

The Austrian-Czech Long-Term Care Project: a model for data sharing

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Introduction: Problems

- Most countries face the challenge of providing high quality long term and nursing home care in a cost-efficient manner. Long-term care (LTC) including institutional Long term Care (iLTC) is one of the main problems of public health and health policy in Europe and the world
- Around the world, practitioners, nursing staff etc. are trying to find alternatives to traditional nursing home care



Hogewey, the Netherlands

Introduction: Problems

- Policy Makers need reliable data to make informed decisions for future developments
- Currently available data are not sufficient
- International collaborations are difficult (differences in culture, structure, financing etc.)
- International research findings do not enter practice fast enough
- Research data of publicly funded research are not accessible

Literature:

- EC. (2013a). Evidence on Demographic and Social Trends. Social Policies' Contribution to Inclusion, Employment and the Economy SWD. Brussels.
- EC. (2013b). Investing in Health SWD. Brussels: European Commission.
- EC. (2013c). Long-term care in ageing societies - Challenges and policy options Commission Staff Working Document. Brussels: European Commission



Nursing home structure and association with agitation and use of psychotropic drugs in nursing home residents in three countries: Norway, Austria and England

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Key points

- Significant differences in agitation and psychotropic drug use were found among the nursing homes in the three countries.
- These differences remained after adjustment for age, gender and dementia severity.
- These findings suggest that differences in agitation are related to organisational and structural difference among the nursing homes rather than different patient characteristics.
- Norwegian homes with higher staff-resident ratio, had relatively low agitation *and* low antipsychotic drug use.

Introduction/ Problem

- OECD* is repeatedly commenting on the slow progress in dementia research.
- The OECD suggests a more effective collection and use of data from publicly funded studies in the future.
- This could substantially help advancing our knowledge around dementia care and treatment.
- New concepts of common data collection across studies, data sharing, data re-use, open access publishing, publishing data sets, all concepts of “open science” and “big data” should be explored in this context.

Literature:

Anderson,G. and J. Oderkirk (eds.) (2015), Dementia Research and Care: Can Big Data Help?, OECD Publishing, Paris.DOI: <http://dx.doi.org/10.1787/9789264228429-en>

* The Organization for Economic Co-operation and Development



Performance of Hippocampus Volumetry with FSL-FIRST for Prediction of Alzheimer's Disease Dementia in at Risk Subjects with Amnestic Mild Cognitive Impairment

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Stockholm OECD workshop (September 20-21, 2015) conclusions

- Potentially, the linking and sharing of different data sources could be beneficial.
- Publicly funded research data should be made accessible for other researchers
- In order to be successful, singular efforts need to be coordinated, clear goals (research questions) defined and general standards developed (e.g. data management plan).
- Data experts need to be involved in the planning of research studies.
- Data sharing could have a dramatic impact on the advancement of Dementia research, but only if the implementation adheres to strict scientific and moral standards.



Challenges defined at the Workshop

1. Trust
2. Additional burden and workload to prepare data for sharing
3. Motivation (Credit/reward)
4. Broker/governance: Who provides the technical and organizational structures?)



Prevalence of dementia in nursing homes

- 58% residents already had a diagnosis of dementia
- 31,8% had no diagnosis, but scored within the range of possible dementia
- 10.2% other, undefined

Literature

- Lithgow, S., Jackson, GA., Browne, D. (2011). Estimating the prevalence of dementia: cognitive screening in Glasgow nursing homes. *Int J Geriatr Psychiatry*. 2012 Aug 27(8): 785-91.doi:10.1002/gpps.2784. Epub 2011 Nov 14.





JAMDA

journal homepage: www.jamda.com

Special Article

An International Definition for “Nursing Home”



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Definition 'Nursing home'

- (1) is a facility that provides 24-hour functional support for people who require assistance with ADL/IADL and have identified health needs;
- (2) may or may not be staffed with health care professionals;
- (3) provides long term care and/or rehabilitation as part of hospital avoidance or facilitate early hospital discharge;
- (4) does not function as a hospital ward and is not hospital based;
- (5) may play a role in providing palliative and/or hospice care at end of life.

