

Participant Information Sheet

What is the impact of storytelling on healthcare professionals managing children's health?



1. Invitation to research

My name is Mary Lockwood. I'm a PhD student at Manchester Metropolitan University. I would like to invite your child to take part in a study called 'What is the impact of storytelling on healthcare professionals managing children's health?'

I am running this research study to find out if storytelling may help children with lived experience of engaging with healthcare professionals. I want to find out if listening to children's stories helps health professionals learn how to make better decisions when treating children. This information sheet is designed to answer some questions you may have.

Why is this study being done?

Children who have to engage with healthcare professionals face a lot of pressures (e.g. with health/school/friends/etc).

I want to discover if storytelling may be a way of helping healthcare professionals find out more about what children think and feel about their health. Storytelling may be a way of helping children communicate about their health by giving them a voice.

My theory is that better communication leads to better decision making, which leads to better outcomes and less potential risk of trauma for children and their families.

We won't know if storytelling can help children with experience of engaging with healthcare professionals unless we work with children to find out. That's why I'm doing this study.

2. Why has my child been invited?

Children aged 5 -11 years old with lived experience of engaging with healthcare professionals are being invited to take part in this study. Your child has been invited because they fit these criteria.

Lived experience of engaging with healthcare professionals is a term that applies to anyone who has been a patient (e.g. visiting a doctor or having an operation). For example, children with long term health conditions are likely to have lived experience of engaging with healthcare professionals.

3. Does my child have to take part?

No. It is up to you and your child to decide. We will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to your child participating. We will also ask your child to sign an assent form. You are free to withdraw your child from the study at any time, without giving a reason.

4. What will my child be asked to do?

Every child will be asked to attend up to six storytelling sessions with a Storyteller. The Storyteller has enhanced DBS clearance. Sessions take place at a location convenient to the parent/guardian and child.

In the first session, parents/guardians can stay with their child. This helps to build trust with the storyteller, and everyone can get to know each other. Afterwards, the child will attend the sessions on their own without parents/guardians present in the room. The Storyteller will play games and work with the child to help them tell their own story through a character which the child will invent.

We will make the child's story into a short film which will be put on YouTube.

Your child's voice will be recorded to narrate their story, but children will not be named so their identities stay protected.

Some children may want to have their names associated with their story. If this happens, we will consult with parents/guardians about including the child's first name on the film's title page. At no point will a child ever be identified by their full name. No photographs or video footage of your child will be used in the film.

The child and their parents/guardians will watch the finished film and decide whether they wish it to be a private or public listing on YouTube. All YouTube comments will be disabled.

Researchers involved in the study will watch the story, as may researchers and healthcare professionals in future studies. Children can show their film to their friends and family if they want.

5. Are there any risks if my child participates?

Storytelling is designed to be a fun activity and it is not our intention to cause unpleasant emotions.

There is a small risk that a child may become distressed if they recall an upsetting event. If this occurs, the storyteller is a trained professional who will help minimise distress. Parents/Guardians will be informed, and professional psychological support will be available for the child if needed. Safeguarding procedures will be followed at all times.

6. Are there any advantages if my child participates?

Your child may have fun telling their story and enjoy the storytelling experience. Your child's story will be made into a book which they can take home with them. Unfortunately, we cannot offer financial payment or reimburse travel expenses.

Your child's story may help influence future guidelines and practices for healthcare professionals who manage children's health.

7. What will happen with the data I provide?

When you agree to participate in this research, we will collect from you personally identifiable information.

The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner's Office (ICO) and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw your child from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties. The exception to this rule is if potential safeguarding risks to your child are discovered, in which case appropriate authorities will be informed. A copy of the University's safeguarding policy can be found at: https://www.mmu.ac.uk/policy/pdf/policy_ref_Safeguarding.pdf

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use and agrees confidentiality and information security provisions. It is the University's policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose.

Data handling: data will be only handled by the researcher and their named supervisory team.

Data retention: We will only retain your personal data for as long as is necessary to achieve the research purpose. In the case of this study, data will be held for 20 years. This is to fulfil guidance on the storage of records for children and young people, which state records should be retained until the child is 25, or eight years after their death if sooner. YouTube videos will be a finished product

and uploaded with the consent of parents/guardians and the assent of children. These films can be stored indefinitely, with the understanding that videos will be removed if requested.

Data storage: data will be stored on encrypted and password protected hard drives locked in a secure University storage facility and will only be accessible to the named researcher and their supervisory team.

Participant confidentiality: Data will be pseudo-anonymised at the earliest opportunity following its collection. Participants will be referred to by pseudonyms which they will choose themselves. Your child's real name will be replaced with the name of the character they create.

For further information about use of your personal data and your data protection rights please see the [University's Data Protection Pages](#).

8. What will happen to the results of the research study?

Results will be reported in my PhD thesis. Results may be written up as case studies that explain what the study has done and what has been learned. These may be circulated to interested public and professional groups. We may publish academic articles. We may publish results in the media. Participants will be emailed a summary of results and feedback after the project has ended.

9. Who has reviewed this research project?

This research project is supervised by Director of Studies Dr Nigel Cox. It has been reviewed by Dr Nigel Cox and Manchester Metropolitan University's Ethics Committee.

10. Who do I contact if I have concerns about this study or I wish to complain?

Please raise any concerns with Mary Lockwood: mary.lockwood@stu.mmu.ac.uk

If you feel uncomfortable discussing concerns or complaints with Mary, please contact the Director of Studies Dr Nigel Cox: n.cox@mmu.ac.uk // tel: 0161 247 2235 // 3.35 Brooks Building, 53 Bonsall Street, Manchester, M15 6GX.

Alternatively, please contact Professor Juliet Goldbart, Faculty Head of Research Ethics and Governance: j.goldbart@mmu.ac.uk // tel: 0161 247 2578 // 1.03 Brooks Building, 53 Bonsall Street, Manchester, M15 6GX.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the dataprotection@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH.

You also have a right to lodge a complaint in respect of the processing of your child's personal data with the Information Commissioner's Office as the supervisory authority. Please see:

<https://ico.org.uk/global/contact-us/>

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT