Plan Overview

A Data Management Plan created using DMPonline

Title: Exploring the Psychosocial Needs of Adults with Haematology Cancer under Watch and Wait

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Project abstract:

The presence of unmet needs has been found to correlate with a poorer quality of life, increased low mood and increased anxiety in people living with cancer (Pereira et al., 2020). Unmet psychosocial needs provide a tangible understanding for individuals' psychological distress and are therefore targets for intervention. Preliminary evidence suggests that haematology cancer (HC) patients under "watch and wait" (a monitoring process whereby no medical intervention is provided) report elevated psychological distress, compared to both the wider cancer population and the general population. However, there is limited research exploring the needs of these patients. Therefore, this research aims to identify the needs of this population to advance understanding of what support is necessary, through qualitative methodology.

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Exploring the Psychosocial Needs of Adults with Haematology Cancer under Watch and Wait

Data description

What data will you create?

I will generate qualitative interview responses (anonymised transcripts), recording interviews using Microsoft Teams (either audio or video), generating an MP4 file.
Transcripts of interviews will be created using the Automated Transcription Service, with files created in .txt form. The volume of data will be determined by the responses given by the respondents, I expect up to 30 interviews will take place which will generate up to 30 audio files and transcribed files, which in total will equate to <4GB data. I plan to create an Excel document saved as a .xls with all the anonymised
transcribed responses to each question and conduct thematic analysis.

Data collection / generation

What are your methodologies for data collection / generation? How will you ensure data quality? What data standards will you use?

I will collect new data during interviews conducted over Microsoft Teams, an established software tool supported by the University of Nottingham for conducting video and phone calls which can be recorded. If participants are unable to use the internet, they will be offered a telephone call and this will also be recorded on Microsoft Teams and the mobile phone for back up. The MP4 video files generated by Microsoft Teams and phone recording will be saved to a University of Nottingham OneDrive folder and deleted from the laptop and phone the recordings are made on. During the interviews, each participant will be asked the
same prompt questions to maintain consistency and encourage relevant responses.

I will be using the Automated Transcription Service, a tool approved and supported by the University of Nottingham to do the initial transcription of the recordings. I will check through each transcription personally
to ensure accurate transcription, data quality and anonymity. I will adhere to the UK Data Service guidance on anonymising qualitative data. To use the Automated Transcription Service the MP4 files will be converted to MP3. The Automated Transcription Service automatically deletes MP3 files when the transcription is completed and generates a text file of the transcript which will be saved in another University of Nottingham OneDrive folder.

When participants provide demographic information, I will assign each participant with a pseudonym. I will save the file with the identifying pseudonym on the University of Nottingham OneDrive and separately to any file which could identify the identity of the person assigned to the pseudonym to further protect anonymity.

I will create an Excel spreadsheet to conduct thematic analysis. I will import responses to questions from the .txt file into the .xls file using a tab for each question. Using Excel for the thematic analysis will enable to me to efficiently code and theme each response. This document will only contain anonymised responses and no identifiable information.

Data storage and security

Where and how will data will be stored, backed-up, transferred, and secured during the active phase (short to medium term) of research?

I will store data on the University of Nottingham OneDrive. OneDrive is a secure, cloud storage technology and it is the University's preferred location for storing personal and commercially sensitive data. I will only
be using OneDrive and Teams to capture, store and back up data as they meet University Information Security and General Data Protection Regulation (GDPR 2018) standards for handling personal and
commercially sensitive data and comply with the University of Nottingham Research Data Management Policy.
Using OneDrive means that the folders can only be accessed by me. I will ensure that original recordings of Teams calls are deleted once transcribed. I will create a separate folder for the transcribed
anonymised data, to ensure that no one could access either dataset and identify participants. I will save the demographic

information in another OneDrive folder. This way no one could identify a participant by their pseudonym, and only I can access each folder.

OneDrive storage and processing services comply with ISO 27001 international standard and BS7799 British standard of information management and security. OneDrive automatically backs-up data, offers
continual failover support with a maximum of one hour data loss, and encrypts data both in transit and at rest. There are no associated budget costs to using OneDrive as it is freely available for University of Nottingham students.

Data management, documentation, and curation

What are your principles, systems, and major standards for data management and creation? What metadata and documentation will you keep?

All data will be managed according to the University of Nottingham's data management policy, ensuring that all the research data I generate is managed in a manner that is FAIR – Findable, Accessible,
Interoperable and Reusable.

I will save data using a system of folders and file names. I will create folders labelled by data type and activity for example "Transcriptions". Within the folders I will use good file name conventions including the date. For example, transcriptions of interviews will be saved in the following format:
Trans01 _2022-18-02.doc : transcript with participant 01, interviewed on 2 February 2022.

