

## Documentation for Functional Limitations Datasets

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## **FUNCTIONAL LIMITATIONS AND DISABILITY DATASET (FuncLimDis)**

### **1. Overview of Functional Limitations and Disability dataset**

The Functional Limitations and Disability Dataset contains two types of data.

The functional limitations data use information from the walking difficulty and stair-climbing difficulty questions at each annual and semi-annual contact to calculate endpoints that indicate if and when the participant began having limitations. These data differentiate between any limitation (little or some difficulty) and severe limitation (lot of difficulty), and between incident limitation (first occurrence) and persistent limitation (two consecutive visits with limitation.) Days to event are calculated from baseline to the date of limitation for incident endpoints, and from baseline to the date of the first of two consecutive reports of limitation for persistent endpoints.

The disability data complement the functional limitation data. The disability endpoints are based on questions asked at each annual visit regarding walking and stair climbing difficulty, as above, plus questions regarding difficulty with Activities of Daily Living (ADL) and other important functions.

The Functional Limitations and Disability Dataset contains the standard variable HABCID which is a participant's Health ABC Enrollment ID# without the 2-letter prefix. Other standard variables like:

GENDER	Gender (1=Male; 2=Female)
RACE	Race (1=White; 2=Black)
SITE	HABC Clinic site: (1=Memphis; 2=Pittsburgh)

can be merged from the participant history file (PH) into the functional limitations and disability dataset. You can download the most recent PH file from the Health ABC website.

There are 3075 participants listed in the Functional Limitations and Disability Dataset.

### **2. General description of Functional Limitations data**

The Functional Limitations data combine information from the walking difficulty and stair-climbing difficulty questions asked at each contact (e.g., 6-Month Follow-Up Contact, Q4&5) across all contacts to determine whether, and if so when, a participant became functionally limited.

When the walking difficulty or stair difficulty questions were not answered at one or more visits (e.g., due to a missed visit), or when the answer given was "Does not do", the missing data is filled in by interpolating between the most recent prior visit with data and the first following visit with data. The exact specifications of how these values are imputed are included later in this document.

Besides the standard variables listed above, the Functional Limitation data consist of calculated status variables as follows (x indicates the x-month contact):

**STATxMO (Status at the x-Month Contact)**

- Values
- 1 – Completed Contact
  - 2 – Dead
  - 3 – Missed due to illness or in nursing home/LTC facility
  - 4 – Missed for other reason

**WALKxMO (Walking Status at x-Month Contact)**

- Values
- 0 – No difficulty
  - 1 – Little/Some Difficulty
  - 2 – Lot of Difficulty /Can't Do
  - 3 – Difficulty due to illness or in nursing home/LTC facility
  - 4 – Dead
  - 5 - Does not do
  - . – No Information/Unknown/Refused

**STRxMO (Stair Status at x-Month Contact)**

- Values
- 0 – No difficulty
  - 1 – Little/Some Difficulty
  - 2 – Lot of Difficulty /Can't Do
  - 3 – Difficulty due to illness or in nursing home/LTC facility
  - 4 – Dead
  - 5 – Does not do
  - . – No Information/Unknown/Refused

“Putative limitation” is assigned to both walking and stair status if the contact was missed for a reason associated with limitation (e.g., too ill, in a nursing home or long term care facility (LTC)). From the walking and stairs status variables, a number of functional limitation endpoints are calculated.

**Incident Walking Limitation (ILW)**

ILW is based on the first report of having any difficulty or not being able to walk 1/4 mile.

- ILW Values:
- 0 – Endpoint not Achieved / Live
  - 1 – Endpoint not Achieved / Dead
  - 2 – Endpoint Achieved

**Incident Stair Climbing Limitation (ILS)**

ILS is based on the first report of having any difficulty or not being able to climb 10 steps.

