
A study to gather insights around the relational dynamics between nurse, teacher and individual with Intellectual Disabilities.

A Data Management Plan created using DMPonline

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Project abstract:

Heritage2Health (H2H) empowers nurses and pupils with moderate and profound learning disabilities (MPILD) to understand the nursing professional partnership and relationship through drama projects. H2H seeks to improve the healthcare experience of people with MPILD by ensuring people with MPILD are listened to and recognised for their abilities. Since COVID-19 H2H projects have to move to a virtual platform and require an accessible APP to support projects. Aim To produce an Accessible APP to support the professional-partnership and relationship between student nurses and pupils with MPILD during H2H Virtual Drama Projects. Questions What APP-features may support the professional relational process during a pilot virtual H2Hdrama project? What are stakeholders (student nurses, teachers, facilitators) views on APP design, that would ensure accessibility for pupils with MPILD? Objective To undertake an ethnographic study (including participant observation, interviews and focus groups) alongside a pilot virtual H2H Drama Project with Dysart School.

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Data Collection

I will be collecting data from a:

Ethnographic Study
Focus Group
Interviews

The data will be collected via Google Meets through an online ethnographic study.

Focus groups will be conducted online through Microsoft Teams.

User interviews will be recorded with the consent of the user.

Documentation and Metadata

Thematic analysis will be conducted after the data is gathered from the ethnographic study, users interviews and focus groups. The Student Researcher will redact the data to share with the rest of the team building the APP. This will take the form of:

- An empathy map; this will be extracting what potential users are doing, thinking, feeling and saying. This will help write a persona for the rest of the team to understand the people we are designing for. It will support the team to take a holistic approach to the design. Keeping the process user centred, the aim is to support our team to empathise with the user.
- Personas; A persona will be a redaction of all the data collected from our participants. There will be two personas, a nurse and a young person with MPILD. The personas will support the team to design for that persona rather than a group of people. This will support a more empathetic approach to design.
- User Journeys; this supports the team to understand the pain points of the persona and what their current journey looks like. This allows the team to remedy these pain points early on in the process.
- A problem statement for the ideation process. This equips the team with a problem to solve, this will be followed by more questions such as “How might we” questions to break the problem down and create solutions.

From this redactive data, the team will ideate resulting in features for the APP. The App will then be built and test with users. The data gathered from the testing phases will be redacted into small **problem statements** for the team to amend any issues that arise. Once amendments are made the APP will be released for phase two of the project, this will be used by St Philips Special Needs School, Dysart School and Salutem Healthcare.

Ethics and Legal Compliance

An ethics application has been sent and we are waiting approval. We have used the Data Ethics Framework as a guide to make sure we're covering every necessary detail. Below is a summary of how we have prepared.

We will have consent forms for all the data collected and only obtain information that is needed to aid the app. This study is carried out with public interest in mind. We will be adopting GDPR guidelines when processing data (Data Protection Act, 2018). We will be informing participants of how 'personal data collected about them will be used, stored, processed, transferred and destroyed (Data Protection Act, 2018).

The privacy and confidentiality of the individuals will be respected and they will be anonymised in the research documents. All recordings made will be to aid data gathering and once obtained will be kept securely in password protected documents until the end of the project and then destroyed.

We are only asking questions relevant to the application. We are not making assumptions of what our user want or need. We are striving to work with our users to create a relevant application by interviewing them so they are involved in decisions that will affect them. The paper 'Nothing about us without us' (Callus M, 2017), highlights the lack of choice and control people with ID have over their own lives, especially decisions made that affect them. The paper highlights this as human rights issue and strives for 'equality and participation on an equal basis with others' (Callus M, 2017). Our research methods are in response to this, to involve our users throughout the whole process.

All our participants will take part voluntarily, free from coercion. No harm will come to participants and we will be working in partnership with individuals that support our vulnerable users and know them well. The process will be completely transparent and participants will understand the intended use of the data collected. Our research has been designed carefully to benefit and include the individual (Ethical Obligations, 2020).

Kingston University have IPR rights.

Storage and Backup

- Data will only be used for the purpose of this project and for reporting the findings.
- Data will be held securely, and password protected on Kingston University System.
- Data will be backed up on the student researchers computer where all files will be password protected and destroyed after use.
- Only the Research student and Project Supervisors will have access to Data.

Data will be held securely, and password protected on Kingston University System. When data through recordings, this will then be transcribed. All the data once redacted will be destroyed. Kingston University have a robust system for keeping data secure, if there was a breach this would be handled by Kingston University.

Selection and Preservation

The meta-data will be stored long term for the student researcher for portfolio purposes. Data will be held securely, and password protected on Kingston University System.

Heritage to Health will write a paper about the relational dynamics between nurse and person with learning disability. This will only be done with consent from the users and another ethical application will be needed.

Apart from the meta data, the data will be destroyed on completion of the project.

Data Sharing

The data will be shared within a working team but only the meta-data will be shared on the primary data.

The data will be shared with the supervisor if support is needed.

Meta-data will be shared with Heritage to Health, they intend to write a paper on the relational dynamics between person with learning disabilities and nurses.

Data will be shared with participants after the study for their input as this is a participatory research study.

All long term data will be redactive and the individuals involved in the study will not be identifiable. All information that identifies participants will be restricted and the only access will be by student researcher and supervisor.

Responsibilities and Resources

Implementing DMP: Jessica Reynolds

Data management activity: Jessica Reynolds

Data ownership: Jessica Reynolds

Redactive data ownership: Jessica Reynolds and Kingston University

Policies in place: Jessica Reynolds and Theresa Nash

Google Meets (for virtual drama project, as used by Dysart School).

Recording software to gather data (interviews, destroyed on completion of project).

Adobe XD Prototyping tool (to create App prototype)

Software development tools (to create the App.)

What's App (communication for drama project nurses and facilitators only, not data).

Trello (organise design sprints).

Lucid Chart (user Flow Diagrams).

Mural (affinity Map tool to assist in redaction of data).

