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Deliverable D2.2: Data Collection Report

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Contents

Deliverable 2.2: A report on data collection efforts in different settings (e.g. long term care, social care)' data accessibility and preparation (e.g. open access data sets), (ESRs 6-10)

1 Introduction

The first Working Package group 2 (WP 2) meeting in Brussels October 25th, 2018 focused on the potential and actual difficulties of access to long term care facilities, municipalities, policymakers, inpatient and outpatient services, social media and patients records. The members of WP2 discussed the ethical issues concerning the use of social media pictures and this was addressed in the Deliverable 2.1. Additionally, the group discussed the possible challenges of data collection, in terms of culture, availability, accessibility, any permissions needed (open access, purchased) and challenges.

To achieve consistency of this Deliverable and facilitate the group discussion, two ESRs from WP2 developed a template on the basis of the comments from Professor Angela Kydd (WP 2 leader). The template was then used by all Early Stage Researchers (ESRs). A group Skype meeting took place on 15 January 2020 to discuss and reflect upon the challenges of data collection of each project. It gave an opportunity for all ESRs to learn from each other's experiences of data collection in diverse settings. Each ESR reported several challenges and were reminded by the leader that how they addressed these challenges was an essential component of being a robust researcher. Section 3 of this Deliverable addresses the challenges and solutions of data collection.

Section 2 shows the template used and presents the work of ESRs 6, 7, 8, 9, 10 (sections 2.1-2.5) to explain the way in which research data was collected, stored and assessed.

2 Template for Deliverable 3

ESR Name, Project Number and Institution	
Please state where you received ethical approval from	
Title: A report on data collection related to ageism as a barrier to 1/ provision of relevant support and services with a particular focus on /…/	
Research Questions / Aims and Objectives	
Purpose of data collection	
Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)
Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …

Storage of data collection	e.g. how data is safely stored and when it will be destroyed
Data quality assessment	
Any permissions needed	e.g. open access, purchased and financing …
Challenges and solutions	e.g. language barriers, cultures …
Other relevant issues	
Conclusive remark	

2.1 Laura D. Allen, ESR 6

ESR Name, Project Number and Institution
Laura D. Allen
ESR #6, Bar-Ilan University

Please state where you received ethical approval from	
Bar-Ilan University; Robert Gordon University pending	
Title: A report on data collection related to ageism as a barrier to 1/ provision of relevant support and services with a particular focus on the meanings of autonomy and age in the care home	
Long-Term Care	
Research Questions / Aims and Objectives	
To understand how the meaning of autonomy is constructed in the context of a care home, and how meanings of autonomy and age are interrelated.	
Purpose of data collection	
To understand the meanings stakeholders in the care home attribute to autonomy after the recent change in the health and social care standards of Scotland. The stakeholders of interest are the residents, nursing staff, and inspectors. I will apply a novel approach to collecting data by implementing a temporary "short story club" with residents in a focus group format. I will facilitate an open discussion on the themes of selected short stories that are relevant to the research topic.	
Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)
Data collection for the project is currently being planned and will be collected July to October 2020 through Robert Gordon University in Aberdeen, Scotland. Bon Accord Care is an organization of three long-term care homes, one dementia care home, and one rehabilitation facility in Aberdeen. They are eager to work with researchers in the School of Nursing and Midwifery at RGU, and a relationship has been formally established. I will collect data through focus group discussion with residents (3-4 groups), care home managers (2-3 groups), and care staff (2-3 groups). With the residents in particular, I will lead a short story club that will run once a week for 4 weeks to spark discussion of themes relevant to the research topic. Additionally, I will conduct 2-3 focus group discussions with inspectors from the Aberdeen Care Inspectorate. I made contact with a senior care inspector during my secondment at RGU	