ILS Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved

**Incident Lower Extremity Limitation (ILL)**

ILL is based on the first report of either having any difficulty or not being able to walk 1/4 mile or having any difficulty or not being able to climb 10 steps (either one satisfies the definition, both not required).

ILL Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved

**Incident Severe Walking Limitation (ISLW)**

ISLW is based on the first report of having a lot of difficulty or not being able to walk 1/4 mile.

ISLW Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved

**Incident Severe Stair Climbing Limitation (ISLS)**

ISLS is based on the first report of having severe difficulty or not being able to go up stairs.

ISLS Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved

**Incident Severe Lower Extremity Limitation (ISLL)**

ISLL is based on the first report of having a lot of difficulty or not being able to walk 1/4 mile or having any difficulty or not being able to climb 10 steps (either one satisfies the definition, both not required).

ISLL Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved

## Persistent Walking Limitation (PLW)

PLW is based on two consecutive reports of having any difficulty walking 1/4 mile.

PLW Values: 0 – Endpoint not Achieved / Live  
 1 – Endpoint not Achieved / Dead  
 2 – Endpoint Achieved  
 . – Lost to follow-up.

For this and all of the following persistent limitation variables, there are several general principles of how these endpoints are assigned. Starting with the 6-month contact, walking and stair climbing status are determined every 6 months. Since it was a requirement for enrollment in Health ABC that participants be able to walk 1/4 mile and climb a flight of stairs without difficulty, the earliest date that a persistent limitation can begin is the date of the 6-month contact, based on a report of limitation at both the 6-month contact and the 12-month contact. The handling of missing data for participants who died, were lost to follow-up, or missed a visit is outlined below.

Table 1 below shows an example of calculating the persistent walking limitation endpoint based on responses from the 6-month visit and the 12-month visit. If an endpoint is reached (PLW=2) based on these two visits, the onset date of the limitation will be the date of the 6-month visit. If no endpoint is reached, the algorithm proceeds through each semi-annual visit comparing each pair of sequential visits until it either reaches an endpoint of limitation at two consecutive contacts, or the end of the participant's visit history (due to death, loss to follow-up, or reaching the Year 17 Quarter 3 visit.)

**Table 1**

	WALK6MO=0 no difficulty	WALK6MO=1 little/some	WALK6MO=2 lots/can't do	WALK6MO=3 putative	WALK6MO=. missing
WALK12MO=0 no difficulty	PLW=0	PLW=0	PLW=0	PLW=0	Requires interpolation
WALK12MO=1 little/some	PLW=0	PLW=2	PLW=2	PLW=2	Requires interpolation
WALK12MO=2 lots/can't do	PLW=0	PLW=2	PLW=2	PLW=2	Requires interpolation
WALK12MO=3 putative	PLW=0	PLW=2	PLW=2	PLW=2	Requires interpolation
WALK12MO=4 dead <sup>1</sup>	PLW=1	PLW=2	PLW=2	PLW=2	Requires adjudication
WALK12MO=. missing	Requires interpolation	Requires interpolation	Requires interpolation	Requires interpolation	Requires interpolation

<sup>1</sup> Incident limitation followed by death at the next follow up is considered persistent limitation at the same level of limitation (any or severe) as the incident endpoint.

**Persistent Stair Climbing Limitation (PLS)**

PLS is based on two consecutive reports of having any difficulty going up stairs. It is determined as shown above for walking, but based on the stair-climbing question.

- PLS Values: 0 – Endpoint not Achieved / Live
- 1 – Endpoint not Achieved / Dead
- 2 – Endpoint Achieved
- . – Lost to follow-up

**Persistent Lower Extremity Limitation (PLL)**

PLL is based on two consecutive reports of either having any difficulty walking 1/4 mile or having any difficulty walking up 10 steps without resting. The consecutive reports must involve the same function (i.e. two walking or two stairs not one walking followed by one stairs).

