

# Patient Registries

Shez Partovi MD

CMIO, Barrow Neurological Institute

Cofounder, Emerge.MD Inc.

# Registry experience

- Multiple Sclerosis Registry
- Parkinson's Registry
- Inflammatory Bowel Disease Registry
- Caregiver Registry
- Back Pain Registry
- Provider Registry
- Chronic Regional Pain Syndrome
- Tissue Bank Registry
- Diabetes Registry/Microsoft HealthVault

# Registry experience

- Largest registry 45,000 participants
- Longest registry 7 years
- Total of 30 online patient registries since 2001

# Key Operational Question

- What method of enrollment?
- Who enters the data?

# Enrollment Paradigms

- Provider-driven (e.g. nurse practitioner)
- Subject-driven (e.g. self enrollment by patient)

# Data Entry Models

	Provider-Driven Entry	Subject-Driven Entry
Provider-driven	tight control highest cost	tight control loose cost
Subject-driven	loose control moderate cost	loose control low cost

# Enrollment

- Subject-driven (self enrollment)
- Provider-driven
- Hybrid

# Provider-driven Enrollment

## Case Example:

- Back Pain Registry
- Location:
  - Barrow Neurological Associates
  - Phoenix, AZ
- How did they do it?



# Back Pain Registry

Test Application - all data will be overwritten - spinedb\_phx\_demo - Version 3.0

## Log In

**Username:**

**Password:**

Login

[Did you forget your login info?](#)



Back Pain Registry - Emerge.MD - Windows Internet Explorer

http://stage-spinedb.emergemd.net/Users/Register.aspx?proxyEdit=1&clearstack=true

File Edit View Favorites Tools Help

Back Pain Registry - Emerge.MD

Username: useradmin

# Back Pain Registry

Test Application - all data will be overwritten - spinedb\_phx\_stage - Version 3.0

Manage Accounts

Verify Accounts

Review Demographic Changes

Manage Client Communications

Register New Participant

Action Log

## Register

Required Fields are marked with a \*.

Preferred Language: English

Desired Username: \*

Password: \*

Confirm Password: \*

E-mail Address: \*

### Disclaimer (Terms of Use)

**Terms of Use:**  
 This web site is an educational and informational service provided by Emerge.MD, with the express condition that users agree to be bound by the terms and conditions set forth in this User Agreement, as they may be modified from time to time. Your consultation and use of this web site constitutes your

Do you agree to the terms of the registry?  
 I agree

Submit

carefully checked.com

POWERED BY emerge.md



**Gender: \***

- Male  Female

**Is your current pain a result of the following? \***

- Car Accident  
 Work Injury  
 Neither

**What was the date of the car accident?**

- Unknown  
 Date of Accident

**Is there legal action pending over the current problem? \***

- Yes  No

**When did you start having the pain? \*****Were you doing anything to cause the pain when it started? \***

- Yes  No

**Where is your pain? \***

	Right Side	Left Side	Both	None
Head	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neck	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Upper Back	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lower Back	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shoulder	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arm above elbow	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arm below elbow	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Hand	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Leg above knee	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

[Switch To 1 Page View](#)

## Testing and Treatment History

**Have you had an EMG/Nerve Conduction Study? \***

Yes  No

**What was the date of the EMG/Nerve Conduction study? \***

Unknown

Date of the Study

**What were the results of the EMG/Nerve Study? \***

**Have you had physical therapy? \***

Yes  No

**When did your therapy start?**

Unknown

Date of first therapy session:

**How many physical therapy sessions did you have? \***

**What did therapy do for you? \***

**What type of therapy did you have? \***

- Heat  Massage  
 Ultrasound  Electrical Stimulation  
 Exercise  Stretching  
 Traction  Other  
 Unknown  None of the Above

**Have you had epidural steroid injections? \***

Yes  No  Unknown



# Back Pain Registry

Username:  
useradmin

Test Application - all data will be overwritten - spinedb\_phx\_stage - Version 3.0



Manage Accounts



Verify Accounts



Review Demographic Changes



Manage Client Communications



Register New Participant



Action Log

## Current Account Demographics

GlobalID: **1039**  
User Name: **tester**  
Last Name: **Tester**  
First Name: **John**  
Inactive: **No**

## Response Comparison

	New - Mar 21, 2008	Previous - Mar 21, 2008
<b>MRN</b>	1234567	1234567
<b>Centricity</b>	1234	1234
<b>LastName</b>	Tester	Tester
<b>FirstName</b>	John	John
<b>Sex</b>	Male	Male
<b>SSN</b>	987654321	987654321
<b>DOB</b>	02/15/1966	02/15/1966
<b>Handed</b>	Both	Both
<b>Email</b>	tester@emergemd.com	tester@emergemd.com
<b>ApptDate</b>	03/14/2008	03/14/2008
<b>Comments</b>		



[Accept Demographics](#)



[Accept and Edit Demographics](#)



[Done With Account](#)



## Potential Duplicate Accounts

There are no potential duplicate accounts.