Literature

- Sanford, A. M., Orrell, M., Tolson, D., Abbatecola, A. M., Arai, H., Bauer, J. M., ... Vellas, B. (2015). An International Definition for 'Nursing Home'. Journal of the American Medical Directors Association, 16(3), 181–184.
<http://doi.org/10.1016/j.jamda.2014.12.013>



Nursing Homes in Austria and the Czech-Republic

- the population in Austria and the Czech-Republic is aging quickly and the need for iLTC will increase
- lack of reliable information on the cognitive, physical and social status of residents and care staff

Literature

- EC. (2013a). Evidence on Demographic and Social Trends. Social Policies' Contribution to Inclusion, Employment and the Economy SWD. Brussels.
- EC. (2013c). Long-term care in ageing societies - Challenges and policy options Commission Staff Working Document. Brussels: European Commission



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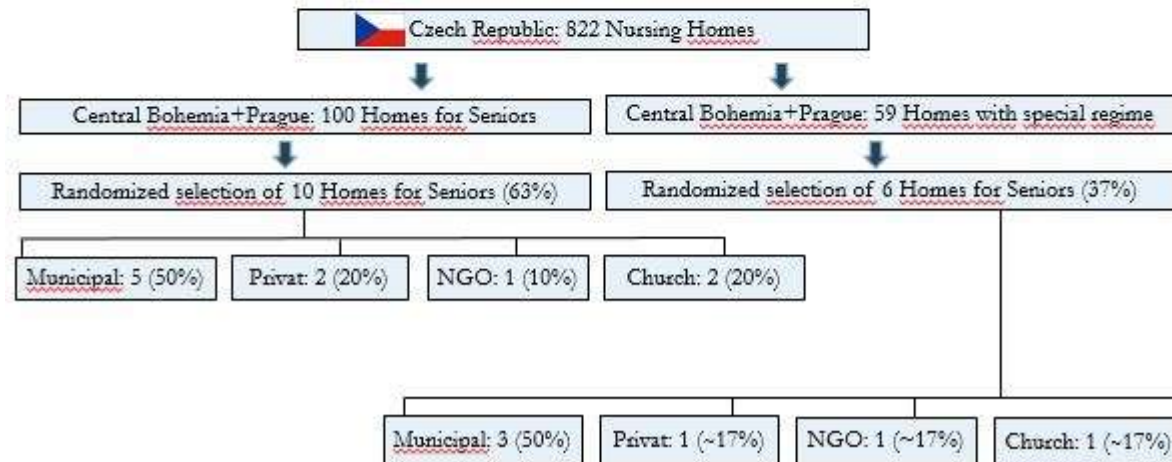
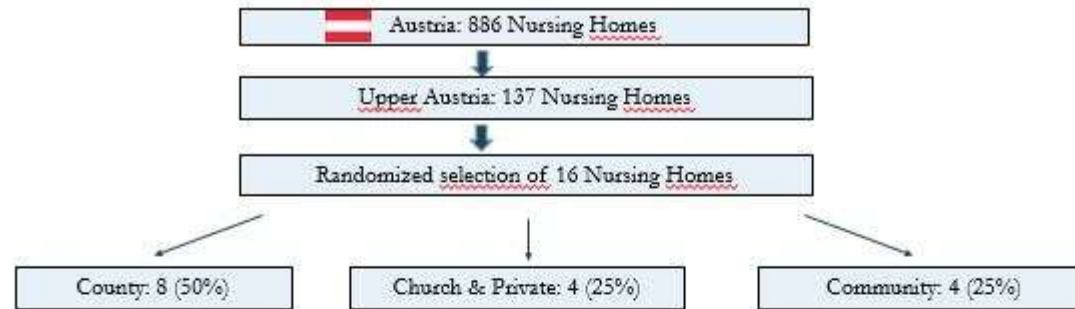


Project description

- 1000 persons living in nursing homes in Austria and the Czech Republic will be included into the study
- The nursing homes investigated will be randomly drawn from all nursing homes in a geographical region



Population selection



Objectives

- Medical and social conditions of persons living in nursing homes
- 2 Centres (located at the Charles University and the Danube University)
- A common study protocol
- One data collection system build on Open Source technologies (a MySQL database hosted on a Linux Debian Server, located at the Danube University Krems, Austria)
- Separate and common data analysis
- Prepare Data for data sharing