- PLL Values: 0 – Endpoint not Achieved / Live
- 1 – Endpoint not Achieved / Dead
- 2 – Endpoint Achieved
- . – Lost to follow-up

After interpolation there are 16 theoretical combinations of the final Walking and Stairs endpoints (Table 2). It is possible to have (for example) the walking endpoint = “Endpoint not achieved / Live” and the stairs endpoint = “Endpoint not achieved / Dead.” This can only happen due to censoring when data for one (walking, in this example) are not complete through the last visit before death, but data for the other (stairs) are complete.

**Table 2**

	PLW=0	PLW=1	PLW=2	PLW=.
PLS=0	PLL=0	PLL=1	PLL=2	PLL=0
PLS=1	PLL=1	PLL=1	PLL=2	PLL=1
PLS=2	PLL=2	PLL=2	PLL=2	PLL=2
PLS=.	PLL=0	PLL=1	PLL=2	PLL=.

**Persistent Severe Walking Limitation (PSLW)**

PSLW is based on two consecutive reports of having a lot of difficulty or not being able to walk 1/4 mile.

- PSLW Values: 0 – Endpoint not Achieved / Live
- 1 – Endpoint not Achieved / Dead
- 2 – Endpoint Achieved
- . – Lost to follow-up

Like PLW, PSLW can only be determined after the 12-month contact has occurred from the possible combinations of the WALK6MO and WALK12MO variables as shown in Table 3 below (severe difficulty must persist for 2 consecutive contacts). If an endpoint is reached (PSLW=2) based on these two visits, the onset date of the limitation will be the date of the 6-month visit. If no endpoint is reached, the algorithm proceeds through each semi-annual visit comparing each pair of sequential visits until it either reaches an endpoint of limitation at two consecutive contacts, or the end of the participant's visit history (due to death, loss to follow-up, or reaching the Year 17 Quarter 3 visit.)

**Table 3**

	WALK6MO=0 no difficulty	WALK6MO=1 little/some	WALK6MO=2 lots/can't do	WALK6MO=3 putative	WALK6MO=. missing
WALK12MO=0 no difficulty	PSLW=0	PSLW=0	PSLW=0	PSLW=0	PSLW=0
WALK12MO=1 little/some	PSLW=0	PSLW=0	PSLW=0	PSLW=0	PSLW=0
WALK12MO=2 lots/can't do	PSLW=0	PSLW=0	PSLW=2	PSLW=0	Requires interpolation
WALK12MO=3 putative	PSLW=0	PSLW=0	PSLW=0	PSLW=0	Requires interpolation
WALK12MO=4 dead	PSLW=1	PSLW=1	PSLW=2	PSLW=0	Requires adjudication
WALK12MO=. missing	PSLW=0	PSLW=0	Requires interpolation	PSLW=0	Requires interpolation

## **Persistent Severe Stair Climbing Limitation (PSLS)**

PSLS is based on two consecutive reports of having a lot of difficulty or not being able to go upstairs. It is determined as shown above for walking, but based on the stair-climbing question.

PSLS Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved  
. – Lost to follow-up

## **Persistent Severe Lower Extremity Limitation (PSLL)**

PSLL is based on two consecutive reports of having a lot difficulty or not being able to walk 1/4 mile or climb up 10 steps without resting. The consecutive reports must involve the same function (i.e. two walking or two stairs not one walking followed by one stairs).

PSLL Values: 0 – Endpoint not Achieved / Live  
1 – Endpoint not Achieved / Dead  
2 – Endpoint Achieved  
. – Lost to follow-up

This variable is created from PSLW and PSLS in the same way that PLL is created from PLW and PLS (see Table 2).

## **Days-to-Event Variables**

Analyses of these outcomes may require time-to-event variables as well as the endpoint indicator variables. These variables are included in the form of a series of days-to-event variables whose names correspond to the endpoint variable name followed by DAY (e.g., PLWDAY). Functional limitations date variables include dates for those visits a participant actually completed. For participants who missed their visit, we added the "target date" for when their visit should have been done. Both of these dates (actual visit dates and target dates for when there was a missed visit) are used to calculate days-to-event.