### Review

	Pending Account
<b>GlobalID</b>	1007
<b>UserName</b>	testuser1
<b>Last</b>	User1
<b>Middle</b>	
<b>First</b>	Test
<b>Email</b>	testuser1@emergemd.com
<b>Gender</b>	Male
<b>BirthDate</b>	08/25/1960
<b>Phone (Home)</b>	
<b>Phone (Work)</b>	
<b>Street</b>	
<b>Apt</b>	
<b>City</b>	
<b>Region</b>	
<b>RegionCode</b>	
<b>Country</b>	
<b>Date Enrolled</b>	02/22/2008
<b>Verified</b>	Yes
<b>Inactive</b>	No
<b>Reason Inactive</b>	
<b>Last Demographics Edit</b>	2/22/2008 7:26:02 AM
<b>Survey Response Count</b>	2



  
[Verify Pending Account](#)

  
[Verify And Edit Pending Account](#)

  
[Done With Pending Account](#)

  
[Discard Pending Account](#)



Verify Accounts



Review Demographic Changes



Manage Client Communications



Register New Participant



Action Log

## Demographics

**User ID:** 1039  
**User Name:** tester  
**MRN:** 1234567  
**Centricity Number:** 1234  
**Last Name:** Tester  
**First Name:** John  
**Social Security Number:** 987654321  
**Date of Birth:** 02/15/1966  
**Appointment Date:** 03/14/2008

[Edit Demographics](#)

[Send Invitation Email](#)

[Unverify Account](#)

[Reset Password](#)

[Send An Email](#)

## Account Properties

**Account Active**

[Click to deactivate this account.](#)

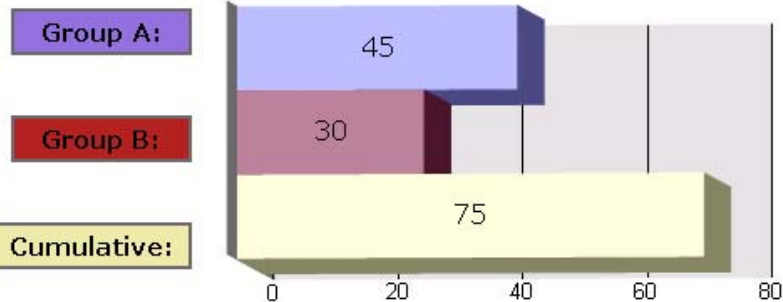
Completed Questionnaires	Started	Completed	Edited By
<a href="#">PDQ Scale</a>	Feb 28 2008	Feb 28 2008	useradmin

Active Questionnaires	Description
<a href="#">Patient Admission Form</a>	

100%

## PDQ Scale Scoring

**Name:** John Tester  
**MRN:** 1234567  
**Centricity:** 1234



[Return to Main Page](#)



# Back Pain Registry

Username: useradmin

Test Application - all data will be overwritten - spinedb\_phx\_stage - Version 3.0



Verify Accounts



Review Demographic Changes



Manage Client Communications



Register New Participant



Action Log

Return to Global ID 1039

PDQ Scale

1 Total Pages

Return to Main Page >>

Edit PDQ Scale >>

Print >>

## Responses

Show Unanswered Questions

Does your pain interfere with your normal work inside and outside the home?

5

Does your pain interfere with personal care (such as washing, dressing, etc.)?

5

Does your pain interfere with your traveling?

5

Does your pain affect your ability to sit or stand?

5

Does your pain affect your ability to lift overhead, grasp objects, or reach for things?

5

Does your pain affect your ability to lift objects off the floor, bend, stoop or squat?

5

Does your pain affect your ability to walk or run?

5

Has your income declined since your pain began?

5

Do you have to take pain medication everyday to control your pain?

5

Does pain force you to see doctors much more often than before your pain began?

5

Does your pain interfere with your ability to see the people who are important to you as much as you would like?

5

Does your pain interfere with recreational activities and hobbies that are important to you?

