

The Multiple Possibilities of Using REDCap in Pediatric Rheumatology

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Overview



- Introduction & Background
- REDCap in Research
 - PedVas
 - CAPRI Registry
 - OPT-JIA
- REDCap for clinical care

Introduction & Background

- **Introduction:**

- Research Coordinator, Division of Rheumatology at BCCH
- UBC graduate, Bachelors of Science

- **Background:**

- Introduced to REDCap in 2012
 - 2 CIHR funded grants
- 25 studies/projects have used REDCap as their database

REDCap in Research



CIHR IRSC

 Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

- **Pediatric Vasculitis Initiative (PedVas)**

- Funded by the Canadian Institute of Health Research (CIHR) in 2012
- **Goal:** to improve the long-term outcome for children with Chronic Primary Vasculitis by combining sophisticated genomic and bio-informatic technologies with clinical data to improve diagnosis and enable optimal treatments

REDCap in Research



- **International study**
 - 64 participating sites across the globe
 - 560 patients recruited since 2012
- **Using REDCap as the study database:**
 - Clinical data form completed by physicians
 - Tracking biological samples collected from around the world

PedVas Network as of September 2017



REDCap in Research



- Provides a disease activity score report for each patient

Count Nervous New/Worse	<input type="text" value="0"/>	View equation Disclaimer
Total Nervous Persistent	<input type="text" value="0"/>	View equation Disclaimer
Total Nervous New/Worse	<input type="text" value="0"/>	View equation Disclaimer
DATA LOCKING (for data managers ONLY)		
to be answered by DATA MANAGERS ONLY	<input type="radio"/> Locked	
Is "PVAS Scoring and Report" form locked?	<input type="radio"/> Unlocked	reset
for data managers only		
Click here to PRINT PVAS FORM		
Form Status		
Complete?	<input type="text" value="Incomplete"/>	
Lock this record for this form?	<input type="checkbox"/> Lock	
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.		
Save Record		

