excluded must be confirmed in written format (by email) and/or verbal.

10. What are the possible disadvantages, burdens and risks of taking part?

There is a risk during this study that you may become more aware of the difficulties in the environment around you. A raised awareness of the impact your condition has on your daily routine, which could be seen as emotionally distressing.

During the study if you feel this study is negatively impacting you, please inform the Lead Investigator (Lucie Dick) and you can stop your contribution to the study immediately, no reasoning needed. If you need support, please contact charities such as:

Mind: https://www.mind.org.uk/need-urgent-help/using-this-tool/

Samaritans: https://www.samaritans.org

Wren Project: https://www.wrenproject.org/getsupport

11. What are the possible advantages or benefits of taking part?

The Autoimmune and wider disabled community may benefit as the results of this work by the changes we hope to eventually see in the urban environment. As a thank you for your participation the Leo Lion Foundation have kindly donated a £50 shopping voucher.

12. Will my data be kept confidential?

The images you take during this study (stage 2) will be under the ownership of the researcher and supervisory team. Any images the participant wishes to not be included in any publications, workshops, conferences etc, will be identified by email at the end of Stage 2 or during Stage 3. Once the study has completed the participant will have 10 working days to notify the Lead Investigator if they would like any further images removed from being used elsewhere.

The raw data, which identifies you, will be kept securely by the researcher and their supervisor on a password protected research folder on the Universities system.

Data collected is as per section 9 of this document. In a list format it is:

- *Notes (Stage 1)*
- *Audio transcript (Stage 3)*
- *Name, postcode*
- *A brief description of your medical conditions and symptoms*
- *Image and narration (Stage 2)*
- *Consent forms*

Any data shared will be anonymised, to ensure that you as the participant cannot be identified. When using direct quotes, a pseudonym will be used. When using images they will be carefully edited and anonymised to protect the anonymity of the participant. As part of the wider PhD thesis, "personas" will be created to help professionals understand the limitations and opportunities living with an autoimmune condition can bring to the built environment. These "personas" will not be based on one participant, but a number of them, to help protect anonymity.

The data, when made anonymous, may be presented to others at academic conferences, or published as a project report, academic dissertation or in academic journals or book. It could also be made available to any commissioner or funder of the research.

Anonymous data**, which does not identify you**, will be publicly shared at the end of the project and made open access. A CC-BY licence will be applied to this publicly shared data. This will allow anyone else (including researchers, businesses, governments, charities, and the general public) to use the anonymised data for any purpose that they wish, providing they credit the University and research team as the original creators. No restrictions will be placed on this shared anonymised data limiting its reuse to only non-commercial ventures.

The raw data, which would identify you, will not be passed to anyone outside the study team without your express written permission. The exception to this will be any regulatory authority which has the legal right to access the data for the purposes of conducting an audit or enquiry, in exceptional cases. These agencies treat your personal data in confidence.

The raw data will be retained for a minimum of 10 years. When it is no longer required, the data will be disposed of securely (*e.g.* electronic media and paper records / images) destroyed.

The School of Architecture, Art and Design of the University of Portsmouth wishes to process your personal data (that is, collect, use, store and destroy data that identifies you) as part of the Lead Investigators PhD study. If you have any queries about this study please contact lucie.dick@port.ac.uk or if you have any general queries about how your data will be processed, please contact the University's Data Protection Officer, Samantha Hill, using any of the following contact details:

Samantha Hill, 023 9284 3642 or information-matters@port.ac.uk
University House, Winston Churchill Avenue, Portsmouth, Hampshire, PO1 2UP, UK

We ask for your consent to process the data we ask for in the study, so that we can conduct the research as described in the participant information sheet. We will only share your personalised data with the main supervisory team within the University of Portsmouth.

Your personal data will be held securely on University servers we will not store your data outside the EU for 10 years, and securely destroyed after that date.

Although you have the right to request a copy of the personal data we hold about you, to restrict the use of your personal data, to be forgotten, to data portability, and to withdraw your consent for the use of your data, it is possible that we may not be able to fully comply with those rights where your data has been used for the research and / or has been anonymised. For more information on your rights in general, please see the information on the following links:

https://www.port.ac.uk/about-us/structure-and-governance/legal/data-protection-and-gdpr/requesting-your-data

You also have the right to lodge a complaint about the use of your personal data to initially the University (email information-matters@port.ac.uk) and then, if you are unhappy with our response, to the Information Commissioner's Office (ICO) – for more information please see https://ico.org.uk/your-data-matters/raising-concerns/ .

13. What will happen if I don't want to carry on with the study?

As a volunteer you can stop any participation in the photographic narrative study and interview at any time, or withdraw from the study at any time before (XX/XX/2025), without giving a reason if you do not wish to. If you do withdraw from a study after some data have been collected you will be asked if you are content for the data collected thus far to be retained and included in the study. If you prefer, the data collected can be destroyed and not included in the study. Once the research has been completed, and the data analysed, it will not be possible for you to withdraw your data from the study. Please note that if you do discontinue from the study after the completion of Stage 2 and do not wish to continue onto Stage 3, you are still eligible to receive the shopping voucher.

To withdraw from the study, please send an email to lucie.dick@port.ac.uk.

14. What if there is a problem?

If you have a query, concern or complaint about any aspect of this study, in the first instance you should contact the researcher(s) if appropriate. If the researcher is a student, there will also be an academic member of staff listed as the supervisor whom you can contact. If there is a complaint and there is a supervisor listed, please contact the Supervisor with details of the complaint. The contact details for both the researcher and any supervisor are detailed on page 1.

If your concern or complaint is not resolved by the researcher or their supervisor, you should contact the Head of Department:

The Head of Department: Dr Lynne Mesher

Department / School of Architecture, Art and Design +44 (0)23 9284 5452

University of Portsmouth Ethics-cci@port.ac.uk

Eldon Buildings

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If the complaint remains unresolved, please contact:

The University Complaints Officer

023 9284 3642 complaintsadvice@port.ac.uk

15. Who is funding the research?

This research is being funded by the University of Portsmouth.

None of the researchers or study staff will receive any financial reward by conducting this study, other than their normal bursary as an employee/ student of the University.

16. Who has reviewed the study?

Research involving human participants is reviewed by an ethics committee to ensure that the dignity and well-being of participants is respected. This study has been reviewed by the Creative and Cultural Industries Faculty Ethics Committee and been given favourable ethical opinion.

Thank you

Thank you for taking time to read this information sheet and for considering volunteering for this research.