5

Do you need the help of your family and friends to complete everyday tasks (including both work outside the home and housework) because of your pain?

5

Do you now feel more depressed, tense, or anxious than before your pain began?

5

Are there emotional problems caused by your pain that interfere with your family, social, or

# Enrollment

- Subject-driven (self enrollment)
- Provider-driven
- Hybrid

# Subject-driven Enrollment

## Case Example:

- Muhammad Ali Parkinson's Registry
- Location:
  - Barrow Neurological Institute
  - Phoenix, AZ
- How did they do it?



## Log In

---

**Username**

**Password**

Login

[Did you forget your login info?](#)

If you are not a current participant,  
please enroll here. >

NOTE: If you have already registered, please do not re-register. Call MAPRC at 1 (877) 287-7122 and we will be happy to help you log in.



### Register

---

If you have already registered, please do not re-register. Call MAPRC at 1 (877) 287-7122 and we will be happy to help you [log in](#). You may begin the enrollment by entering the information below. In order to ensure your privacy, your password should have at least one number and one letter in it, and be at least 5 characters long.

Desired Username:

Password:

Confirm Password:

Email Address:

## Information Page

---

The purpose of the Registry is to facilitate the development of new therapies and healthcare services to improve the quality of life for people with PD. It will also accelerate the process of informing participants of more effective treatments.

Please read the following informative statements before you sign your consent:

- By being enrolled in the Registry, you agree to be notified of research studies for which you may be eligible, but you are not obligated to enter any study.
- You will NOT be excluded from future studies if you decline to participate in a specific study or project.
- The data you provide may be used in scientific publications, in summary form only as aggregated data with all personal information identifiers removed.
- Your name will not be released to any individuals outside of the Registry Management Team without your written consent, nor will it be sold for advertising or fund raising.
- Participation in the Registry is completely voluntary and is of no cost to you.
- You will continue receiving additional questionnaires every six months for purposes of updating the Registry and gathering new information.
- You may receive the Southwest Parkinson News report free of charge if you wish (Unfortunately, we can only mail within the United States).
- If at anytime you wish to unsubscribe from the Registry, you can do so in writing to:

[info@maprc.com](mailto:info@maprc.com) or...  
Parkinson's Disease Registry,  
500 W. Thomas Road, Suite 720,  
Phoenix, AZ 85013

- The Registry is expected to continue until a cure for PD is found.
- Unless and until you enter into a research study there is no patient relationship and any patient relationship may or may not be with the Muhammad Ali Parkinson Research Center

Please retain an additional copy of this form for your records. [Click here to print this page.](#)  
Other than medical questions, which should be directed to your physician, please direct questions to [info@maprc.com](mailto:info@maprc.com).

By accepting below, I give my permission for the following information to be entered into the Registry. I understand that this information will be used for research purposes only, and that all responses will be kept private and confidential. I am willing to be notified of any studies for which I may be eligible.

[Read the Disclaimer \(Terms of Use\)](#)

[Read about our Privacy Policy](#)

Do you agree to the terms of the enrollment?

- I Agree
- I Disagree

Continue

## Please Tell Us About Yourself

---

Last Name

First Name

Middle Name

*Full middle name*

## Details

---

Date of Birth

*mm/dd/yyyy format*



Gender

- Female  Male

What is your racial/ethnic origin?

- Asian Indian  
 White (not Hispanic)  
 Asian or Pacific Islander  
 Native American  
 African American  
 Hispanic/Latino  
 Arab  
 Other:

What country do you live in?

Select:

Continue

## Medical History

---

Please tell us whether you have the following symptoms.

	Yes	No	Unsure
Tremors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stiffness, cramping or heaviness in a limb	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Slowness of movements <i>(cramped handwriting, low voice, difficulty with fine motor skills such as doing buttons or getting change from a pocket, shuffling gait)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dyskinesia (involuntary writhing or fidgety movements)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Balance problems requiring a walker or wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hallucinations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive difficulties or dementia <i>(trouble managing finances, keeping up with current events or getting lost easily)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep disturbance with marked snoring, gasping breath or thrashing about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repeated strokes (more than 1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Passing out spells or near passing out, particularly when standing up (commonly, not just once in a while)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Urinary or bowel incontinence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Medical History

---

Please tell us whether you have the following symptoms.

	Yes	No	Unsure
Tremors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stiffness, cramping or heaviness in a limb	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Slowness of movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Medical History

---

Have your tremors started slowly and progressed over time, say over the course of months to years?

- Yes
- No
- Unsure

Did your tremors start on one side of the body?