Study Id: 1	Visit Name: Time-of-diagnosis	Visit Date: 2016-10-20
Paediatric Vasculitis Activity Score 2008		
<p>An item will be marked as active if abnormality due to active vasculitis is newly present or worse over the last 4 weeks or persists for less than 3 months. If ALL items are persistent and represent smouldering/low grade/grumbling disease, and there are no new/worse features, the box at the bottom right corner will be checked off. At the very first assessment all active items are considered as active/worse. If there are no abnormalities in a system, the "None" column will be marked with a circle. For items present longer than 3 months refer to the Vasculitis Damage Index to score damage. Major items marked with an asterisk *</p>		
1. General	none	active
Myalgia	<input type="radio"/>	<input type="radio"/>
Arthralgia or arthritis	<input type="radio"/>	<input type="radio"/>
Fever ≥ 38 degrees C	<input type="radio"/>	<input checked="" type="radio"/>
Weight loss $> 5\%$ body weight	<input type="radio"/>	<input type="radio"/>
2. CUTANEOUS		
Polymorphous exanthema	<input type="radio"/>	<input type="radio"/>
Livedo	<input type="radio"/>	<input checked="" type="radio"/>
Panniculitis	<input type="radio"/>	<input type="radio"/>
Purpura	<input type="radio"/>	<input checked="" type="radio"/>
Skin nodules	<input type="radio"/>	<input type="radio"/>
Infarct (nail edge lesion, splinter haemorrhage)	<input type="radio"/>	<input type="radio"/>
Ulcer (full-thickness necrosis)	<input type="radio"/>	<input type="radio"/>
*Gangrene (extensive necrosis)	<input type="radio"/>	<input type="radio"/>
Other skin vasculitis (specify below)	<input type="radio"/>	<input checked="" type="radio"/>
3. MUCOUS MEMBRANES/EYES		
Mouth ulcers/granulomata	<input type="radio"/>	<input type="radio"/>
Genital ulcers	<input type="radio"/>	<input type="radio"/>
Adnexal inflammation	<input type="radio"/>	<input type="radio"/>
Significant proptosis	<input type="radio"/>	<input type="radio"/>
*Red eye (Epi)scleritis	<input type="radio"/>	<input checked="" type="radio"/>
Red eye conjunctivitis/blepharitis/keratitis	<input type="radio"/>	<input type="radio"/>
Uveitis	<input type="radio"/>	<input type="radio"/>
Blurred vision	<input type="radio"/>	<input type="radio"/>
Sudden visual loss	<input type="radio"/>	<input type="radio"/>
*Retinal vasculitis/retinal vessel thrombosis/retinal exudates/haemorrhages	<input type="radio"/>	<input type="radio"/>
4. ENT		
Nasal discharge/crusts/ulcers/granuloma	<input type="radio"/>	<input type="radio"/>
Paranasal sinus involvement	<input type="radio"/>	<input type="radio"/>
Subglottic stenosis/hoarseness/stridor	<input type="radio"/>	<input type="radio"/>
Conductive hearing loss	<input type="radio"/>	<input type="radio"/>
*Sensorineural hearing loss	<input type="radio"/>	<input type="radio"/>
5. CHEST		
Wheeze or expiratory dyspnea	<input type="radio"/>	<input type="radio"/>
*Endobronchial/endotracheal involvement	<input type="radio"/>	<input type="radio"/>
Nodules or cavities	<input type="radio"/>	<input type="radio"/>
Pleural effusion/pleurisy	<input type="radio"/>	<input type="radio"/>
Infiltrate	<input type="radio"/>	<input type="radio"/>
*Massive haemoptysis/Alveolar haemorrhage	<input type="radio"/>	<input type="radio"/>
*Respiratory failure	<input type="radio"/>	<input type="radio"/>
6. Cardiovascular	none	active
Loss of pulses	<input type="radio"/>	<input type="radio"/>
Bruits over accessible arteries	<input type="radio"/>	<input type="radio"/>
Blood pressure discrepancy	<input type="radio"/>	<input type="radio"/>
Claudication of extremities	<input type="radio"/>	<input type="radio"/>
Ischaemic cardiac pain	<input type="radio"/>	<input type="radio"/>
Cardiomyopathy	<input type="radio"/>	<input type="radio"/>
Congestive cardiac failure	<input type="radio"/>	<input type="radio"/>
Valvular heart disease	<input type="radio"/>	<input type="radio"/>
Pericarditis	<input type="radio"/>	<input type="radio"/>
7. ABDOMINAL		
Abdominal pain	<input type="radio"/>	<input type="radio"/>
Peritonitis	<input type="radio"/>	<input type="radio"/>
Blood in stools or bloody diarrhea	<input type="radio"/>	<input type="radio"/>
Bowel ischaemia	<input type="radio"/>	<input type="radio"/>
8. RENAL		
Hypertension >95 th centile (for height)	<input type="radio"/>	<input type="radio"/>
Proteinuria >0.3 g/24h >20 mmol/mg creatinine	<input type="radio"/>	<input type="radio"/>
*Haematuria $\geq 2+$ or 5 rbc/hpf or red cell casts	<input type="radio"/>	<input type="radio"/>
GFR 50-80ml/min/1.73 m ²	<input type="radio"/>	<input type="radio"/>
GFR 15-49 ml/min/1.73 m ²	<input type="radio"/>	<input type="radio"/>
GFR < 15 ml/min/1.73 m ²	<input type="radio"/>	<input type="radio"/>
*Rise in creatinine $> 10\%$ or Creatinine clearance (GFR) fall $> 25\%$	<input type="radio"/>	<input type="radio"/>
9. NERVOUS SYSTEM		
Headache	<input type="radio"/>	<input type="radio"/>
*Meningitis/encephalitis	<input type="radio"/>	<input type="radio"/>
Organic confusion/cognitive dysfunction	<input type="radio"/>	<input type="radio"/>
Seizures (not hypertensive)	<input type="radio"/>	<input type="radio"/>
*Stroke	<input type="radio"/>	<input type="radio"/>
*Cord lesion	<input type="radio"/>	<input type="radio"/>
*Cranial nerve palsy	<input type="radio"/>	<input type="radio"/>
*Sensory peripheral neuropathy	<input type="radio"/>	<input type="radio"/>
*Motor mononeuritis multiplex	<input type="radio"/>	<input type="radio"/>
NO NEW/WORSE DISEASE <input checked="" type="checkbox"/>		
Check mark indicates there is no new/worse abnormality present in ANY of the systems above and active items represent low grade grumbling disease		
PVAS SCORE: "		

REDCap in Research

CAPRI Registry



- **Canadian Alliance of Pediatric Rheumatology Investigators Registry (CAPRI Registry)**
 - Funded by The Arthritis Society in 2016
 - **Goal:** to collect information on disease course, outcomes and medication adverse events in Canadian children with Juvenile Idiopathic Arthritis



REDCap in Research

CAPRI Registry



- **National Registry**
 - 13 participating centres across Canada
 - **540** patients enrolled since 2017
- Using REDCap as the registry database
 - Clinical data from physicians
 - Patient and parent questionnaires
- Plugins created to allow simple access to physician forms:
 - Same username and password
 - Forms opened in survey mode

REDCap in Research CAPRI Registry

A screenshot of a web browser showing the REDCap CAPRI login page. The URL is <https://redcap.pediatrics.ubc.ca/capri/index.php>. The page features the REDCap logo and a "CAPRI LOG IN" section with fields for "Username" and "Password", and a "Log in" button.