Working time plan

- March 2016, start of the Project

Time plan workpackages	Year 1			Year 2		
	1 - 4	5 - 8	9 - 12	13 - 16	17 - 20	21 - 24
WP 1 Project management	█	█	█	█	█	█
T1.1 Joint project management	█	█	█	█	█	█
T1.2 Study coordination	█	█	█	█	█	█
WP 2 Preparatory Phase	█	█	█			
T2.1 Meeting of study management and coordination	█					
T2.2 Preparation of study protocols	█	█				
T2.3 Recruitment of the study sample	█	█	█			
T2.4 Recruitment of nursing home research assistant	█	█	█			
T2.5 Research staff training in each country and between study centers	█	█	█			
WP 3 Data Collection Phase		█	█	█		
T3.1 Regular data check by the data base manager/study coordinator		█	█	█		
T3.2 Mid term study coordinator and study management meeting			█			
WP 4 Data Analysis Phase				█	█	█
T4.1 Start of data analysis				█	█	
T4.2 Meeting on study results					█	
T4.3 Publication of study results						█

Study protocol

Assessment Domain	Operationalization	Source of information
Domain A: Resident		
Identification	Study ID	Data Manager
Age	Date of birth	Chart
Gender	Male or Female	Chart
Size of Unit		
Cognition	MMSE (Folstein et al, 1975) / BCRS GDS (Reisberg, 1982)	Resident
Functioning	Barthel Index	Care Team
Dementia type	Alzheimer's dementia Vascular dementia, Other (e.g. Parkinson's disease)	Clinician chart review
Mobility	Timed Get up and Go Test Podsiadlo D, Richardson (1991)	Clinician
Mini Nutritional Assessment	(Rubenstein et al, 2001)	chart review
Pain - VAS	The VAS Pain Scale (Hawker 2011)	
Other medical Diagnosis		
Medications		
Behaviour	Behave-AD-FS (Reisberg et al, 1989) E-Behave-AD (Auer et al, 1996) GDS- Yesavage- depression	Care staff Clinician Clinician
Needs	Qualitative	Focus groups with selected residents
Quality of life QOL	PwD version, (Logsdon et al, 1999)	Resident
Domain B: Care Team		
Socio Demographics	ID, Age, Gender, years of education, anonymous	Questionnaire
Burden	PCTB scale (Auer et al, 2015)	Care team
Needs assessment	Qualitative	Focus group care team
Domain C: Relatives of Residents		
Socio Demographics	ID, Age, gender, relation to resident	Questionnaire
Number of visits per week	Qualitative question	Telephone
Needs assessment	Qualitative	Focus groups relatives
Domain D: Environmental Factors		
Size of Institution	Quantitative - total number of residents	Questionnaire Institution
number of units	Quantitative	Questionnaire Institution
staff members	Quantitative - Number, staff/patient ratio	Questionnaire Institution
Social program offered to residents (what and frequently)	Quantitative- number of events/categories	Questionnaire Institution
Medical Service and medical outcome	Quantitative - hospitalizations, Reasons for hospitalizations	Questionnaire Institution

Research Questions (examples): Qualitative and Quantitative Methods

Persons with Dementia

- Cognitive, functional and behavioural status
- Health status
- Social conditions

Care Team

- subjective work related burden
- needs assessment

Relatives

- availability
- needs

Environmental Factors

- Relation of environmental factors (for example Size, social programs) to outcome (e.g behavioural symptoms)



Why Data Sharing?