- Yes
- No
- Unsure

## Medications

	Now	Past	Never
Sinemet (Brand)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levodopa- Carbidopa (Generic)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sinemet CR	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levodopa-Carbidopa CR	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parcopa (brand) Carbidopa- Levodopa Orally Disintegrating Tablets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Requip	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mirapex	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Permax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Amantadine (Symmetrel)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tasmar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stalevo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comtan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Selegiline (Eldepryl, Atapryl, Carbex, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antidepressants (Prozac, Zoloft, Paxil, Celexa, Effexor, Remeron, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antipsychotic (Clozaril, Zypresxa, Seroquel, Risperdal, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Apomorphine (Apokyn)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Medications

	Now	Past	Never
Sinemet (Brand)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levodopa- Carbidopa (Generic)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sinemet CR	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levodopa-Carbidopa CR	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parcopa (brand) Carbidopa- Levodopa Orally Disintegrating Tablets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Who Prescribed? *	Total Number of Years on Therapy *	Side Effects *
Requip			
Mirapex			
Permax			
Amantadine (Symmetrel)			
Tasmar			
Stalevo			
Comtan			
Selegiline (Eldepryl, Atapryl, Ca etc.)			
Antidepressants (Prozac, Zoloft Celexa, Effexor, Remeron, etc.)			
Antipsychotic (Clozaril, Zypresx Seroquel, Risperdal, etc.)			
Apomorphine (Apokyn)			



Thank you for participating in the Parkinson's Disease Patient Registry

[Print Your Responses >](#)

[Return to Home Page >](#)

Responses	<a href="#">Show Unanswered Questions</a>
<b>Do you have tremors?</b> Yes	
<b>Do you have stiffness, cramping or heaviness in a limb?</b> No	
<b>Do you have slowness of movements?</b> No	
<b>Do you have dyskinesia (involuntary writhing or fidgety movements)?</b> Unsure	
<b>Do you have Balance problems requiring a walker or wheelchair?</b> No	
<b>Do you have hallucinations?</b> No	
<b>Do you have cognitive difficulties or dementia?</b> Yes	
<b>Do you have sleep disturbance?</b> No	
<b>Do you have repeated strokes?</b> No	
<b>Do you have passing out spells?</b> No	
<b>Do you have urinary or bowel incontinence?</b> No	
<b>Have your tremors started slowly and progressed over time, say over the course of months to years?</b> No	
<b>Did your tremors start on one side of the body?</b> Yes	

# Self-Enrollment Concerns

- Erroneous enrollment
  - Valid participant, but duplicate enrollment
  - Honest mistake (IBD vs IBS)
  - Intentional but random (hoax)
  - Malicious and systematic (competitor)

# Self-Enrollment

- Erroneous enrollment
  - We cannot prevent it
  - However, we can manage it

# Self-Enrollment

## Erroneous enrollment

- Valid participant, but duplicate enrollment



– Why not screen for duplicates is real-time?

– Use administrative application to verify new accounts

– Computer-assisted pattern matching

– Options: verify as new enrollee, merge with current account, delete new account



