
Plan Overview

A Data Management Plan created using DMPonline

Title: Design your life: Developing and validating a practice-centred participatory design approach to empower autistic young adults in daily life

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Project abstract:

Moving into adulthood presents a variety of challenges for young adults on the autistic spectrum. Many have the ambition and capacity to live (more) independently, yet also need appropriate support. Increasingly, assistive technologies are considered, possibly embedded in the home. However, many technologies are never tried, or quickly abandoned. One cause may be that many products do not fit individual needs, contexts and capabilities. Young adults on the spectrum have highly heterogeneous needs and talents. In this project we investigate the power of participatory design - not in early stages of new product development - but as a part of daily practice, to enable young adults in adapting their own home environment. We ask how autistic young adults could create tailored supportive environments, using minimal technological resources. Grounded in real-world cases, involving young adults and their care-givers, we develop and validate the Design Your Life approach. With this approach individuals and care-givers iteratively envision, select, adapt and evaluate personalized, technological, supportive 'arrangements'. The process ensures integration of the arrangement in the social network and with practical organisation of the home environment. At minimum it consists in creatively selecting and combining 'off the shelf' technologies and personalizing where possible. Users with more technical skills may include building new elements themselves. We investigate whether such co-created arrangements empower young adults in daily life, as well as whether the participatory process helps young adults and care-givers form a shared understanding into personal goals, capabilities and needs.

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Design your life: Developing and validating a practice-centred participatory design approach to empower autistic young adults in daily life

General Information

Name applicant and project number

Aut.19.007
Jelle van Dijk

Name of data management support staff consulted during the preparation of this plan and date of consultation.

Maria Kamp
Simone Fricke

1. What data will be collected or produced, and what existing data will be re-used?

1.1 Will you re-use existing data for this research?

If yes: explain which existing data you will re-use and under which terms of use.

- Yes

We will share data with another project called Design Your Life RAAK-SIA that is conducted in collaboration with us with lead organisation HAN University of applied sciences. These data will be collected largely in parallel to the data we collect ourselves, so it is not *already* existing data but once it exists, we will be able to re-use it. Conversely HAN University will be able to make use of the data we have gathered in this project. Both parties sign a mutual agreement about this.

The phd student in this project will collaborate closely with another Phd student in a number of case studies: both in developing and evaluating a 'toolkit'. Both students will share and may use all raw and processed data generated through these case studies on the basis of a mutual agreement signed by both parties, as basis for their own research projects and questions, as part of the overall project. The other Phd student works under responsibility and Data Management policies and storage facilities of HAN university, within the Data Management requirements of a closely related SIA-RAAK grant project. Each phd student will initially store the data on their own safe server space and then share relevant raw data (e.g. video files or interview transcripts etc) through a shared folder on SurfDrive.

1.2 If new data will be produced: describe the data you expect your research will generate and the format and volumes to be collected or produced.

Qualitative data

- in depth open interviews in the form of video- and audio- recordings
- written transcriptions of interviews
- open/freeform written responses in questionnaires
- ethnographical field-notes made during site visits
- information drawn from publicly shared expressions on social media platforms such as Twitter, Facebook, Instagram and Reddit.

Quantitative data

- responses to questionnaires with fixed answer categories (e.g. Likert scales)
- Data generated by certain household devices and digital applications.

Formats:

- Digital videofiles
- Digital audiofiles
- Digital photographs
- Text documents
- Digital device usage Datalogs (also text files)

Volume:

0.9 GB * hour (HD); 20 cases * 30 hours = 540GB Videos

2MB * Photograph; 20 * 500 photos = 20GB Photos

Total estimation: Max 600GB (mostly video).

1.3. How much data storage will your project require in total?

- 100 – 1000 GB

Estimation:

0.9 GB * hour (HD); 20 cases * 30 hours = 540GB Videos

2MB * Photograph; 20 * 500 photos = 20GB Photos

Total estimation: Max 600GB (mostly video).

2. What metadata and documentation will accompany the data?

2.1 Indicate what documentation will accompany the data.

We will share as meta-data explanatory documents in each main folder of the raw data describing how the data was collected and using which methods and how the data was processed if it concerns processed data (like video transcripts or interview analyses). If there will be any automatic data processing like statistical analyses or automated coding/ selection of data using software, the code of this software will be stored in the folder where the processed results are stored and within the code there will be clear instructions and explanations as code commentary on what the code does, with what purpose, and based on what methods/techniques.

NB: many of the data we collect are private and sensitive, personal qualitative information (for example video's of people explaining how they live their daily lives in their home environment). These data will never be shared beyond this project (and the accompanying RAAK project), so the meta-data we write will be mainly in order for the research methods to be rigorous and transparent from a research perspective but not in particular focused on sharing this data with a wider research community than the phd students and staff involved in the Design Your Life Project (which involves both this current project and the RAAK-SIA project managed by HAN university).