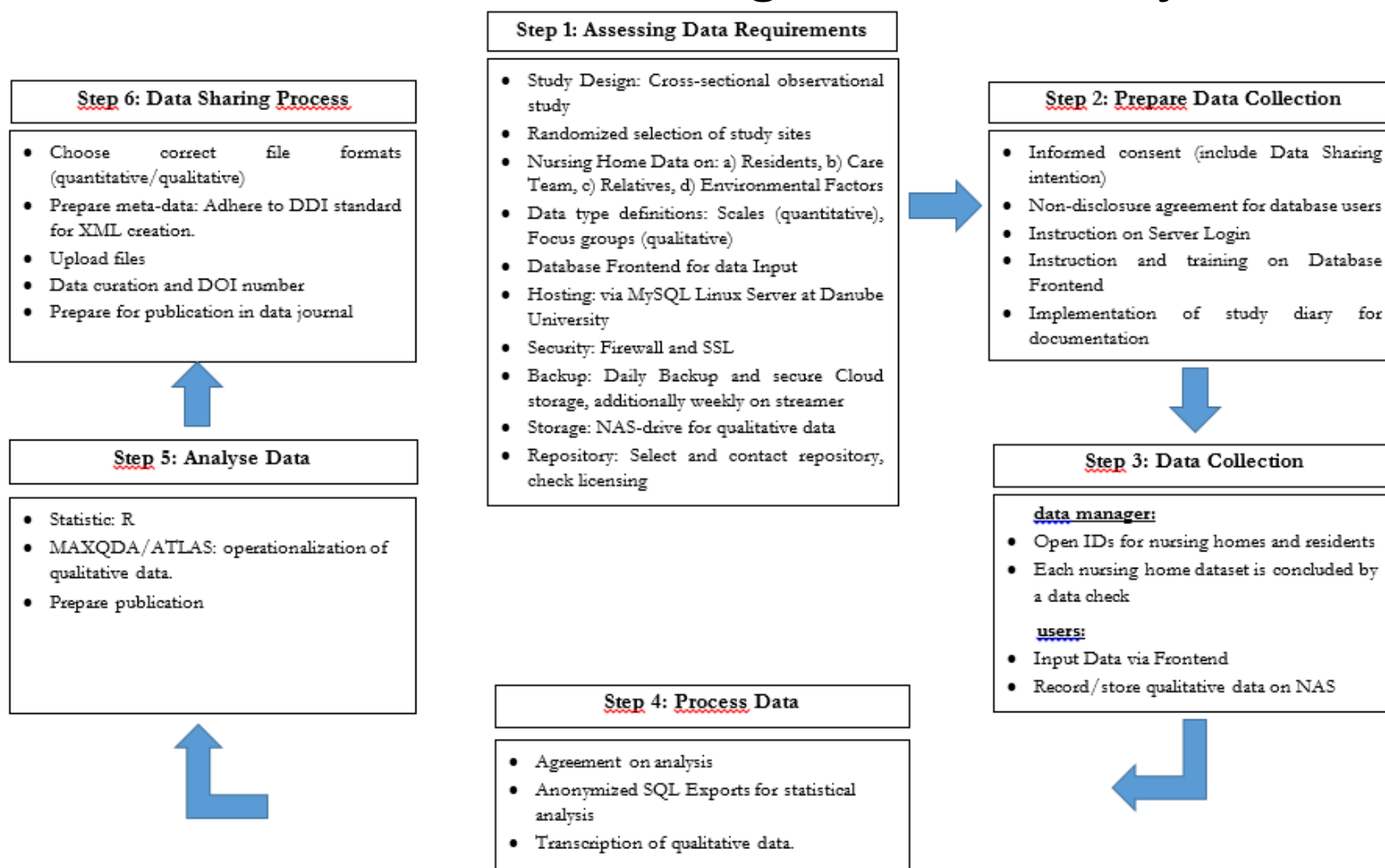
- The OECD suggested Open Data Sharing to speed up progress in dementia research
- Advancements in the Human Genome Project through Data Sharing
- Data Sharing requires a data management plan, which structures the whole research project!

Literature

- Anderson, G. and J. Oderkirk (eds.) (2015), *Dementia Research and Care: Can Big Data Help?*, OECD Publishing, Paris. DOI: <http://dx.doi.org/10.1787/9789264228429-en>
- Pereira, S., Gibbs, R., & McGuire, A. (2014). Open Access Data Sharing in Genomic Research. *Genes*, 5(3), 739–747. <http://doi.org/10.3390/genes5030739>



The data management plan of The Austrian-Czech Long Term Care Project



Project Website:

<http://www.donau-uni.ac.at/demdata>

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For Discussion in the think tank

- jointly identifying and defining research questions to address
- jointly established measuring instruments (test instruments, indicators, guidelines);
- benchmarking, i.e. comparison of EU countries' performance and the exchange of best practices
- Commonly implement projects of best practice



Thank you!