For any given endpoint, if the participant has not yet achieved the endpoint, the days-to-event equals the date of most recent contact or the target date (DATE<sub>xxMI</sub>) minus the baseline clinic visit date (CV1DATE). A value of 1 (one) in DATE<sub>xxTARGET</sub> variables indicate that the date is a target date. A value of 0 (zero) means an actual visit date is available.

To find the set of participants who have attained one of these endpoints (e.g. PLW) as of a particular contact (e.g. the Year 2 = 12-month clinic contact), the criterion would be  $PLWDAY \leq (DATE_{12MI} - CV1DATE)$ .

For incident limitation variables:

- If the endpoint has been achieved, the days-to-event equals the actual visit date (or, if the visit was not completed, a target date for that visit) at which the endpoint was achieved minus CV1DATE.

- If the participant has died without achieving the endpoint, the days-to-event equals DOD minus CV1DATE.
- If the participant has died but, due to missing data immediately preceding death, it cannot be determined whether the endpoint was achieved, the record is output for adjudication. The Decedent Proxy Interview is used to determine whether the participant was limited prior to their death. If there is no Decedent Proxy Interview, the endpoint is set to “Not achieved / Live” and the days-to-event variable is calculated as of the last visit date (or target date, if the visit was not completed) with actual (or interpolated) difficulty data minus CV1DATE.
- If an endpoint has not been achieved and information about that activity is incomplete (participant refused to answer, responded “does not do” or missed the most recent contact(s)), the days to event equals the contact/target date with actual/imputed difficulty data minus CV1DATE.

For persistent limitation variables, the days to event is determined by the date of the first of the two successive determinations of limitation.

- For example, if a participant has limitation at both the 12-month and 18-month contacts, the days to event equals DATE12MI minus CV1DATE.
- For all cases where the persistent limitation value is 0 (endpoint not achieved/live), the days to event equals the date of the next to last contact/target date minus CV1DATE.
- For those cases where the participant has died without achieving the endpoint, days to event usually equals DOD minus CV1DATE. However, in cases where the participant missed visits immediately prior to death or failed to answer the required questions on limitations, and there was no decedent proxy interview to determine function prior to death, the endpoint is adjusted to 0 (endpoint not achieved/live) and the days-to-event variable equals the date of the last contact/target date before death.
- In rare cases neither the stair nor the walking endpoint has been reached, and information about one of these activities is incomplete (participant refused to answer, responded “does not do” or missed the most recent contact). In these cases, the days to event for the combined endpoint is conservatively set at the later of the two days to event variables. This applies both to incident and persistent endpoint variables. For example, if PLW=0 and PLWDAY=6248 (participant had no difficulty walking through the Year 17 Quarter 3 contact), but PLS=0 and PLSDAY=6091 (participant had their first difficulty walking at the Year 17 Quarter 1 contact but refused to answer stair question at the Year 17 Quarter 3 contact), then PLL=0 and PLLDAY=6248. If future contacts reveal that the participant has difficulty with stairs and adjudication assigns difficulty to the intervening contacts, then PLLDAY may change to an earlier value.

### **3. Interpolation and adjudication**

When a participant misses a visit, refuses to answer questions related to difficulty walking or climbing stairs, or answers “does not do” to the questions, it may be necessary to fill in imputed values for that visit in order to calculate an endpoint.

Cases when the participant said they “do not do” the activity. Starting at the 12-month contact, one response option for both the walking and stairs questions was “Does not do.” A follow-up question queried the main reason that the participant did not do the activity. The examiners were

directed (and an edit used to check) that any response that was health related should be recorded as having difficulty. Thus, “does not do” responses are presumably for non-health related reasons. When a participant responded “does not do” one or more times bracketed by informative responses (e.g., no difficulty>does not do>a little/some difficulty), the lesser of the bracketing responses was assigned to the “does not do” response. If one or more “does not do” responses came at the end of the follow-up period (e.g., “does not do” for Year 14) following a response of no difficulty, then the data for that participant were censored as of the last informative response. If one or more of the “does not do” responses was followed by death, the rules for patterns involving death (below) were followed.

