Participant Information Leaflet for parent/carers

Study Title:	Home Education Experiences of Children with Special Educational Needs and Disabilities (SEND)
Investigator(s):	Dr Emma Langley (Project Lead)

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

The study is being conducted by Dr Emma Langley in the Department for Education Studies at the University of Warwick. The study is funded by the University Participatory Research Fund (PRF).

What is the study about?

This project aims to understand the experiences of home education among families of children aged 7–16 with Special Educational Needs and Disabilities (SEND), in a supportive and inclusive way. We are particularly interested in your child's everyday learning, including their routines, activities, and the moments that matter most to them. As part of the study, your child will take photographs to show what home education looks like in their daily life. These photographs will help us build a clearer understanding of home education and raise awareness about it. What we learn from this project will also help to shape a larger UK-wide study on home

education in families of children with Special Educational Needs and Disabilities.

What would taking part involve?

This project involves working with your family to understand your child's experience of home education by capturing their everyday learning through photographs.

- First, we will meet (at your home or another convenient place) to get to know you and your child, and to talk about your journey into home education. This will be a relaxed conversation that will be audio-recorded, with your permission. I will then introduce the project and explain the 'photo-voice' approach. Your child will be provided with an instant print camera and will have two weeks to take photos that represent what home education means to them, with your support if needed.

- Next, we will meet again to look at the photos together and talk about what they show in a second recorded conversation. This will help us understand your child's experiences. Your child will also be supported to create short descriptions of their pictures.

- Finally, there will be an optional opportunity to share your child's photographs in a showcase alongside other families to help raise awareness of home education. Taking part in this is entirely your choice.

The project takes a flexible and inclusive approach to support your child's meaningful participation. Each stage can be adapted to suit their needs, and we can arrange a conversation before the first visit to discuss any adjustments. If you decide to take part, you (as the legal guardian) will be asked to complete a short online questionnaire. The first section asks you to give informed consent. The second section asks for some basic demographic information about you which is optional and some mandatory information your child (e.g. age, gender, ethnic background, Special Educational Needs or Disability). This information helps us understand who has taken part in the research.

Do I have to take part?

No. Participation in this study is completely voluntary, and choosing not to take part will not affect you or your child in any way.

We have provided a separate information sheet about the study for your child, which we ask you to read together, so you can ask any questions before deciding whether to take part. We will ask for your consent and your child's agreement (assent) to participate.

At the first visit, we will check that both you and your child are happy to take part. The study will be explained to your child in an age-appropriate way so they understand what to expect. If your child does not want to take part, they will not be included, even if you have given consent.

We will continue to check that your child is happy to take part at each stage of the project. The researcher will pay close attention to your child's comfort and understanding and will use supportive tools (such as visuals or break cards) where needed. Your child will also be asked if they are happy to continue before the second visit.

You and your child can withdraw from the study at any time, without giving a reason, by contacting a member of the research team. Further details about withdrawing are provided later in this document.

What are the possible benefits of taking part in this study?
Taking part in this research offers an opportunity for you and your child to share your experiences of home education with a wider audience. The process of taking photographs is intended to be enjoyable and empowering experience that can help spark meaningful conversations between you, your child, and the researcher. After the photographs have been copied for the study, your child will be able to keep the originals.

What are the possible disadvantages, side effects or risks, of taking part in this study?
We do not anticipate any risks to taking part in the research, however we recognise that you and your child may have had difficult or upsetting experiences related to school, and these may come up during the project. Talking about photographs and the experiences they represent can also sometimes bring up strong emotions.

To support your wellbeing, you and your child will always remain in control of your involvement. You can take a break, pause an activity, choose not to answer a question, or stop taking part in the study at any time, without giving a reason. The researcher will pay close attention to how your child is feeling, including any signs of discomfort, and will respond appropriately. Activities can be

adapted to suit your child's needs, and your advice and guidance will be important in helping to ensure this. The researcher will also work closely with you throughout the project to help ensure your child feels safe, supported, and comfortable taking part.

If you become concerned about your own or a family member's wellbeing during the research, we recommend that you contact your General Practitioner (GP) or one of the helplines listed below:

Samaritans 0330 094 5717
Mencap: 0808 808 1111

Expenses and payments

As a thank you for taking part, your child will receive a £50 electronic shopping voucher for each home visit. This is provided regardless of how much your child takes part during the visit, and choosing to withdraw from the study at any stage will not affect receiving the voucher.
After each visit, the voucher will be sent to you (the parent or carer) by email within 24 hours. The voucher is intended as a token of appreciation for your child's time and contribution, rather than an incentive to take part. If you and/or your child chooses to take part in the optional showcase or dissemination activity, you will receive an additional £25 voucher to thank you for your time. Taking part in this activity is completely optional and not required to be involved in the main study.

Will my taking part be kept confidential?

Your participation in the study will be kept confidential. All the information we collect about you will be handled in confidence and stored securely. All data will be held in a password protected file and kept on a secure server at the University of Warwick and will only be accessible to the immediate research and administrative team. We will hold your personal data separately from your data, using a unique participant ID number to link the data. To protect your anonymity, we will delete this ID number and the original recording of your conversations 7 days after the second visit. Direct quotations may be used in future reports and publications, however these will not be directly identifable as pseudonyms (fake names) will be used.

If at any point during the study you or your child disclose that they or someone else may be at risk of harm, we cannot uphold confidentiality and have a duty of care to report this immediately via the University Safeguarding procedure. If there is an immediate risk to a person, the

researcher will report this straight away to the relevant authorities.

What will happen to the data collected about me?

As a publicly funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

Contact details that you provide will be stored securely until the end of the study (01/09/27). You can request that this information is deleted at any time by emailing Emma Langley (e.langley.1@warwick.ac.uk). However, please note that if you choose to remove your contact details before the end of the project, we will not be able to send you updates about the study or its findings.

Photographs and recorded conversations will be anonymised 7 days after the second visit. This means that all identifying information will be removed, and the link between your identity and your data will be permanently deleted.

Your anonymised demographic information, photographs, and conversation data will be securely stored on the university server for up to 10 years. After this time, it will be safely deleted by the study lead, Emma Langley, or a designated member of the department.

Data Sharing

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

If you provide consent, this data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here:
https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice or by

contacting the Legal and Compliance Team at infocompliance@warwick.ac.uk.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. You and your child are free to withdraw from the study at any time without providing a reason and without the loss of the thank you voucher.

If you have already taken part in both visits, you can withdraw from the study or request changes to your data **for up to 7 days after the second visit**. You will be reminded of this deadline by email, along with information on how to do this.

After this 7-day period, it will no longer be possible to withdraw your data, as analysis will have begun.

What will happen to the results of the study?

The findings of the study will be used in several ways:

- Showcase of stories: There will be an optional opportunity to take part in a showcase of children's photographs and stories. This will be developed together with families who choose to take part, and you will help decide the format and content.
- Participant feedback: At the end of the study, we will share a summary of the main themes and findings with you in a short newsletter and an accompanying video.
- Academic dissemination: The findings from the study will also be written up and submitted for publication in an academic (peer-reviewed) journal.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC) (Ref No: **230/25-26**).

Who should I contact if I want further information?

Project lead Emma Langley: e.langley.1@warwick.ac.uk / 02476 522 160

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below,

who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 02476 575733

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Thank you for taking the time to read this Participant Information Leaflet