Username: useradmin



muhammad ali

PARKINSON RESEARCH CENTER

# The Parkinson's Disease Registry



Manage Accounts



Verify Accounts



Review Demographic Changes



Statistics



Manage Client Communications



Register New Participant



Action Log



## Verify Pending Account

GlobalID: **3365**

User Name: **StudEPatient**

Last Name: **Patient**

First Name: **Study**

Inactive: **No**

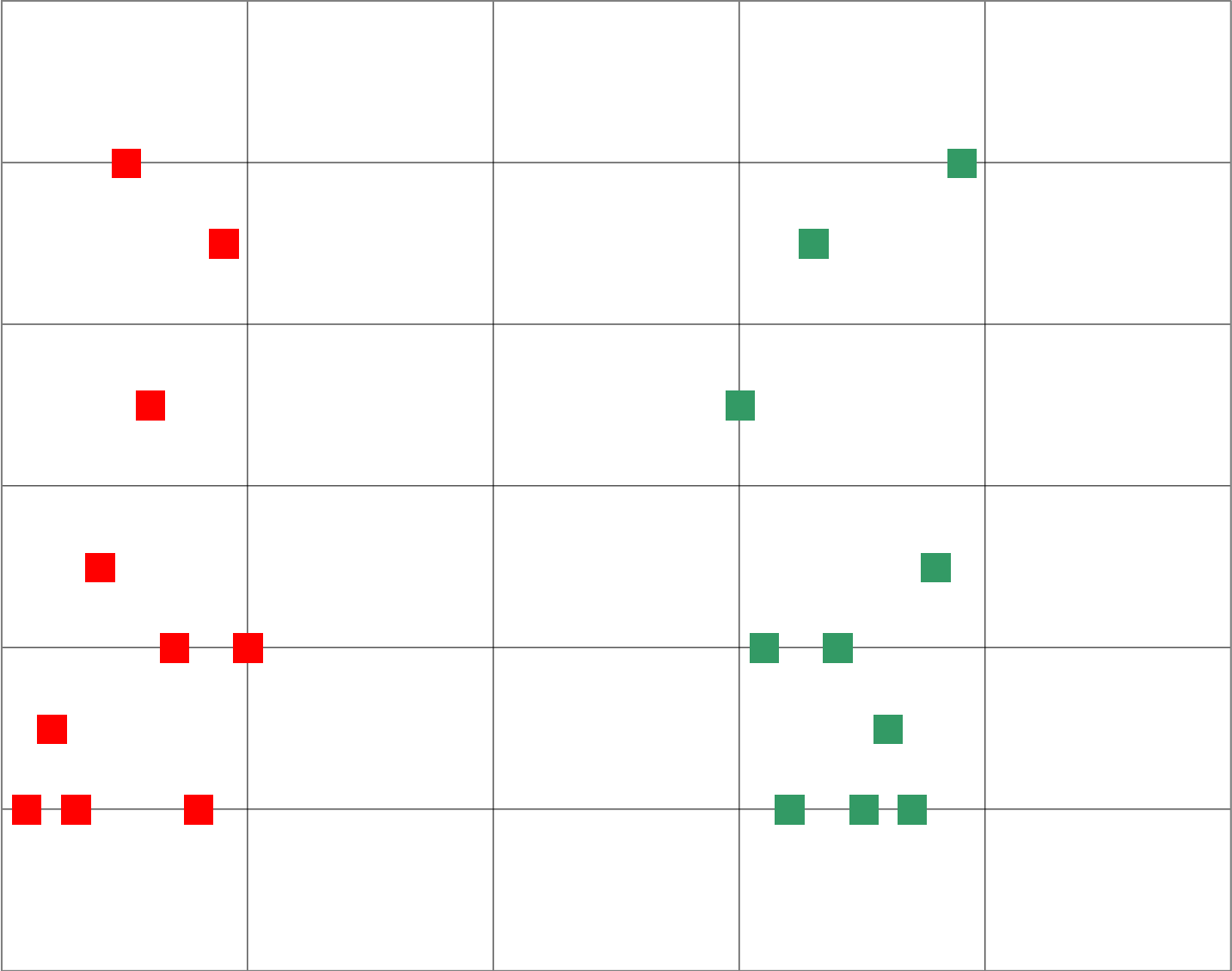
## Potential Duplicate Accounts

GlobalID	UserName	Last	Middle	First	Email	Gender	BirthDate	DateEnrolled	Verified	Inactive
<b>3364</b>	StudyPatient	Patient	The	Study	StudyPatient@home.com	Female	10/02/1976	04/24/2006	Yes	No

## Compare

	Pending Account (to keep active)	Potential Duplicate Account
<b>GlobalID</b>	3365	3364
<b>UserName</b>	StudEPatient	StudyPatient
<b>Last</b>	Patient	Patient
<b>Middle</b>	Edward	The
<b>First</b>	Study	Study
<b>Email</b>	StudEPatient@home.com	StudyPatient@home.com
<b>Gender</b>	Male	Female
<b>BirthDate</b>	04/29/1948	10/02/1976
<b>Phone (Home)</b>		(602) 345-8672
<b>Phone (Work)</b>		
<b>Street</b>	234 America Way	123 Elm Street

Person X → two accounts → merged



DS A1 @ t1

DS B1 @ t2



Username: useradmin1



muhammad ali

PARKINSON RESEARCH CENTER

## The Parkinson's Disease Registry



Manage  
Accounts



Verify  
Accounts



Review  
Demographic  
Changes



Statistics



Manage Client  
Communications



Register  
New Participant



Action  
Log



Logout

### Client Communications Manager



[Create New Batch](#)

### Management Options



**Manage**  
**Search Templates**



**Manage**  
**Email Templates**



**Manage**  
**Email Batches**



**Add Field**



**Remove Field**


### Accounts Which Have...

Verified  Yes


Inactive  No

Email

[Toggle Advanced](#)