As part of the University of Nottingham research ethics review, I will provide copies of the interview questions, demographic data collection questions and online consent forms. I will provide descriptive metadata including the filename, DOI and date of creation. For the Excel sheet I use for thematic analysis of anonymised data, I will provide a text file explaining the tabs used for ease of understanding in the future.

Ethics & Privacy

Are there any ethical or privacy related issues associated with your data?

Basic demographic data (age, gender, ethnicity, employment status and haematology cancer diagnosis) will be collected at the beginning of the interview, and the participant assigned a pseudonym to enable
me to anonymise the individual. Participants will have the option to decline to answer any of the demographic questions.

Email addresses will be collected during participant recruitment to schedule Microsoft Teams calls, to send and receive consent forms, and to send a summary report if requested, but this information will not be used for data analysis or published in further studies. All identifiable details will be removed from the study data and transferred to another folder and protected securely on OneDrive. Participants will be informed that they can withdraw their participation at any stage up until one week after the interview. After this time, the interview will be transcribed and anonymised and all identifiable information will be removed.

As I will be working with personal data, I will ensure that I comply with the Data Protection Act 2018, including GDPR requirements. This will include providing research participants with the relevant privacy
information as part of the participant information sheet and ensuring appropriate safeguards for the storage and handling of data are in place - this is built into the OneDrive software which is GDPR compliant.

Data preservation

How will you ensure the long term storage and preservation of data?

I will adhere to General Data Protection Regulation, 2018, to ensure the protection of the research and protection of participants rights and privacy.

Anonymised research data created by the project will be deposited in the University of Nottingham research data archive, https://rdmc.nottingham.ac.uk. A DataCite DOI is issued for each published dataset facilitating the ability to cite the data
in associated research outputs. The University of Nottingham data archive is underpinned by commercial digital storage which is audited on a twice-yearly basis for compliance with the ISO 27001 standard.

University of Nottingham will retain and preserve research data in line with University of Nottingham requirement for a minimum of 7 years, but data will be retained for longer periods of time where it is of
continual value to users.

Data sharing and access

How will the data generated be shared and published?

All data will be anonymised, ensuring it would not be possible to identify an individual from their responses.
All data processing and sharing will adhere to the University of Nottingham Data Protection Policy. The dataset will not contain any personally identifiable or commercially sensitive information and thus will be shared via the University of Nottingham data archive under a CC-BY license. There will be no need to update the data past the project period. All published outputs will contain a Data Availability Statement
including the data cite DOI which directs to the relevant data set. Data will be released at the same time as any published outputs which are underpinned by the data or by 1 year from the end of the project at the
latest.

Roles & responsibilities

Who will be responsible for managing data, data security, data quality, and data security both during the award and post-award?

The chief investigator will be responsible for the storage and management of the data collected during this study. The overall responsibility for data security is held by the University of Nottingham Chief information security officer. Whilst the data is being analysed it will be accessible to any member of the study team, the use of UoN One Drive will facilitate this and allow for team members
based at different locations to still have access to the data set.

Relevant policies

What are the relevant institutional, departmental or study policies on data sharing and data security?

We will ensure that our research aligns with the requirements of the University's Research Data Management Policy, Information Security Policy, Code of Research Conduct and Research Ethics. As we are working with personal data, we will abide by the University’s Handling Restricted Data Policy and Data Protection Policy. All third party commercial data or new data that may be suitable for commercial exploitation will be protected by the University's Intellectual Property policy.

IPR

Who will own the copyright and IPR of any data that you will collect or create? Will you create a licence(s) for its use and reuse? If you are planning to use existing data as part of your research, do any copyright or other restrictions determine its use?

Copyright & IPR for all project research data is owned by University of Nottingham.

Budgeting

What are the costs or funding required for capturing, processing, storing, and archiving your data?

Project funding will be used to transcribe data using the University of Nottingham Automated Transcription Service. This will cost a

maximum of £22.50 (30 hours at £0.75/hour).
University of Nottingham's free allowance for OneDrive is enough for the expected needs of this project and no extra allocation needs to be costed for.
No extra archiving capacity will be needed over the free UoN allocation.

Further Help

Would you like your plan to be reviewed by specialists in Libraries?

Saving this plan after checking the "Yes" box will immediately notify Libraries DMP review service, please only do this when you are ready for review.

- No

Would you like a reminder and further guidance on depositing your data? If so, indicate when would be most useful.

Guidance is sent out twice a year, but you can contact library-researchsupport@nottingham.ac.uk at any time for further support.

- Jan 2023