A screenshot of the REDCap user dashboard. The user is logged in as "CAPRI (felice_test)" with a "Logout" button. Two main buttons are visible: "New Patient" and "Existing Patient".



A screenshot of the REDCap patient selection screen. The user is logged in as "CAPRI (felice_test)". The group is "BCCH". A dropdown menu is open, showing a list of patient IDs: 00267, 00267, 00287, 00490, 00785, 00792, 01231, 01508, 01587, and 01966. A "go back" button is visible on the left.

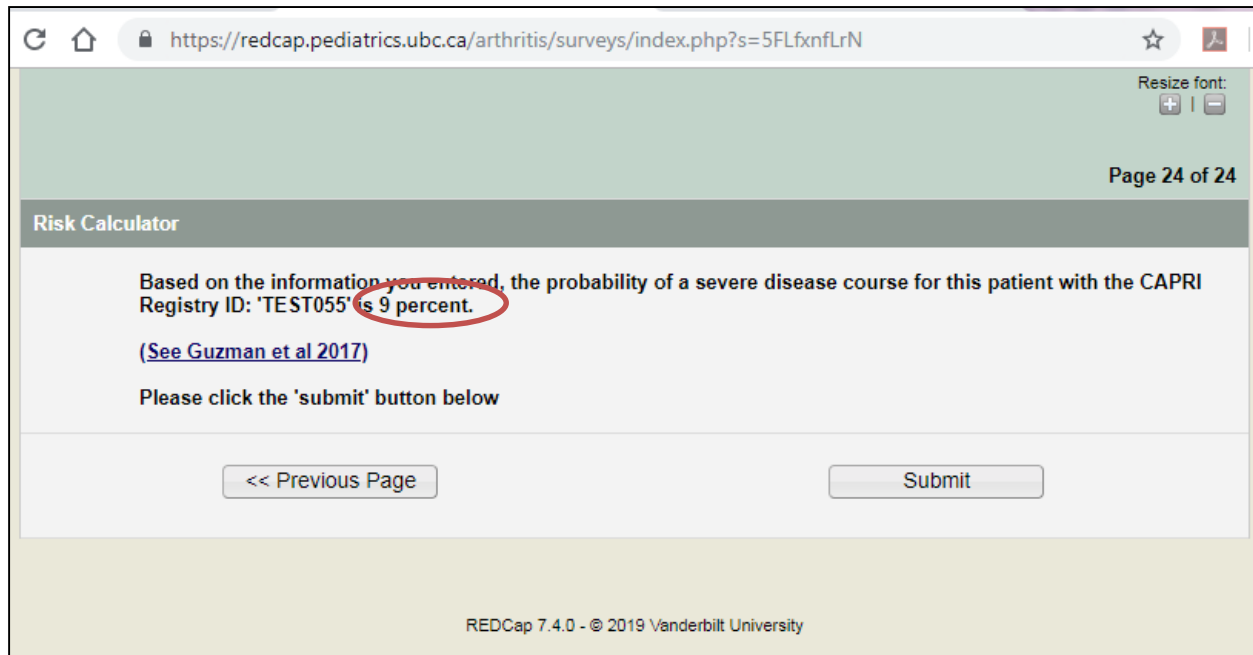
A screenshot of the REDCap CAPRI JIA Registry Enrollment form. The page is titled "CAPRI JIA Registry ENROLLMENT" and is "Page 1 of 24". The form includes several sections: "ReACCh or LEAP involvement" with two radio button questions, "Date of Visit", "MO Initials", "Date of first clinic visit", "Date of first JIA symptom", and "Date of JIA diagnosis". Each date field has a calendar icon and a "Today" button. A "Next Page >>" button is at the bottom.



