

GEOPD Minimal Dataset

Kirsten Roomp

Bioinformatics Core

Luxembourg Centre for Systems Biomedicine

Background on REDCap™

Research Electronic Data Capture

- **2004:** Initially developed and deployed at Vanderbilt U. Medical Center by Paul Harris
- **2006:** REDCap system was offered to other institutions and a consortium of domestic and international users was formed
- **Today (12/2018):**
 - >3200 active institutional partners in 128 countries
 - >600k projects with over >800k users

Beth Israel Deaconess Medical Center
Duke University
Kent State University
Northwestern University
Oregon Health & Science University
Stanford Univ. School of Medicine
University of Colorado-Denver
University of Pennsylvania
UW Seattle

Cornell University
The Cleveland Clinic
Columbia University
Mayo Clinic
Partners HealthCare (2009)
Stony Brook University
University of New Mexico
University of Minnesota
Vanderbilt University

Children's Hospital Boston
Case Western Reserve University
University of Cincinnati/Cincinnati Children's Hospital
Medical University of South Carolina
Singapore Clinical Research Institute
The Methodist Hospital Research Institute
The University of Kansas Medical Center
University of Massachusetts Medical School
Yale University

Background on REDCap™ (2)

Research Electronic Data Capture

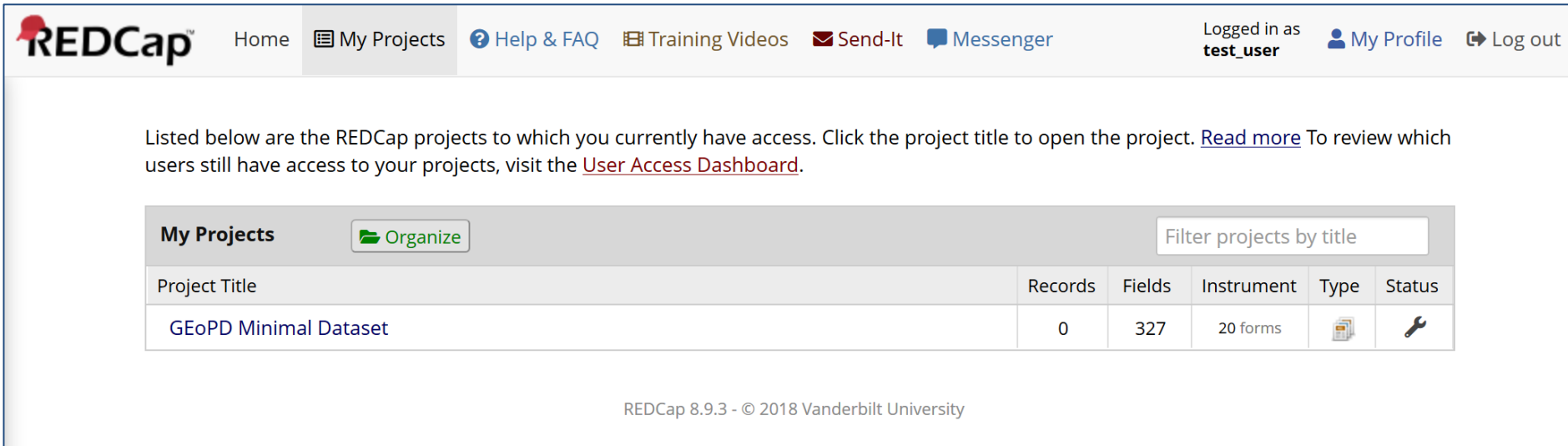
- Free for not-for-profit partners (license agreement with Vanderbilt U)
- REDCap Cloud for commercial entities
- Web-based application
- Simplified methodology for building projects
- Feature rich

Technical Details

- For **end-users**, most web-browsers are compatible:
 - IE, Firefox, Safari, Chrome, Opera
- **Server side:**
 1. Web server with PHP (e.g. Apache or IIS) that has the PEAR package installed
 2. MySQL database server
 3. Email server

Access to Project



<https://geopd-redcap.uni.lu/redcap/>



The screenshot shows the REDCap web interface. At the top, there is a navigation bar with the REDCap logo and several menu items: Home, My Projects (highlighted), Help & FAQ, Training Videos, Send-It, and Messenger. On the right side of the navigation bar, it indicates the user is logged in as 'test_user' and provides links for 'My Profile' and 'Log out'.

Below the navigation bar, a message states: "Listed below are the REDCap projects to which you currently have access. Click the project title to open the project. [Read more](#) To review which users still have access to your projects, visit the [User Access Dashboard](#)."