last summer, who expressed an interest in my research. I will utilize a snowball sampling technique, while also making use of the extensive network in the School of Nursing and Midwifery to contact other care inspectors.	
Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …
Audio recordings and ensuing transcriptions will be primary data collected by the ESR and will be qualitative in nature.	
Storage of data collection	e.g. how data is safely stored and when it will be destroyed
Audio recordings and transcripts will be stored in the archival (R:) drive at Robert Gordon University and will be destroyed according to the university's policy. The data will not be made open access because of the potentially identifiable information of the care home residents. It will be ensured that the UK General Data Protection Regulation (GDPR) guidelines are ultimately applied to keep the data safe.	
Data quality assessment	
I am experienced in qualitative interviewing, and I am taking a course on qualitative data collection now, to ensure high quality interaction with the participants. Transcripts of the interviews will be compared with the audio files to ensure accurate transcription.	
Any permissions needed	e.g. open access, purchased and financing …
The primary data collection proposal will be reviewed by the ethics committee at Robert Gordon University. Prof. Angela Kydd has agreed to act as my supervisor while I am collecting data at RGU this summer, and her additional hours (16 working days) will be costed from my research funds.	

Challenges and solutions	e.g. language barriers, cultures …
In order to access data of this type (with care home professionals and stakeholders), data could not be collected in Israel because of the language barrier. The primary data that I will collect will be in Scotland where English is the spoken language.	
Other relevant issues	
None.	
Conclusive remark	
Primary data collection will be completed by November 2020.	

2.2 Jovana Brkic, ESR 7

ESR Name, Project Number and Institution Jovana Brkic ESR #7, Charles University, Faculty of Pharmacy
Please state where you received ethical approval from
The first study has been approved in several countries (Bulgaria, Croatia, Czech Republic, Estonia, Ethiopia, India, Serbia, Spain, and Turkey) by ethical committees of participating health care and long-term care institutions, and academic institutions. Documents for ethical committees submitted to the local ethical committees in Belgium. The second study, in which national lists of registered medicinal products will be used, does not require ethical approval.

Title: A report on data collection related to ageism as a barrier to 1/ provision of relevant support and services with a particular focus on /…/
Inappropriate Prescribing and Availability of Medication Management Services in Older Patients in Europe
Research Questions / Aims and Objectives
Aims: · To determine the prevalence and risk factors associated with potentially inappropriate prescribing in an international cross-sectional sample of older adults in different settings of care - long-term care, acute care, and ambulatory care. · To determine the availability of high-risk medication and safer alternatives for older patients on pharmaceutical markets in different countries.

Purpose of data collection	
The purpose of data collection is to: · Gather and interpret data about the characteristics and outcomes of older persons across a variety of health and social services settings using a comprehensive instrument. · Gather and interpret data about the availability of high-risk medication across several countries.	
Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)
· Data (medication use, health status, symptoms, diseases, syndromes, and results of recent laboratory tests) will be collected from older patients' medical records and from interviews with older patients and/or health care professionals using structured data collection form. Trained researchers will collect data in different settings of care - long-term care, acute care, and ambulatory care. · Data will be collected from national lists of registered medicinal products and national lists of reimbursed medicinal products via desk research.	

Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …
Data collected will be: · Primary and quantitative (a number of scales are part of the instrument) · Secondary quantitative data	
Storage of data collection	e.g. how data is safely stored and when it will be destroyed
Data will be safely stored in the servers of Charles University. The original data will be preserved and will not permitted to alter.	
Data quality assessment	
Quality control of data will take place during: · Data collection - using validated scales, and clear instructions · Data entry - designing a purpose-built database with validation rules and detailed labelling of variables and record names · Data checking - double-checking, and statistical analyses	
Any permissions needed	e.g. open access, purchased and financing …
No	
Challenges and solutions	e.g. language barriers, cultures …

As this is an international study, we have faced several challenges:

- Organizing and conducting research in several countries – it was planned to conduct research in four more countries (Albania, Lithuania, Portugal, and Slovakia) but it was not feasible due to different organizational obstacles.
- Obtaining ethical approval and collecting data in several countries are time-consuming processes.
- Language barriers – translation and cultural adaptation of research documents and documents for Ethical committees.

Other relevant issues	
No	
Conclusive remark	
Data collection is in progress, and no issues have been encountered.	

2.3 Abodunrin Aminu, ESR 8

ESR Name, Project Number and Institution

Abodunrin Aminu

ESR #8, Robert Gordon University

Please state where you received ethical approval from

The ethical approval for this project was obtained from the Robert Gordon University School of Nursing and Midwifery Ethics Review Committee.