Cases involving death. If a participant reported difficulty at one contact and died before the next contact, the difficulty was presumed to have persisted until death. If death was preceded by one or more missed contacts (other than missed due to disability, see below), and/or one or more “does not do” responses, information from the Decedent Proxy Interview was used to determine the onset of difficulty, if any. Since it has been well documented that proxies over-report functional limitation (Elam, et al. Am J Public Health. 1991; 81:1127), proxy reports of “some difficulty” or “a lot of difficulty” were both coded as “1: Little/some difficulty.” If the proxy reported that the participant was “unable to do” the activity, it was adjudicated as “2: Lot of difficulty/can’t do.” The proxy’s estimated date of onset of difficulty was compared to the visit window for which information was missing and, if the reported onset of difficulty occurred before the end of the visit window, the difficulty was assigned to that contact. Decedent proxy information was never used to override a participant’s own response before death.

Please note that when a Decedent Proxy Interview was completed for a Health ABC participant, clinic staff would review their Decedent Proxy Interview to determine difficulty status. That process has now been automated; if there is a date of death then the decedent proxy's estimate of how long before death the difficulty began is used to create an estimated onset date for the limitation. A decedent proxy can estimate how long ago the limitation began in days, weeks, months or years. Weeks are multiplied by 7, months are multiplied by 30 and years are multiplied by 365 to get the number of days prior to death the limitation began. This number of days is subtracted from the date of death to calculate the onset date. If participant difficulty data are missing for any contacts that fall within the onset date and date of death, then the decedent proxy's responses are used.

Cases involving putative difficulty. When a participant missed a contact due to illness or being in a nursing home/long term care facility a value of “3:Putative limitation” was assigned to both WALKxxMO and STRxxMO. Putative difficulty was imputed as “1:a little/some” for endpoint calculations.

Cases involving missed contacts or refusal to answer a question. Like “does not do,” missing responses bracketed by informative responses were imputed to the lesser of the bracketing responses. Thus a report of no difficulty>missing>a little/some would be treated as no difficulty>no difficulty>a little/some; a little/some>missing>a lot of difficulty would be treated as a little/some>a little/some>a lot of difficulty; and a little/some>missing>little/some would be treated as three little/somes in a row.

If an analyst wishes to examine the WALK<sub>xx</sub>MO and STR<sub>xx</sub>MO variables underlying a particular outcome variable, the “does not do,” missing, and putative limitation responses were left as is in the respective WALK<sub>xx</sub>MO and STR<sub>xx</sub>MO variables, the imputed values from the interpolation or adjudication are in a separate set of variables renamed WALK<sub>xx</sub>MI and STR<sub>xx</sub>MI, respectively. If no interpolation or adjudication was done for a contact, then WALK<sub>xx</sub>MO= WALK<sub>xx</sub>MI and STR<sub>xx</sub>MO=STR<sub>xx</sub>MI. However, the endpoints assigned are the functional limitation outcomes that should be used in all analyses of functional limitation. That is, analysts are strongly discouraged from second-guessing the interpolation and adjudication process and calculating new endpoints.

#### **4. General description of Disability data**

Disability is typically conceptualized as the loss of the ability to perform tasks necessary to maintain independence. The loss of ability can either be a report that a person cannot do a task or that the person needs assistance in performing the task either from another person or an assistive device. Some analysts use a less stringent definition of disability to include the report of any difficulty in performing Activities of Daily Living (ADL) and/or difficulties with other important functions.