2.2 Indicate which metadata will be provided to help others identify and discover the data.

We will create a central document at the root of the tree of folders on the online drive where the data will be stored which explains the folder and document structure and logic. Furthermore:

We will share as meta-data explanatory documents in each main folder of the raw data describing how the data was collected and using which methods and how the data was processed if it concerns processed data (like video transcripts or interview analyses). If there will be any automatic data processing like statistical analyses or automated coding/ selection of data using software, the code of this software will be stored in the folder where the processed results are stored and within the code there will be clear instructions and explanations as code commentary on what the code does, with what purpose, and based on what methods/techniques.

3. How will data and metadata be stored and backed up during the research?

3.1 Describe where the data and metadata will be stored and backed up during the project.

- Institution networked research storage

The data of this project will be stored on internal protected servers of the UT. All data that need to be shared with HAN university in

service of the project at large will be copied and shared to a shared and protected SURF DRIVE.

3.2 How will data security and protection of sensitive data be taken care of during the research?

- Additional security measures (please specify)

Data gathered will be stored on encrypted laptop disk or encrypted password protected mobile device, thereafter immediately transferred to encrypted internal institution servers of the faculty which are only accessible by the phd student and main supervisors/projectleader.

4. How will you handle issues regarding the processing of personal information and intellectual property rights and ownership?

4.1 Will you process and/or store personal data during your project?

If yes, how will compliance with legislation and (institutional) regulation on personal data be ensured?

- Yes

We will gain personal consent from each participant, also for the type of data to be gathered e.g. participants can indicate whether they agree with making notes, audio recording or video recording and in what contexts (e.g. in interview room or in personal home environment).

The entire research procedure will be subjected to the faculties' ethical board for approval. All data will be pseudonymized and where it is difficult to anonymize the raw data (e.g. when using video) explicit consent will be asked and ensurance will be made that these data are only accessible by the main researchers and will never be shared elsewhere, unless with explicit additional consent (for example additional consent may be asked to be able to present a photo or video at a talk or in a publication, in which a person is visible and recognizable).

4.2 How will ownership of the data and intellectual property rights to the data be managed?

All data gathered under this project name will be owned by UT, and all data gathered under the related HAN project will be owned by HAN, but an agreement will be signed that both parties mutually share all these data for use, in service of the project as a whole.

5. How and when will data be shared and preserved for the long term?

5.1 How will data be selected for long-term preservation?

Question not answered.

5.2 Are there any (legal, IP, privacy related, security related) reasons to restrict access to the data once made publicly available, to limit which data will be made publicly available, or to not make part of the data publicly available?

If yes, please explain.

- Yes

Almost all data will not be available for re-use by any other party than the beforementioned partner organisation HAN university, because it is sensitive data about the personal lives of (vulnerable) people, and we will often make use of audio and video which

cannot be easily anonymised. So there will be practically no raw data coming from this research that can be used by others. Apart from source and format of data being sensitive, the stories and creative expressions of the participants (content) are also not easily anonymised as they address their own personal lives and living environment. Finally much of our analyses will stay at the individual, case study level, and so there will be not a lot of 'group level' generalisations (this is precisely a starting point for the research, that group generalisations are difficult and undesirable for the goal of this research and the heterogeneity of the target group).

However, all processed data that do discuss insights and patterns at the more generic group level will be anonymised in such a way that they can be shared with others, and this of course also goes for the publications, presentations and advisory reports that result from this research. At this moment we see only one such dataset which can be shared which are the individual scores on two 'well being' and 'personal autonomy' scales that we will gather in year 3 of the project, these are anonymous quantitative data that cannot be related back to the people themselves. We will publish such data and results online and freely for others to use on the project website.

5.3 What data will be made available for re-use?

- Other (please specify)

At this moment we see only one such dataset which can be shared which are the individual scores on two 'well being' and 'personal autonomy' scales that we will gather in year 3 of the project, these are anonymous quantitative data that cannot be related back to the people themselves. We will publish such data and results online and freely for others to use on the project website.

5.4 When will the data be available for re-use, and for how long will the data be available?

- Data available upon completion of the project

The data will remain available for as long as the open source online repository maintains it.

5.5 In which repository will the data be archived and made available for re-use, and under which license?

We will store the data that can be shared openly (which is very limited in this project) via 4TU.ResearchData under a CC BY-NC Creative Commons license.

5.6 Describe your strategy for publishing the analysis software that will be generated in this project.

There will be practically no analysis software generated in this project, most of the analysis is qualitative, research-through-design co-design research. There is one quantitative study using scales and if we need any software to analyse the data (which I doubt) we will publish it at 4TU.ResearchData under a CC BY-NC Creative Commons license.

6. Data management costs

6.1 What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

The basic infrastructure (e.g. enough storage space) is available and already paid for within our research group.

The PhD student will take care of (documentation, sharing data) according to a clear structure and meta-documentation as indicated earlier. The student gets additional help in this process from a junior researcher, for which 38K salary budget is allocated in year 2 and 3 of the project, which is when the bulk of the raw data will be gathered.

If needed there will be some budget available to buy extra server storage within the UT and at the SURF DRIVE.