



Systems and practices to enhance longitudinal data completeness

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Overview

- Background on visit window
- Implementation of visit windows
- Other tracking mechanisms
- Missing data within visit
- Discussion

Background

- Index date
 - Date of (re)enrollment
 - Time 0
- Visit window
 - NACC uses ~12-month window
 - Follow-up 1 (F1): 6-18 months
 - F2: 18-30 months
 - And so on...
- More than 1 visit allowed per window
- Visit: Regular, telephone, milestone
- Missed follow-ups
 - Visits after each window are considered missed

Allowable window calculations

- Determine Index date
 - Date of initial packet
 - Date of first follow-up packet after rejoin
- Calculate minimum date
 - Beginning ~6 months from index date
- Calculate maximum date
 - Beginning ~18 months from index date
- Result gives approximate 12 month visit window
- Follow-up number is determined
 - This specifies which window to display
 - Ex. For F3, the ideal window is calculated as ~30-~42 months from index

Other considerations

- What is the index date?
- What visit are we currently on?
- Was last visit accounted for?
- What was the last packet type – regular, phone, milestone?
- Was the last visit accepted by NACC?
- What is subject's current status?

Allowable window implementation

Current Visit #	10	✓	⌵	📄
Current UDS Visit #	7	✓	⌵	📄
Current Accepted UDS Visit #	5	✓	⌵	📄
Location of Visit	In-Clinic	✓	⌵	📄
Age	37	👤	⌵	📄
Section 1: To be recorded prior to or at time of visit.				
Did subject report for appointment?		✓	⌵	📄
If No, Reason		✓	⌵	📄
Allowable window for current visit	15 Nov 2012 [⌵]	✓	⌵	📄
Minimum Visit Date				
Maximum Visit Date	10 Nov 2013 [⌵]	✓	⌵	📄
Check here to recalculate Allowable window for current visit		☐	✓	⌵

The Mayo Clinic ADC attempts to track the allowable window

Tracking future visits

Page: Next Visit Planning - Cycle 02  

Will subject participate next year?	1=Yes  
If No, Reason	 
Derived Month of Next Follow-up Visit	Oct  
Derived Year of Next Follow-up Visit	2014  
Will the derived date work for the subject? (e.g. snowbird)	1=Yes  
Provide month if subject cannot be seen at derived follow-up date	 
Provide year if subject cannot be seen at derived follow-up date	 
Cycle Number	02  

Derived month and year to aid in planning the next visit

Post visit summary

Page: Post-Visit Summary - Cycle 05



Section 2: To be recorded after the subject is done with the visit.

Non-psychometric validity:

1=Satisfactory

Section 3: To be recorded after all possible data is collected and entered for this visit.

Is Visit Complete?

? This cycle cannot be completed in ALZ1002 Master Track until this box is checked. Make sure to check this box after all data has been entered.

Opened To Site from System (26 Mar 2013) Cancel

Were there any Adverse Events?

? This field is required. Please complete.

Opened To Site from System (26 Mar 2013) Cancel

If yes, specify

Cycle Number

05

Used to signal all data has been collected and entered

Effect on missed follow-up rates

Before implementation

After implementation

Table 2: Missed Follow-up Visit Rates by ADC As of 9/1/11

Center	F ₁	F ₂	F ₃	F ₄
Arizona	23%	16%	32%	28%
Boston University	13%	22%	23%	25%
Columbia University	17%	21%	24%	27%
Duke University	12%	9%	11%	9%
Emory University	21%	12%	23%	28%
Florida	22%	29%	39%	60%
Indiana University	35%	16%	15%	22%
Johns Hopkins University	21%	22%	23%	25%
Massachusetts ADRC	14%	18%	27%	27%
Mayo Clinic	23%	24%	25%	33%
Mount Sinai	8%	8%	5%	3%
New York University	53%	22%	8%	18%
Northwestern University	9%	21%	16%	9%
Oregon Health & Science University	10%	9%	17%	33%
Rush University	23%	45%	16%	19%
University of California, Davis	13%	22%	21%	21%
University of California, Irvine	12%	10%	15%	25%
University of California, Los Angeles	17%	19%	7%	8%
University of California, San Diego	7%	17%	16%	24%
University of California, San Francisco	21%	18%	25%	20%
University of Kentucky	17%	20%	19%	24%
University of Michigan	3%	10%	11%	9%
University of Pennsylvania	34%	39%	31%	34%
University of Pittsburgh	38%	29%	38%	25%
University of Southern California	25%	22%	16%	6%
University of Texas, Southwestern	20%	21%	22%	23%
University of Washington	17%	13%	10%	9%
University of Wisconsin	0%	—	—	—
Washington University, St. Louis	22%	28%	27%	30%
Median	17%	20%	20%	24%

Table 2: Missed Follow-up Visit Rates by ADC As of 9/1/13

Center	F ₁	F ₂	F ₃	F ₄	F ₅
Arizona	13%	17%	28%	29%	29%
Boston University	14%	23%	24%	23%	16%
Columbia University	13%	18%	19%	15%	14%
Emory University	20%	12%	14%	14%	15%
Indiana University	31%	18%	17%	18%	23%
Johns Hopkins University	20%	22%	22%	22%	21%
Massachusetts ADRC	16%	20%	32%	24%	16%
Mayo Clinic	11%	12%	15%	18%	17%
Mount Sinai	6%	6%	3%	3%	5%
New York University	50%	23%	12%	15%	21%
Northwestern University	8%	16%	14%	9%	8%
Oregon Health & Science University	8%	6%	10%	14%	9%
Rush University	19%	35%	37%	16%	25%
University of California, Davis	14%	23%	26%	21%	27%
University of California, Irvine	13%	14%	14%	22%	26%
University of California, Los Angeles	24%	31%	20%	11%	8%
University of California, San Diego	9%	18%	17%	26%	24%
University of California, San Francisco	20%	20%	19%	18%	21%
University of Kansas	20%	0%	—	—	—
University of Kentucky	14%	19%	17%	20%	22%
University of Pennsylvania	17%	24%	23%	20%	24%
University of Pittsburgh	31%	24%	29%	18%	19%
University of Southern California	21%	19%	11%	7%	7%
University of Texas, Southwestern	17%	16%	22%	22%	32%
University of Washington	14%	13%	10%	9%	7%
University of Wisconsin	0%	0%	3%	—	—
Washington University, St. Louis	23%	29%	28%	29%	29%
Median	16%	18%	18%	18%	21%

Systems for data completeness within visit

- Toggles to signal all data that will be collected is entered
- Queries for required data
- Email reminders for incomplete visits
- NACC errors/alerts coded to run in real time

Any Comments/Questions?