The main content area features a "My Projects" section with an "Organize" button and a search box labeled "Filter projects by title". Below this is a table listing the projects:

Project Title	Records	Fields	Instrument	Type	Status
GEOPD Minimal Dataset	0	327	20 forms		

At the bottom of the interface, the text "REDCap 8.9.3 - © 2018 Vanderbilt University" is displayed.





































Project Design

Data Collection Instrument	Visit 1 (1)	Visit 2 (2)
Demographics	✓	
Controls	✓	
Visit Date	✓	✓
Anthropometry	✓	✓
Exposures/Injuries	✓	✓
DNA	✓	✓
Medications	✓	✓
Medical And Family History	✓	
HPI (History Of Present Illness): Initial	✓	
HPI (History Of Present Illness): Current	✓	✓
HPI (History Of Present Illness): Brain Imaging and PD Surgery	✓	✓
Bower Criteria	✓	✓
Cognitive Screening	✓	✓
Depression Screening	✓	✓
Smell Screening	✓	✓
UPDRS - Part II: Activities Of Daily Living	✓	✓
UPDRS - Part III: Motor Function	✓	✓
MDS-UPDRS - Part II: Motor Aspects of Experiences of Daily Living (M_EDL)	✓	✓
MDS-UPDRS - Part III: Motor Examination	✓	✓
H&Y (Hoehn and Yahr)	✓	✓









Patient Data

Record ID **Test_Patient_1**

Luxembourg, UL

Data Collection Instrument	Visit 1	Visit 2
Demographics		
Controls		
Visit Date		
Anthropometry		
Exposures/Injuries		
DNA		
Medications	 +	
Medical And Family History		
HPI (History Of Present Illness): Initial		
HPI (History Of Present Illness): Current		
HPI (History Of Present Illness): Brain Imaging and PD Surgery		
Bower Criteria		
Cognitive Screening		
Depression Screening		
Smell Screening		
UPDRS - Part II: Activities Of Daily Living		
UPDRS - Part III: Motor Function		
MDS-UPDRS - Part II: Motor Aspects of Experiences of Daily Living (M_EDL)		
MDS-UPDRS - Part III: Motor Examination		
H&Y (Hoehn and Yahr)		




Legend for status icons:

-  Incomplete
-  Unverified
-  Complete
-  Many statuses (mixed)
-  Incomplete (no data saved) ?
-  Partial Survey Response
-  Completed Survey Response
-  Many statuses (all same)

Repeating Instruments

Medications

Visit 1

1		Levodopa 500 MG Oral Tablet [Larodopa]
2		Risperidone 0.25 MG Disintegrating Oral Tablet
3		coenzyme Q10 30 MG/ML Oral Solution

+ Add new

Demographics

Demographics

Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID Test_Patient_1
To rename the record, see the record action drop-down at top of the [Record Home Page](#).

PI ID
* must provide value

Study ID
study specific; e.g. EH#


Date of birth
* must provide value Y-M-D


Sex
* must provide value M F reset

Race

Patient Handedness	Retired
Years of education that were completed	Retired? <input checked="" type="radio"/> Yes <input type="radio"/> No reset
Work	Retired which year <input type="text" value="1995"/>
Currently working?	Reason stopped working <input checked="" type="radio"/> PD related <input type="radio"/> not PD related reset
Works/worked in	Death
Longest lifetime occupation	Patient died? <input type="radio"/> Yes <input checked="" type="radio"/> No reset
	Patient no longer in study
	Why is patient no longer in study? <input type="radio"/> Dropped out <input type="radio"/> Later excluded from study <input type="radio"/> Lost to followup reset

Controls

 **Controls**


 Editing existing Record ID **Test_Patient_1**


Event Name: **Visit 1**

Record ID	Test_Patient_1
Control?	<input type="radio"/> Yes <input checked="" type="radio"/> No

reset

Visit Date


 **Visit Date**

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID Test_Patient_1


Assessment date
** must provide value*


 Y-M-D

Age at assessment

Years

Anthropometry

 **Anthropometry**

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID	Test_Patient_1
Weight	<input type="text" value="80"/> kg
Height	<input type="text" value="175"/> cm
Unable to measure height	<input type="radio"/> Yes <input checked="" type="radio"/> No reset
BMI	<input type="text" value="26.12"/> View equation Calculated field (kg/m ²)

Exposures/Injuries

Exposures/Injuries

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID

Test_Patient_1

Exposures/Injuries

Over your lifetime, have you ever had a **JOB** in which you mixed, applied, or were exposed in some other way to any type of **pesticide**, including herbicides (kill weeds), fungicides (kill fungus/mold), insecticides (kill insects), rodenticides (kill rats/mice), or fumigants (gas used to kill fungus/mold or insects)?

