Mobile Health: Towards Cross Study Clinical Research in Parkinson's Disease

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Outline

• Introduction to LCSB and NCER-PD project
• NCER-PD platform and “Mobile” involvement
• Using CDISC to support NCER-PD Data management
• Benefits and challenges
An interdisciplinary research centre aims to understand the mechanisms of complex biological systems and disease processes and to enable new ways to cure and prevent human diseases.
Overview: Bioinformatics Core Facility @ LCSB

Data Integration

Data Analysis Pipelines

Service

Network Analysis

Research/R3

Visualisation

Outreach

Text-mining

Clinical & Translational IT

LCSB BioCore

UNIVERSITÉ DU LUXEMBOURG
National Centre for Excellence (NCER) in Parkinson’s Research

Improve **health** of the **elderly** Luxembourgish population, focused on Parkinson’s disease (**PD**: HELP-PD cohort)

- Early Diagnosis and Stratification of PD
- Build national PD registry

- Trans-institutional **collaborative** research centre
- Solving a **well-defined** and **relevant** socio-economic question
- **Long-term** funding commitment (8-12 years)

www.parkinson.lu
NCER-PD Cohorts

(HELP-PD)

Prospective recruitment over 4 years

Longitudinal follow-up

Clinical data

Motor
Cognition
Neurosensory
Psychiatric
Sleep
Autonomic
Quality of Life
Environment

800 patients with typical and atypical PS

800 Control subjects

Biosampling

Blood: DNA, RNA

Urine
Saliva
Nasal Washes
Stool
CSF
Skin biopsies
Colonbiopsy

PARKINSON'S PROGRESSION MARKERS IN TIA TIVE

Play a Part in Parkinson's Research

PARKINSON National Centre of Excellence in Research

Kassel
NCER-PD Data and Computation Platform
"Mobile" involvement in NCER-PD

Mobile EDC

Patient Involvement

**Ongoing Projects: mPower App**

**mPower**


**16 Participants**

Just imagine what we could achieve if we start working together – as equals with different but complementary areas of expertise!

Smart Shoe
Why do we need “Mobile” in NCER-PD

Flying team

Offline EDC when internet is unavailable

Measure walking pattern & predict “freezing”
Why do we need “Mobile” in NCER-PD

HELP-PD Technology for Direct Participation of Patients

To manage her Parkinson’s disease, Sara Riggare spends 1 hour in neurological healthcare and 8,765 hours in selfcare per year.

‘It is also during my 8,765 hours of selfcare that I can observe the effects of my treatment (...)’

‘(...) and what if I could register my observations in a systematic way and bring to my next neurologists’ visit?’

Sara Riggare, 2014

http://www.riggare.se/1-vs-8765

Patient Involvement
NCER-PD Challenges of Data Management

Data integration among different systems

Cross study comparison

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
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<tbody>
<tr>
<td>Non verifiziertes Gefühl, ca. vor 3 Jahren 1x</td>
<td>But even voice heard, about 3 years ago 1x touch sen</td>
</tr>
<tr>
<td>Berührungsempfindung (Schultertippen)1x</td>
<td></td>
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<tr>
<td>Abitur</td>
<td>High School</td>
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<tr>
<td>Albträume und Halluzinationen</td>
<td>Nightmares and hallucinations</td>
</tr>
<tr>
<td>Allopurinol</td>
<td>Allopurinol</td>
</tr>
<tr>
<td>Als ob die Katze am Fenster entlangläuft</td>
<td>As if the cat running along the window</td>
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<tr>
<td>Amalgam</td>
<td>Amalgam</td>
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<tr>
<td>Ansantadin</td>
<td>Ansantadin</td>
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<tr>
<td>Amitriptylin (Saroten)</td>
<td>Amitriptyline (Elavil)</td>
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<td>Amoxicillin</td>
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<td>Amp,</td>
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<tr>
<td>Ananas</td>
<td>Pineapple</td>
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<td>Ankunft 2011</td>
<td>In early 2011</td>
</tr>
<tr>
<td>Angstzustände, Alpträume, Aggressivität</td>
<td>Anxiety, nightmares, aggressiveness</td>
</tr>
<tr>
<td>Anta</td>
<td>Anti</td>
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<tr>
<td>Anlegung eines ventrikuloperitonealen Shunts mit verstellbarem Ventil</td>
<td>Conditioning a ventriculoperitoneal shunt with adjust</td>
</tr>
<tr>
<td>Anrufe angenommen, aber nicht selbst angerufen</td>
<td>Accepted calls, but not even phoned</td>
</tr>
<tr>
<td>Antidepressivum</td>
<td>Antidepressant</td>
</tr>
<tr>
<td>Antidepressivum, kaum eingenommen</td>
<td>Antidepressant hardly takes</td>
</tr>
</tbody>
</table>
Using CDISC to support data management in NCER-PD
Using CDISC to support FAIRness in NCER-PD
NCER-PD CRF & EDC

Multilingual Support
Patient Involvement

90 Forms and 1 Survey
3146 Fields

Multi-Centres (multi-standards)
Ontologies
Applying CDISC in NCER-PD: Annotation eCRF in REDCap

- The new “Field Annotation” field in REDCap enables administrators to map variables to various standards
- However annotation is time consuming
- We developed a GUI tool “ATR” (Annotation Tool for REDCap) to facilitate CDISC annotation in REDCap

www.project-atr.org
Applying CDISC in NCER-PD: Annotation eCRF in REDCap

The domain selection window

Users can map specific CDISC domains to their REDCap variables
Applying CDISC in NCER-PD: Annotation eCRF in REDCap

Main Editing Window

Users enter CDISC (SDTM) annotations and export annotation to REDCap
Populate annotation back to REDCap
Benefits of using CDISC in NCER-PD

• Data integration using standardised data model
• Standardised & Re-useable data collection instruments
  • SysMedPD (EU Project) with partners in London and Lübeck
  • PSA project with a number of partners in Germany integrated in LuxPARK
  • Duesseldorf collaboration with Philip Albrecht (planned)
  • MSA-Promesa from Munich (planned)
  • Oxford collaboration with Michele Hu (planned)
• Reduce post-collection curation
• Facilitate cross-study comparison/re-use of data
Challenges of using CDISC in NCER-PD

• Time consuming for annotation of CRF
• Not yet possible to automatic generate SDTM format from REDCap (working on plugins)
• Data collection instruments not completely covered by SDTM and PD Therapeutic Area

Only 20 out of ~90 are covered. Some of the missing questionnaires, which are widely used:

1) MoCA (Montreal Cognitive Assessment Test)
2) PDQ39 (Parkinson’s disease quality of life questionnaire)
3) Starkstein Apathy Scale
4) SCOPA-AUT (SCales for Outcomes in PAarkinsons disease)
5) PDSS (Parkinson’s Disease Sleep Scale)
6) BDI (Beck Depression Inventory)
NCER-PD: Ongoing Efforts - Ada
Visual Analytics: SmartR

- Dynamic Heatmap
- Volcanoplots
- Correlation Analysis
- Boxplots
- Linegraph
- Variant Map

Coming Soon/in beta: Survival Analysis, Log-Regression, ROC Plots, several others...

etriks1.uni.lu
Parkinson’s Disease (PD) Map
http://minerva.uni.lu
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http://minerva.uni.lu
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