Completed  On Or After  

[Toggle Advanced](#)

Completed  On Or Before  

willing\_update\_online  Yes



# The Parkinson's Disease Registry

- Manage Accounts
- Verify Accounts
- Review Demographic Changes
- Statistics
- Manage Client Communications
- Register New Participant
- Action Log
- 

## Output Manager

Search Fields: GlobalID

Insert Selected Field

Subject:

Muhammad Ali Parkinson's Disease Registry Update Questionnaire

Message:

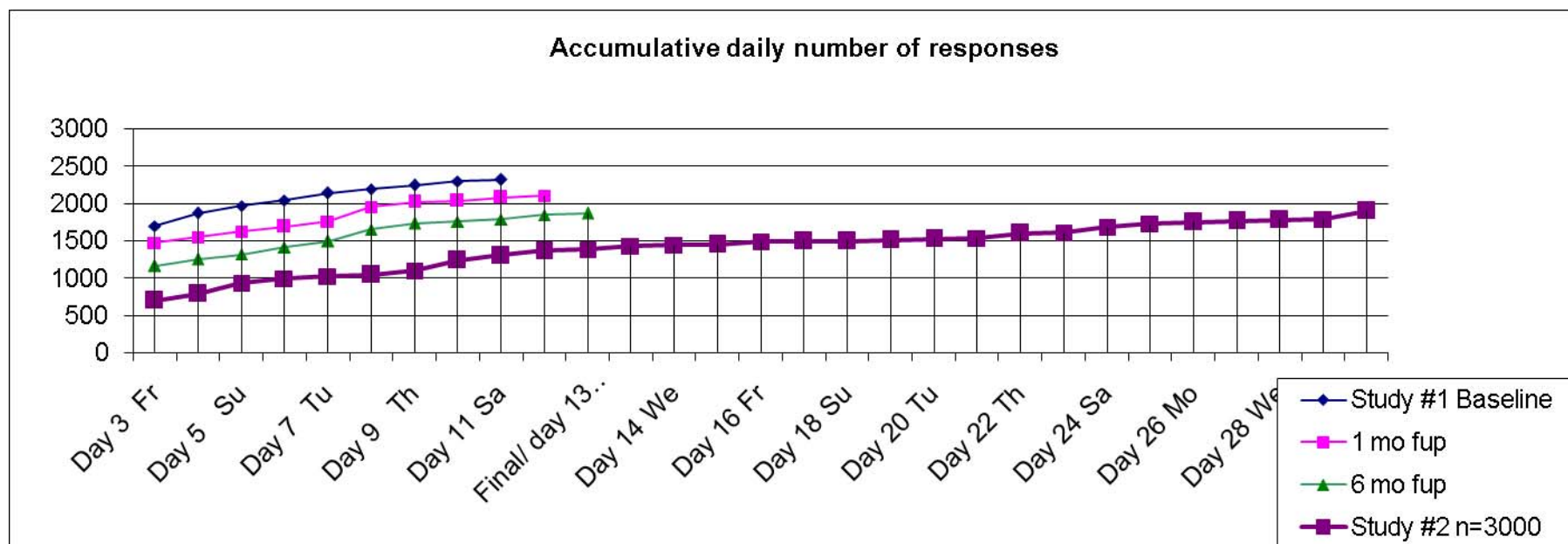
```
Dear {FirstName} {LastName},  
  
RE: Your account name {UserName}  
  
It is time to complete your first semi-annual update questionnaire for  
the Parkinson's Disease Registry study! Some of you enrolled in the  
Registry longer than six months ago but this is the first update cycle  
we have done so you didn't miss anything. Now that the Registry is of  
sufficient size, we will continue the updates on a six-month cycle.  
  
The Registry has over 1,960 members from around the world and we  
continue to grow by about 20 new members per week! Our ultimate goal
```