Title: A report on data collection related to ageism as a barrier to ageing health and wellbeing with a particular focus on /…/	
The relationship between age discrimination and frailty among individuals aged 65 years and over	
Research Questions / Aims and Objectives	
· Is there an association between perceived age discrimination and the development of frailty among individuals aged 65+? · Is there a relationship between perceived age discrimination and health status of individuals aged 65+? · Does a relationship exist between perceived age discrimination, social isolation, and loneliness among individuals aged 65+? · What is the role of health behaviours on the relationship between perceived age discrimination and health status of individuals aged 65+?	
Purpose of data collection	
This project will be utilising publicly available secondary data. Thus, there will not be any data collection. However, the process of accessing the data will be discussed. The data to be utilised is the English Longitudinal Study of Ageing (ELSA). ELSA is a longitudinal survey that has been collected to examine the health and well-being of individuals aged 50 years and over, living in England.	
Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)
ELSA is a harmonised dataset because it has been structured along the Health and Retirement Survey (HRS) and the Survey of Health, Ageing and Retirement in Europe (SHARE). This gives the ELSA potential to provide comparative findings with the rest of Europe. At the baseline data collection in 2002, participants in the Health Survey for England (HSE) whose birth dates preceded March 1952 were recruited into the ELSA study. The ELSA study sample was weighted using the calibration approach to approximate the general population, thus making the ELSA nationally representative data. The ELSA study has continued to collect data from the same participants every two years since the baseline data.	

The ELSA baseline study population consisted of 12,099 participants with a mean age of 65 years (range 50 to 100 years).	
Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …
This project will be quantitatively examining the relationship between age discrimination and frailty among individuals aged 65 years and over, using a secondary dataset (ELSA). The ELSA study has collected data at different Waves (Wave 1 to 9) using computer-assisted questionnaires. It also features nurses' assessments of the physical health of the participants. Thus, the ELSA provides quality longitudinal data that will be relevant for investigating the research questions in this study. The ELSA dataset contains anonymised data that will be analysed to examine the research questions in this study. The secondary data analysis of the ELSA data from Waves 5 (2010), 6 (2012) and 8 (2016) will be conducted. The ELSA study collected data using 150 main questions across all the Waves (1 – 9), and specific questions were introduced in some of the Waves to measure different conditions. For instance, questions on age discrimination was only collected in the Wave 5 of ELSA. Overall, the total information collected in ELSA can be categorised into: (1) Demographic data (2) Economic data (3) Measures of Health, Disability, and Health Behaviour (4) Psychosocial Measures (5) Cognitive function.	
Storage of data collection	e.g. how data is safely stored and when it will be destroyed
The data will be kept in a highly secured and personalised R drive provided on a closed circuit system by the Robert Gordon University (RGU). This data storage system is password protected and ensure that only authorised individuals are able to access the drive. The data will be kept safe from unauthorised access, accidental destruction or loss. It will be ensured that the UK General Data Protection Regulation (GDPR) guidelines are ultimately applied to keep the data safe.	
Data quality assessment	

The dataset (ELSA) to be analysed in this project is publicly available and anonymised. ELSA has a huge citation (UK data archive) and has been used to complete previous PhD dissertations in the past (Rippon et al. 2015).	
Any permissions needed	e.g. open access, purchased and financing …
The ELSA data is an anonymised data managed by the NatCen (a social research agency in Britain) and publicly available through the UK data archive. Although informed consent has already been given by primary participants for the ELSA study, there will be a need to request permission from the UK data archive to access the data. The UK data archive requires that an intending researcher interested in downloading data or requesting data access must obtain an End User Licence (EUL) by registering on the UK data archive platform. This registration is facilitated through the UK Access Management Federation (UKAMF) login. Since Robert Gordon University (RGU) is a registered institution under the UKAMF, the ELSA data was accessed through institutional login after the approval of the RGU School of Nursing and Midwifery ethics committee. Additionally, the UK data archive requires that the user requests for the data under a specific project folder created online, which will include a written abstract that indicates the reason the data is required. Thus, the ELSA data will be accessed through the UK data archive in line with the EUL agreement that confidentiality will be kept, data will not be commercialised without prior knowledge and approval of the UK data archive, and that the data will not be linked to the HSE for identification of participants or specific geographical location.	
Challenges and solutions	e.g. language barriers, cultures …
There is no identifiable potential risk to participants associated with this study as all data is anonymised. The ELSA data does not contain personal identifiers linking study participants to the information in the dataset. However, because this project is a secondary data with huge sets of variables, managing the data has been a little tasking. Cleaning the data to identify the appropriate variables has been time consuming.	
Other relevant issues	
None	