The ability to derive disability end-points in Health ABC is constrained by the consistency of the relevant questions that were asked at each follow-up visit. The relevant questions that were asked on a consistent annual basis were:

1. Because of a health or physical problem, do you have any difficulty walking a quarter of a mile, that is, about 2 or 3 blocks? (If Yes, How much difficulty do you have?)
2. Because of a health or physical problem, do you have any difficulty walking up 10 steps, that is about 1 flight, without resting? (If Yes, How much difficulty do you have?)
3. Do you have to use a cane, walker, crutches, or other special equipment to help you get around?
4. Because of a health or physical problem, do you have any difficulty getting in and out of bed or chairs? (If Yes, Do you usually receive help from another person when you get in and out of bed or chairs?)
5. Do you have any difficulty bathing or showering? (If Yes, Do you usually receive help from another person in bathing or showering?)
6. Do you have any difficulty dressing? (If Yes, Do you usually receive help from another person in dressing?)

Except for Questions 1 and 2 these were not routinely asked on the semi-annual telephone questionnaire.

## Disability endpoints

For each annual visit, the following variables are created for each participant using data from the clinic, phone/home, and proxy questionnaires (x indicates the Year X contact):

**EQUIPx** = Equipment used - Needs a cane or walker to get around at year X

**MOBDISx** = Mobility disability - Cannot walk ¼ mile and/or climb 10 steps at year X

**SEVDIFx** = Severe mobility difficulty - Severe difficulty or cannot walk ¼ mile and/or climb 10 steps at year X

**ADLDIFx** = Activities of Daily Living difficulty - Any ADL difficulty at year X

**ADLDISx** = Activities of Daily Living disability - Needs assistance with an ADL at year X

**ANYDISx** = Any disability - Defined as needing equipment (EQUIPx=1), having severe mobility difficulty (SEVDIFx=1) or having any ADL difficulty (ADLDIFx=1) at Year X

**MAJDISx** = Major disability - Defined as needing equipment (EQUIPx=1), having mobility disability (MOBDISx=1) or needs help with an ADL (ADLDISx=1) at year X

Disability Values: 0 - No disability  
1 - Disability  
2 - Dead

Note: Major disability is a subset of any disability.

Incident disability is defined by two indicator variables if any or major disability, respectively, was reached at any time point covered by the dataset:

**AnyDis** = Incident disability, any (as defined above)

**MajDis** = Incident disability, major (as defined above)

Incident Disability Values: 0 - No  
1 - Yes

The time to disability is defined as the time from baseline until the first annual contact/target date at which any or major disability, respectively, was first reported. Variables are:

**AnyDisDays** = Days from baseline to any disability

**MajDisDays** = Days from baseline to major disability

## **5. Cross reference of dataset names with exact source**

A complete list of variable names can be found in Contents.lst (See Proc Contents for All Outcomes Datasets). Variable names can also be found in listing of calculated variables.

## **6. Dataset structure and contents**

The Functional Limitations and Disability file contains a single observation per participant.

Key variables:

HABCID                      HABC Enrollment ID without the 2-letter prefix

The dataset is sorted by HABCID, and can be merged with other Health ABC datasets by HABCID.

## **7. Condition of data**

### **a. Known data errors:**

None at this time. The data have been edited. Editing will, however, be ongoing (iterative), so use of the most recent dataset is always advised.

### **b. Strength and weaknesses of dataset items:**

Due to initial confusion about the protocol for giving up on attempts to contact a participant and other errors, some participants had contacts out of order. For example, while continuing to attempt to contact a participant for an in-person 12-month (Year 2) visit, the 18-month telephone contact may have been completed. This was particularly prevalent for Year 2 vs 18-month contacts. When the dates of contacts were out of order, the clinics were asked to confirm that the contacts really did occur out of order. If confirmed, the STATxxMO, WALKxxMO, and STRxxMO variables and the associated contact dates used to determine days to event variables for the two contacts were exchanged for the purposes of this dataset. Thus, the information about participant walking and stair status is sequential even if the contacts weren't.