Save Template and Exit

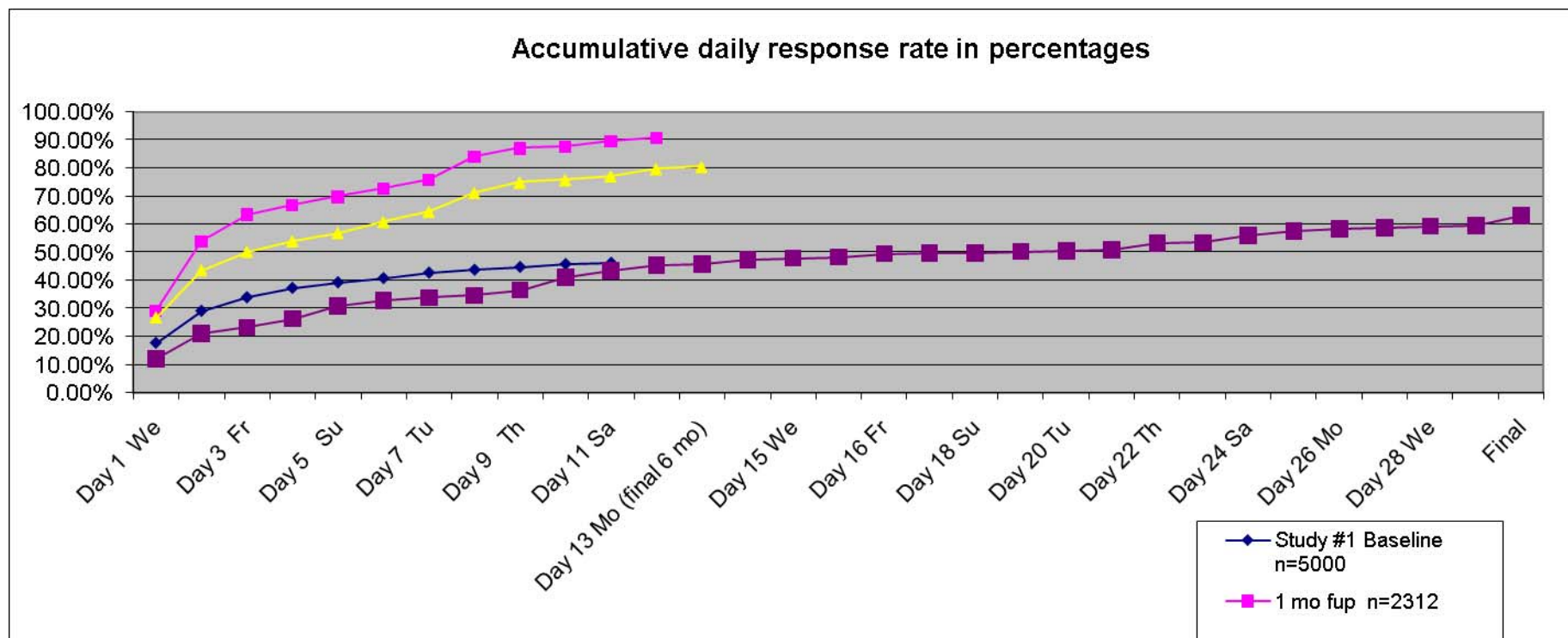
## Options

**Cancel**

# Self-enrollment Case Examples



# Self-enrollment Case Examples





Users



Manage Accounts



Verify Accounts



Review Demographic Changes



Statistics



Manage Search Templates

## Enrollment Statistics

	Online	Paper	Total
Number of Active Accounts	12194	6220	18415
Number of Active New Enrollees	6613	2103	8716
Average Number of New Accounts per Week during previous 28 Days	-	-	42
Number of Accounts with Incomplete Questionnaires	-	-	329
Average Time to Complete Questionnaire (in minutes)	-	-	26

## Update Statistic

**Update Spring 2006**

**04/10/2006 - 05/01/2006**

	Online (including proxy entry)	Paper Imports	Total
Cumulative Number of Accounts Eligible for this Questionnaire	-	-	9093
Number of Accounts that Completed this Questionnaire	1380	0	1380
Number of New Accounts with Incomplete Questionnaires	-	-	93
Average Time to Complete this Questionnaire (in minutes)	-	-	20
Average Number of Completed Questionnaires per Week during previous 28 Days	-	-	870

# Data Reporting & Analysis

- Subscription Reporting Services
  - Results Emailed directly to You
- Ad hoc Queries
  - Rolled Up Summary Data Tables
  - Remotely via Secure Connection
  - Locally on Delivered Data

## Shahram Partovi

**From:** reports@emergemd.com  
**Sent:** Monday, August 15, 2005 11:15 AM  
**To:** Thomas Femiani; Shahram Partovi; Donnie Straus  
**Subject:** EmailFisherGradeAll was executed at 8/15/2005 11:15:09 AM