Conclusive remark	
This data collection process is typical of a secondary data analysis and has been conducted carefully with all appropriate permissions.	

2.4 S M Atiqur Rahman, ESR 9

ESR Name, Project Number and Institution S M Atiqur Rahman ESR #9, Linköping University, Department of Culture and Society.
Please state where you received ethical approval from
There is no need for ethical approval according to the Swedish law concerning the interviews with the professionals (SFS 2008: 192), however, a written informed consent is obtained from the interviewee.
Title: A report on data collection related to ageism as a barrier to 1/ provision of relevant support and services with a particular focus on /…/
Ageism in the care service system: The case of care service assessment for older people 65+ with dementia
Research Questions / Aims and Objectives

Objectives:

- To review the existing empirical literature on how attitudes, stereotypes, discrimination, and ageism have been applied to address issues related to dementia and people living with dementia; (under review)
- To investigate the effects of dementia and age-related stereotypes among care managers while dealing with needs assessment for people with dementia;
- To examine the influence of socio-demographic actors (age, sex, marital status, educational level) in the decision-making process about social care services for people living with dementia;
- To explore the levels of formal care services (home care service or special housing) received by people living with dementia from rural and urban areas.

Purpose of data collection	

- To comprehend the attitude and stereotypes, if any, of the care managers while providing or offering care services to the people living with dementia in Sweden.
- To measure the level of healthcare services for individuals or couples with dementia based on Swedish registry data where the focus will be on demographic factors.

Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)

Primary data will be collected from face-to-face interviews with care managers in different municipalities in Sweden. In addition, Swedish national registry data set will be used for quantitative analysis of heath care facilities in Sweden. Both the data set will be preserved in Linköping university data repository system and will follow Linköping university's research data preservation policy and only the research team will have access to the raw data set.

Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …

1. Primary data (qualitative interview and quantitative Swedish registry data) 2. Existing literature as secondary data	
Storage of data collection	e.g. how data is safely stored and when it will be destroyed
Data will be stored in Linköping university data repository system.	
Data quality assessment	
Qualitative data will be re-checked with audio recorded files and quantitative data will be prevented from any kind of contamination by eliminating data entry errors.	
Any permissions needed	e.g. open access, purchased and financing …
If anyone wants to re-use the data set, they need to take written permission from the research team as well as from Linköping University.	
Challenges and solutions	e.g. language barriers, cultures …
As the researcher came from outside of Sweden, the main barrier during data collection was to communicate with participants. The language barrier was one of the most challenging aspects of this work. However, the language challenge was mitigated by recruiting a professional interpreter during interviews while needed. In addition, it was not easy access to make appointments for interviewing some participants. With the fruitful intervention of the supervisors, this problem was also solved.	
Other relevant issues	
No	
Conclusive remark	
A scoping review has been completed, qualitative and quantitative data collection is in progress.	

2.5 Wenqian Xu, ESR 10

ESR Name, Project Number and Institution Wenqian Xu ESR #10, Linköping University, Department of Culture and Society
Please state where you received ethical approval from
Ethic approval is not needed for this research project.
Title: A report on data collection related to ageism as a barrier to 1/ provision of relevant support and services with a particular focus on /…/
Social media representation of older people generated by Swedish local authorities
Research Questions / Aims and Objectives
The research project specifically investigates the representation of older people (and other age groups) constructed by Swedish municipal organizations on social media (particularly Facebook). Additionally, it investigates whether and how age stereotypes are manifested in media representations (visual images) and media production process (institutional work routines). The research aim is disentangled with the following research questions: · What representations of old age can be identified in municipal social media? · How are visual signs used to construct media representation of old age by municipal public bureaucracies? In particular, which signs, contexts and activities were used? · What are the differences in the representations of adolescents and older people portrayed in municipal social media?