No

During your lifetime, did you or someone else ever use **chemicals** to kill insects, other pests, plants, weeds, mold, or mildew in or around any house or apartment where you lived? Include chemicals used in the house, on the lawn or garden, or on pets.

Yes

In your lifetime, have you **smoked** 100 or more cigarettes (5 packs)?

No


In your lifetime, have you ever regularly drunk **caffeinated coffee**, that is, at least once per week for 6 months or longer?


Yes

Have you ever had a **head injury** or concussion? These may have occurred during sporting activities, from falls, violence, car accidents, or other accidents. Include injuries from both childhood and adulthood.

Possibly

DNA

 **DNA**

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID	Test_Patient_1
DNA Storage?	<input type="radio"/> Yes <input type="radio"/> No reset
Year Stored	<input type="text" value="2016"/>
DNA Lab Director's Last Name	<input type="text" value="Tester"/>
DNA Lab Director's First Name	<input type="text" value="Testie"/>
Candidate Gene Genotyping	<input type="radio"/> Yes <input type="radio"/> No reset
Gene symbol(s)	<input type="checkbox"/> ATP13A2 <input checked="" type="checkbox"/> DJ1 <input type="checkbox"/> DNAJC6 <input type="checkbox"/> FBXO7 <input type="checkbox"/> LRRK2 <input type="checkbox"/> Parkin <input type="checkbox"/> PINK1 <input type="checkbox"/> SLC30A10 <input type="checkbox"/> SNCA <input type="checkbox"/> SYNJ1 <input type="checkbox"/> TAF1 <input type="checkbox"/> VPS35
Whole Genome Genotyping	<input type="radio"/> Yes <input type="radio"/> No reset
Whole Exome Sequencing	<input type="radio"/> Yes <input checked="" type="radio"/> No reset
Whole Genome Sequencing	<input type="radio"/> Yes <input checked="" type="radio"/> No reset

Medications

Medications

Current instance: 1 - Levodopa 500 MG Oral Tablet [Larodopa]

Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID	Test_Patient_1
Add all Parkinson's medications (other medications are optional)	
Medication name	<input type="text" value="Levodopa 500 MG Ora..."/> <input type="text" value="Levodopa 500 I"/>
Medication dose	<input type="text" value="500"/> <small>For levodopa containing drugs, give levodopa dose only</small>
Medication unit	<input type="radio"/> microg <input checked="" type="radio"/> mg <input type="radio"/> g <input type="radio"/> mL <input type="radio"/> IU reset
Dosing interval	<input type="text" value="Once Daily - od"/> <input type="button" value="v"/>
Route of administration	<input type="text" value="Oral"/> <input type="button" value="v"/>
Start date	<input type="text" value="1990-01-01"/> <input type="button" value="31"/> <input type="button" value="Today"/> Y-M-D
Last dose	<input type="text" value="2018-12-11 10:47"/> <input type="button" value="31"/> <input type="button" value="Now"/> Y-M-D H:M

Medical And Family History

Medical And Family History

Editing

Event N

Record ID

Medical hi

Medical Hi

Medical Hi

Medical Hi

Medical Hi

Medical History - Cardiovascular

- None
- Cardiovascular disease
- Hypertension
- Coronary artery disease

Medical History - Autoimmune disease

- None
- Rheumatoid Arthritis
- Systemic Lupus Erythematosus

Family history

Family member diagnosed with Parkinsons

Yes No

reset

Medical History -

- Mother
- Father
- Brother(s)
- Sister(s)
- Grandmother(s)
- Grandfathers(s)
- Son(s)
- Daughters(s)
- Other

Who?

Other medical his

Family member diagnosed with tremor

Yes No

reset

Surgical History

Family member diagnosed with dementia

Yes No

reset

Other surgical history


Sleep Apnea

Expand



Bower Criteria

Bower Criteria

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID Test_Patient_1

First diagnostic level

Parkinsonism Yes No [reset](#)

Essential Tremor (all three of the following: postural tremor in isolation, gradual onset, no other cause, of at least five years duration) Yes No Don't know [reset](#)

Year of onset

Presence (or history) of 2 of 4 cardinal signs

Rigidity Yes No Don't know [reset](#)

Bradykinesia Yes No Don't know [reset](#)

Resting Tremor Yes No Don't know [reset](#)

Impaired Postural Reflexes Yes No Don't know [reset](#)

Differential diagnosis checklist

Failed levodopa / dopaminagonist trial (>1000 mg daily) Yes No [reset](#)

Rapid disease progression to H&Y stage 5 in < 5 years Yes No [reset](#)

Cognitive Screening

Cognitive Screening

✔ Record ID **Test_Patient_1** successfully edited

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID

Test_Patient_1

Select the test

- MoCA (recommended)
 MMSE
 STMS

[reset](#)