REDCap in Research

CAPRI Registry

- To provide answers about the expected disease outcomes for patient and care providers



The screenshot shows a web browser window with the URL <https://redcap.pediatrics.ubc.ca/arthritis/surveys/index.php?s=5FLfxnLrN>. The page is titled "Risk Calculator" and displays the following text:

Based on the information you entered, the probability of a severe disease course for this patient with the CAPRI Registry ID: 'TEST055' is 9 percent.

(See [Guzman et al 2017](#))

Please click the 'submit' button below

Navigation buttons include "<< Previous Page" and "Submit".

Page 24 of 24

REDCap 7.4.0 - © 2019 Vanderbilt University

REDCap in Research

OPT-JIA

- **Ondansetron premedicated trial in Juvenile Idiopathic Arthritis (OPT-JIA)**
 - Funded by The Arthritis Society in 2018
 - **Goal:** Registry based, pragmatic, randomized trial to evaluate if routine premedication with ondansetron reduces methotrexate (MTX) intolerance
 - Closely linked to the CAPRI Registry



REDCap in Research

OPT-JIA

- **National study**
 - Same participating sites as the CAPRI Registry
- Patients randomized to:
 - Starting ondansetron at the same time as MTX
 - Starting ondansetron only if the patient develops MTX side effects
- Patients and Physicians will complete questionnaires at each clinic visit

REDCap in Research

OPT-JIA



- Using REDCap as the study database:
 - Clinical data
 - Patient/parent questionnaires
 - **Randomization**
 - Patients are randomized using a 1:1 ratio using the registry and block randomization by patient weight and centre

REDCap in Research

OPT-JIA

Randomization using REDCap

Event Name: Baseline
CAPRI JIA Registry ID: 48786

Inclusion Criteria

The answer to all the questions below has to be "YES" in order for the patient to be enrolled in the study

	Yes	No
Ages 4-16 years	<input checked="" type="radio"/>	<input type="radio"/>
Diagnosis of JIA as per ILAR criteria, irrespective of JIA category	<input type="radio"/>	<input type="radio"/>
Followed at a CAPRI centre in Canada	<input type="radio"/>	<input type="radio"/>
Starting methotrexate to control JIA manifestations (arthritis, uveitis, psoriasis)	<input type="radio"/>	<input type="radio"/>
Informed written consent to participate	<input type="radio"/>	<input type="radio"/>

Exclusion Criteria

The answer to all the questions below has to be "NO" in order for the patient to be enrolled in the study

	Yes	No
Previous use of methotrexate	<input type="radio"/>	<input type="radio"/>
Known allergy to ondansetron	<input type="radio"/>	<input type="radio"/>
Known congenital Long-QT syndrome	<input type="radio"/>	<input type="radio"/>
Family unable to complete questionnaires in English or French	<input type="radio"/>	<input type="radio"/>

Form Status



Known allergy to ondansetron

Known congenital Long-QT syndrome

Family unable to complete questionnaires in English or French

Randomization

Site type

- BC-Alberta
- Ontario
- Quebec
- Other sites

Weight group

- < 15 kg
- 15-30 kg
- > 30 kg

Randomize

Form Status

Complete?

Lock this record for this form?

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Lock



Randomizing CAPRI JIA Registry ID: "48786"

CAPRI JIA Registry ID: "48786" was randomized for the field "Randomize" and assigned the value "Control" (1).

Close

Already randomized

REDCap in Research

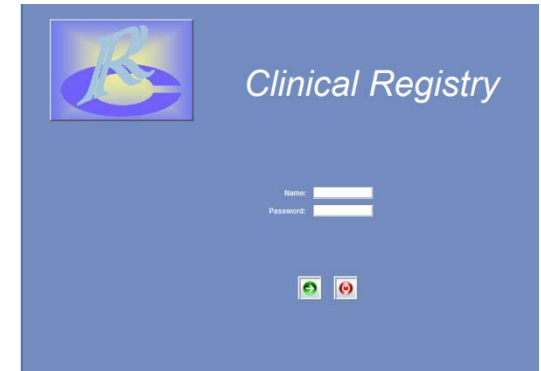
- Summary of why our division continues to use REDCap for research:
 - Capability
 - Availability
 - Flexibility



REDCap in Clinical Care

- **Pediatric Rheumatology Registry**

- Created in 2004, originally using Access
- Tracks all rheumatology patient encounters (4,000/year)
 - Diagnosis, demographics, referrals, trainee & AH involvement
 - Pre-clinic: printed forms to document encounter
 - Post-clinic: data from the forms is entered to the registry
- Managed by the administrative clinical co-ordinator
- **Limitations:**
 - Overloaded
 - Slow and technologically outdated
 - Limited customizations

