



Transfer of existing REGISTRY participants into REGISTRY 3

The transfer of existing REGISTRY participants (R2) [and their] data into the new REGISTRY study design (R3) is done automatically, prior to the launch of the system. However, you do need to manually enroll every participant (i.e. existing R2 participants and new participants) into the REGISTRY (R3) study.

This means that when accessing REGISTRY after the system change over all previously entered R2 data will be available in the new R3 system for the study site staff.

Subject Overview

Subject: Site: Study:

Refresh 16 matching entries found.

Subject	Site	Studies	Created	Last visit	Next visit	#Visits
068-400-45X	test	REGISTRY2	09.06.11	09.06.11		0
111-111-11a	test	REGISTRY2	14.06.11	13.10.11		0
111-111-11b	test	REGISTRY2	14.06.11	14.06.11		0
111-222-333	test	REGISTRY2	10.06.11	10.06.11		0
112-122-221	test	REGISTRY2	13.06.11	13.06.11		0
112-122-222	test	REGISTRY2	13.06.11	13.06.11		0
123-234-345	test	REGISTRY2 Control	10.06.11	10.06.11		0
222-333-443	test	REGISTRY2	09.06.11	09.06.11		0
222-333-44c	test	REGISTRY2 Control	09.06.11	09.06.11		0
234-654-234	test	REGISTRY2	09.06.11	09.06.11		0
234-654-23c	test	REGISTRY2 Control	09.06.11	09.06.11		0
333-111-222	test	REGISTRY2	13.06.11	13.06.11		0
699-065-987	test	REGISTRY2	10.06.11	10.06.11		0
777-777-777	test	REGISTRY2	10.06.11	10.06.11		0
987-654-333	test	REGISTRY2	10.06.11	10.06.11		0
999-999-999	test	REGISTRY2	10.06.11	10.06.11		0

pic: 1

It is essential that all visits that have ever taken place within REGISTRY before the change over of the system are at the very least created (shown below) before the participant is enrolled into the REGISTRY 3 study. It is not essential that all of the data for those visits is entered at that time but the visits previously done must at least be created.

This is very important because the REGISTRY 3 study CRF differs from the REGISTRY 2 study CRF (some assessments from REGISTRY 2 are no longer administered or have been changed, such as the Hamilton, Becks, etc.). Once a participant is enrolled in REGISTRY 3 (R3) it will not be possible to create REGISTRY 2 visits. Then you will not be able to enter the data set for those visits that you have collected in the past.



How to create a REGISTRY 2 visit in the new REGISTRY system?

Choose the respective participant from the participant list, by clicking on the pseudonym/HDID in the first column in the overview table (pic: 1).

An overview for the participant is presented, showing all **REGISTRY 2 visits** that have been entered for the participant (Ongoing Visits and Completed Visits).

Overview for 112-122-222

Visits Studies

Due Visits

Study	ID in Study	Visit	Due Date	Select?
REGISTRY2	112-122-222	Annual	10.07.2011	<input type="checkbox"/> [cancel visit]

Visit Date: **Create Visit**

Special Visits: **Schedule**

Ongoing Visits

Study	ID in Study	Visit	Remark	Visit Date	State
REGISTRY2	112-122-222	Baseline		10.07.2010	♦ editing ↩

pic: 2

If a REGISTRY visit that took place in the past is not listed and you do have data for the visit available at the clinic; that REGISTRY visit **MUST** be created before any further step is taken.

Overview for 112-122-222

Visits Studies

Due Visits

Study	ID in Study	Visit	Due Date	Select?
REGISTRY2	112-122-222	Annual	10.07.2011	<input checked="" type="checkbox"/> [cancel visit]

Visit Date: **Create Visit**

Special Visits: **Schedule**

Ongoing Visits

Study	ID in Study	Visit	Remark	Visit Date	State
REGISTRY2	112-122-222	Baseline		10.07.2010	♦ editing ↩

pic: 3



EUROPEAN HUNTINGTON'S DISEASE NETWORK

When confident that all visits have been created (the data can be entered at a later point) for REGISTRY 2, the participant can then be transferred from REGISTRY 2 to REGISTRY 3 as demonstrated below:

Click on the 'Studies' tab.

Overview for 111-112-113 - edit

Visits **Studies**

Due Visits

Special Visits:

Ongoing Visits

Study	ID in Study	Visit	Remark	Visit Date	State
REGISTRY2	111-112-113	Annual		15.09.2009	♦ editing ⇄
REGISTRY2	111-112-113	Baseline		10.06.2010	♦ editing ⇄

Upcoming Visits

Study	ID in Study	Visit	Earliest Date	Due Date	Latest Date	
REGISTRY2	111-112-113	Annual	09.11.2011	09.06.2012	08.01.2013	[cancel visit]

pic: 4

Then the participant needs to be **enrolled** into the correct subject category, within the inclusion dialog. Choose whether the person is an HD patient or offspring of an HD patient OR a spousal control subject without family background of HD.

Overview for 111-112-113 - edit

Visits **Studies**

New Studies

INCLUSION TO REGISTRY3:

REGISTRY3 uses different assessments for HD patients and their offspring (tested or untested) on the one hand and spouses, companions etc. to these persons on the other hand.

To select the correct battery of assessments, you need to indicate the category the participant belongs to:

HD patient or offspring

Spouse, companion, etc.

pic: 5

After clicking on 'Enroll' the participant will be transferred from REGISTRY 2 to REGISTRY 3 (R3).

Afterwards data entry and visit creation for visits taking place after the R3 launch date (mid June 2011) can be entered.