MoCA (Montreal Cognitive Assessment Test)

Reason test not taken


- Test postponed
 Test no longer possible within study's defined time period
 Subject refused
 Test data lost
 Patient not capable of performing test
 Assessment added later in the study
 Not applicable
 Other


Total score for MOCA

Interpretation

Screening showing possible cognitive impairment

Depression Screening


 **Depression Screening**


 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID	Test_Patient_1
Select the test	<input checked="" type="radio"/> BDI <input type="radio"/> MADRS <input type="radio"/> GDS (short version) reset
BDI (Beck Depression Inventory)	
Reason test not taken	<input type="checkbox"/> Test postponed <input type="checkbox"/> Test no longer possible within study's defined time period <input type="checkbox"/> Subject refused <input type="radio"/> <input type="checkbox"/> Test data lost <input type="checkbox"/> Patient not capable of performing test <input type="checkbox"/> Assessment added later in the study <input type="checkbox"/> Not applicable <input type="checkbox"/> Other
Total score for BDI	<input type="text" value="9"/>
Interpretation	
Screening negative for depression	

Smell Screening

 **Smell Screening**

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID Test_Patient_1

Select the test

Sniffin Sticks Identification Test
 B-SIT

[reset](#)

Sniffin' Sticks Identification Test (SSIT)

Reason test not taken

Test postponed
 Test no longer possible within study's defined time period
 Subject refused
 Test data lost
 Patient not capable of performing test
 Assessment added later in the study
 Not applicable
 Other

Total score for Sniffin' Sticks

UPDRS/MDS-UPDRS

UPDRS - Part II: Activities Of Daily Living	<input type="radio"/>
UPDRS - Part III: Motor Function	<input type="radio"/>
MDS-UPDRS - Part II: Motor Aspects of Experiences of Daily Living (M_EDL)	<input checked="" type="radio"/>
MDS-UPDRS - Part III: Motor Examination	<input checked="" type="radio"/>

UPDRS/MDS-UPDRS

MDS-UPDRS - Part II: Motor Aspects of Experiences of Daily Living (M_EDL)

 Record ID **Test_Patient_1** successfully edited

 Editing existing Record ID **Test_Patient_1**

Event Name: **Visit 1**

Record ID

Test_Patient_1

Reason test not taken

- Test postponed
- Test no longer possible within study's defined time period
- Subject refused
- Test data lost
- Patient not capable of performing test
- Assessment added later in the study
- Not applicable
- Other

Do you wish to document the complete test, or only the final score?

Document complete test 

2.1 Speech

- 0: Normal: Not at all (no problems).
- 1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.
- 2: Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday.
- 3: Moderate: My speech is unclear enough that








Security, Privacy Features

- All transactions are fully encrypted
- Logins use secure authentication
- 2 factor authentication possible
- Identifying data can be flagged in the interface
- Data protection can be applied to those that have restricted access to identifiers

Data Export

- Data can be exported to statistical packages (SPSS, SAS, R or Excel)
- Data access can be granted or restricted when exporting for analysis
- Exports can include identified or de-identified data only on a per user basis

Choose export format

<input checked="" type="radio"/>		CSV / Microsoft Excel (raw data)
<input type="radio"/>		CSV / Microsoft Excel (labels)
<input type="radio"/>		SPSS Statistical Software
<input type="radio"/>		SAS Statistical Software
<input type="radio"/>		R Statistical Software
<input type="radio"/>		Stata Statistical Software
<input type="radio"/>		CDISC ODM (XML)



Log In

Welcome to the GEO-PD REDCap Server of Luxembourg Centre for Systems Biomedicine (LCSB)

Please log in with your user name and password. If you are having trouble logging in, please contact REDCap Administrator@LCSB.

Username:

Password:

Log In

[Forgot your password?](#)

Welcome to REDCap!

REDCap is a mature, secure web application for building and managing online surveys and databases. Using REDCap's stream-lined process for rapidly developing projects, you may create and design projects using 1) the online method from the REDCap website, or 2) the offline method by downloading the REDCap software to your computer. Both methods can be later used to build projects. Projects using either method (or both the two) can be built using these methods.

REDCap provides automated export procedures for seamless data downloads to Excel and common statistical packages (SPSS, SAS, Stata, R), as well as a built-in project calendar, a scheduling module, ad hoc reporting tools, and advanced

REDCap Features

Build online surveys and databases quickly

Build online surveys and databases quickly using the REDCap website. Projects can be built from the REDCap website in less than one day.

Fast and flexible - Conception to production-level survey/database in less than one day.

Export data to common data analysis packages - Export your data to Microsoft Excel, PDF, SAS, Stata, R, or SPSS for analysis.

<https://geopd-redcap.uni.lu/redcap/>