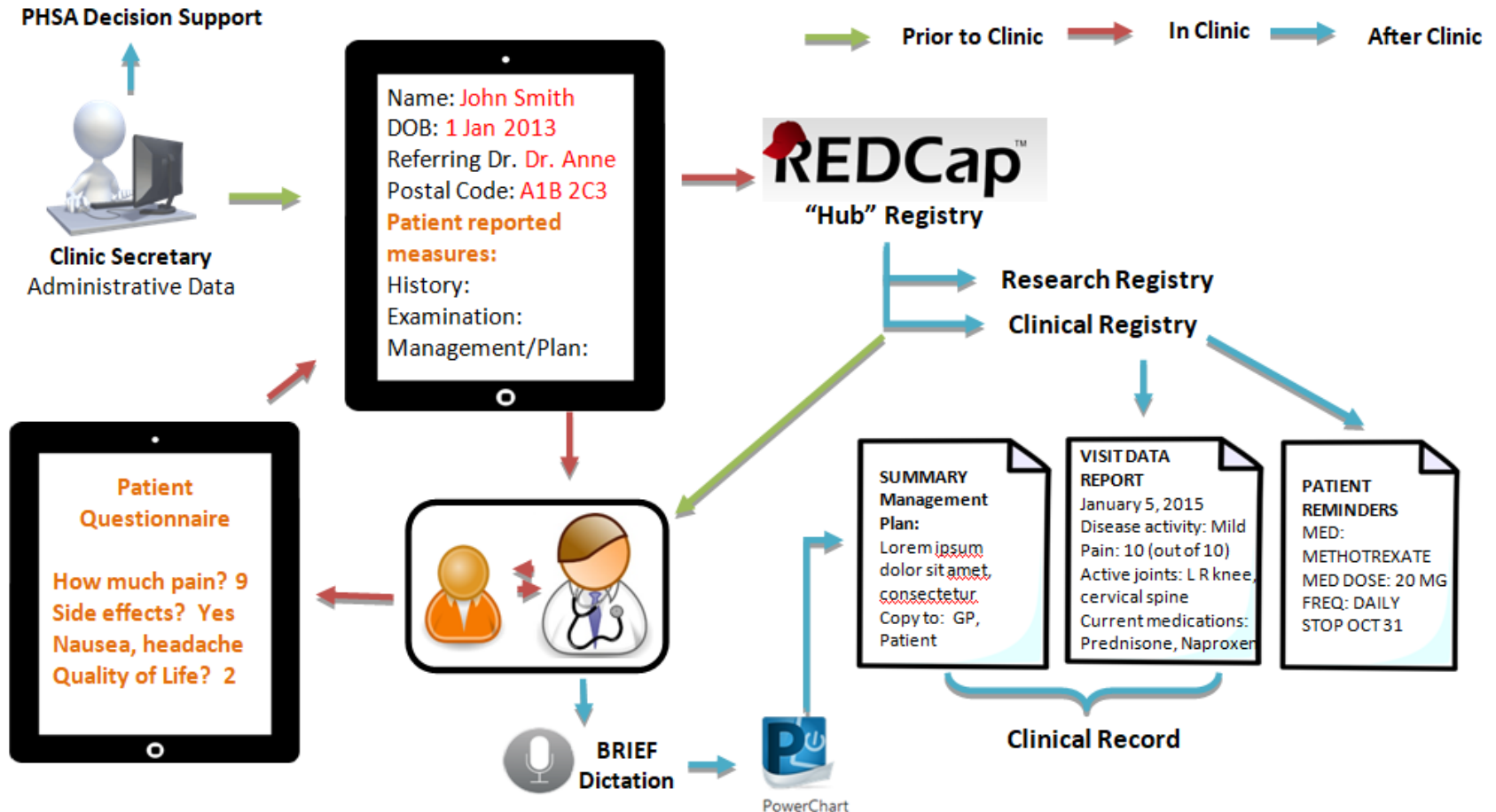


REDCap in Clinical Care

- Decision to move to a different server, Nov 2017
 - Multiple hurdles
- Rheumatology registry was migrated to REDCap, Dec 2018
 - Secure, local server at BCCHRI
 - 3 major changes to database and data collection form
 - Managed by admin coordinator
 - Changes made by research coordinator



REDCap in Clinical Care - Future



Questions