Purpose of data collection	

This research project collects data for gathering research materials for analyses.	
Description of data collection process	e.g. settings, availability, accessibility, procedures (when, who, where and how)
With regard to social media usage of public bureaucracies, 92 per cent Swedish municipalities claimed to have an official Facebook page in 2010; additionally, these municipalities have performed more social media activity on Facebook rather Twitter and Instagram. Likewise, Facebook users in Sweden consist of a larger number of citizens at different ages. The municipality of Norrköping have been using Facebook as the major social media tool to reach a broader range of citizens. Facebook photos of humans and the accompanying captions were extracted as Facebook posts from 33 Norrköping municipal Facebook pages during the first week of 2019. All the Facebook posts are available online and accessible for all Facebook users. The Early Stage Researcher 10 downloaded the Facebook posts, anonymized the posts and stored them in the online space managed by Linköping University. A dataset of 1,000 images was established complying with the following criteria of selecting photos. (1) Duration. This study extracted photos that were published on municipal Facebook pages in 2018. As a special case, it excluded 101 photos from the Facebook album of Cultural Night 2017, although these photos were posted in 2018. Cultural Night in Norrköping is a vital annual event and its photos should be published on Facebook once a year in time. This study aims to evaluate the annual media performance of this municipality during a normalized one-year period; hence, the 2017 album is considered as an overdue media release and should not be admitted into the dataset. (2) Human figure. Concerning the presentation of human figures in the pictures, several types of photos were identified, including portraits, group shots and body images. (3) Compositional images. Given that the three-dimensional real world is captured by two-dimensional images, viewers could construct the spatial configuration of a scene with the help of several photos taken from different perspectives. Hence, this study incorporated these pictures into one compositional image for further analysis, as viewers are inclined to cognitively recognize them as one visual image. (4) Other ruled-out photos. Blurry photos, duplicates and infographics were ruled out because of the poor feasibility for the coding process. Also, movie scenes and posters were excluded as this study focuses on citizens in Norrköping rather than fictional actors.	
Description of collected data	e.g. primary or secondary, scale, qualitative or quantitative …
A dataset of 1,000 photographic images was established. It is considered as qualitative data.	

Storage of data collection	How data is safely stored and when it will be destroyed
The data has been stored in the online space managed by Linköping University for a period of ten years since the project starts, according to the data protection regulations of Linköping University. The data will be destroyed afterwards.	
Data quality assessment	
The data quality is fine since it is sufficient for conducting research. It is also the right type of data to achieve research aims.	
Any permissions needed	e.g. open access, purchased and financing …
Permissions are not needed.	
Challenges and solutions	e.g. language barriers, cultures …
No challenges were identified in data collection.	
Other relevant issues	
None.	
Conclusive remark	
The research performed data collection smoothly without any difficulties. The data analysis started at the beginning of 2019.	

3 Discussion

The working group discussed the challenges of data collection encountered in each project. The language barrier was identified as a common challenge for most of the ESRs, especially those who have planned to collect data from local people. For example, ESR 6 and ESR 9 explicitly described their challenges related

to language as well as getting access to the community to get an appointment for interviews. With respect to ESR 7, who planned to conduct a cross-country study, challenges arose due to trying to navigate different organizational obstacles. As a result, the study may have to change geographic location. Although ESR 8 did not report any potential challenges due to the nature of the study, the project presented different challenges with data cleaning, management and analysis of a very large secondary data set. ESR 10 highlighted his observations on data availability during the collection of social media posts. Since several social media posts were deleted by local authorities, data collection needed to be performed in a short period to ensure a larger corpus.

4 Conclusion

The work produced by the ESRs demonstrated an overview of the challenges related to data collection and data management in different study settings. How the ESRs from different countries encountered the challenges they faced and how they chose to mitigate these challenges with practical and effective solutions, proved to be an important learning curve that will be essential knowledge for their future research studies. Acknowledging that research can be messy and unpredictable prepares all students for anticipating problems and seeking practical solutions.