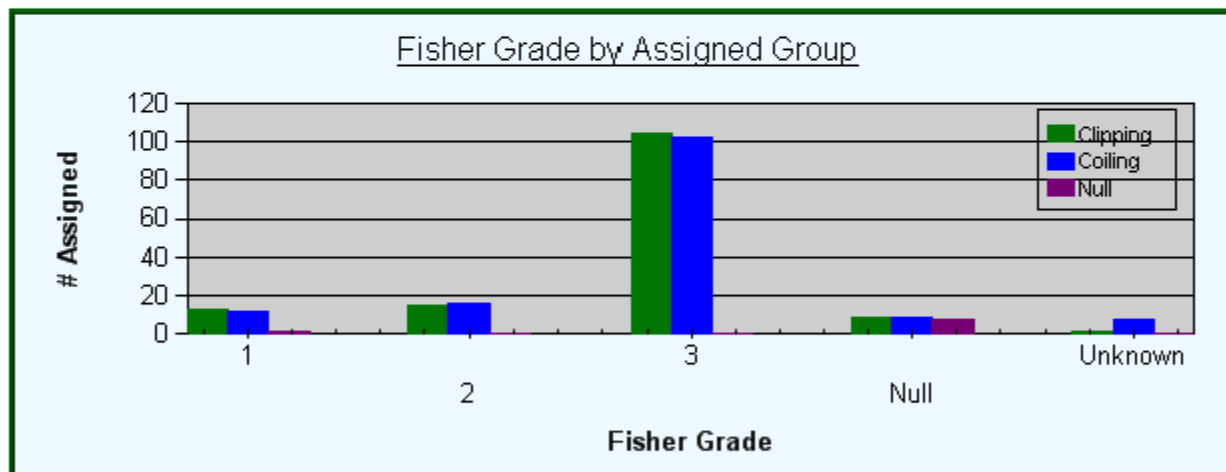
Non-GUI Report 2

### BRAT Fisher Grade Summary

Report Date: 8/15/2005

All Patients

Page 1 of 1



Null - No data entered into database

Unknown - Data unavailable in chart

### Data Table

Fisher Grade: 1

Clipping 13

Coiling 12

Null 4



### Surgical Information Example - with custom code results

Data Type	Column Name	Scale	Item Type	Question
tinyint	DBSSurgery	0=Missing 1=DBS 2=Other (Pallidotomy / Thalamotomy) 3=None	Check Box	Have you had brain surgery?
tinyint	DBSSurgeryType	1=Unilateral 2=Bilateral	Check Box	What type of DBS Surgery did you have?
datetime	DBSUnilateralDate		Date	When was your unilateral DBS surgery?
tinyint	DBSSurgeryStaged	1=Both sides done during one surgery 2=Each side done in a separate surgery	Radio Button	Was your bilateral DBS surgery staged (separate surgeries)?
datetime	DBSBilateralNonStagedDate	Date	Date	What was the date of your bilateral (non-staged) DBS surgery?
datetime	DBSBilateralStagedDate1	Date	Date	When did you have your first bilateral (staged) DBS surgery?
datetime	DBSBilateralStagedDate2	Date	Date	When did you have your second bilateral (staged) DBS surgery?
tinyint	DBSElectrodePlacement	1=Subthalamic Nucleus (STN) 2=Thalamus 3=Unsure	Radio Button	Where in your brain were the electrodes placed? 
<b>PALLIDOTOMY</b>				
tinyint	Pallidotomy	1=Yes	Via Code	Implied Question: (Have you had Pallidotomy surgery?)
tinyint	PallidotomyType	1=Unilateral 2=Bilateral	Via Code	Was your Pallidotomy surgery unilateral or bilateral?
datetime	PallidotomyUnilateralDate	Date	Via Code	When was you unilateral Pallidotomy surgery?
tinyint	PallidotomyBilateralNonStaged	1 = Not Staged 2 = Staged	Via Code	Was your bilateral Pallidotomy surgery staged (separate surgeries)?
datetime	PallidotomyBilateralNonStagedDate	Date	Via Code	When was your bilateral (non-staged) Pallidotomy surgery?
datetime	PallidotomyBilateralStagedDate1	Date	Via Code	When was your first bilateral (staged) Pallidotomy surgery?
datetime	PallidotomyBilateralStagedDate2	Date	Via Code	When was your second bilateral (staged) Pallidotomy surgery?
<b>THALAMOTOMY</b>				
tinyint	Thalamotomy	1=Yes	Via Code	Implied Question: (Have you had Thalamotomy surgery?)

# Ad Hoc Queries

- “Garbage In, Garbage Out” is at work in query generation.
- Most consistent cause of “Garbage Out” has been inadequate experience mining the painstakingly collected data