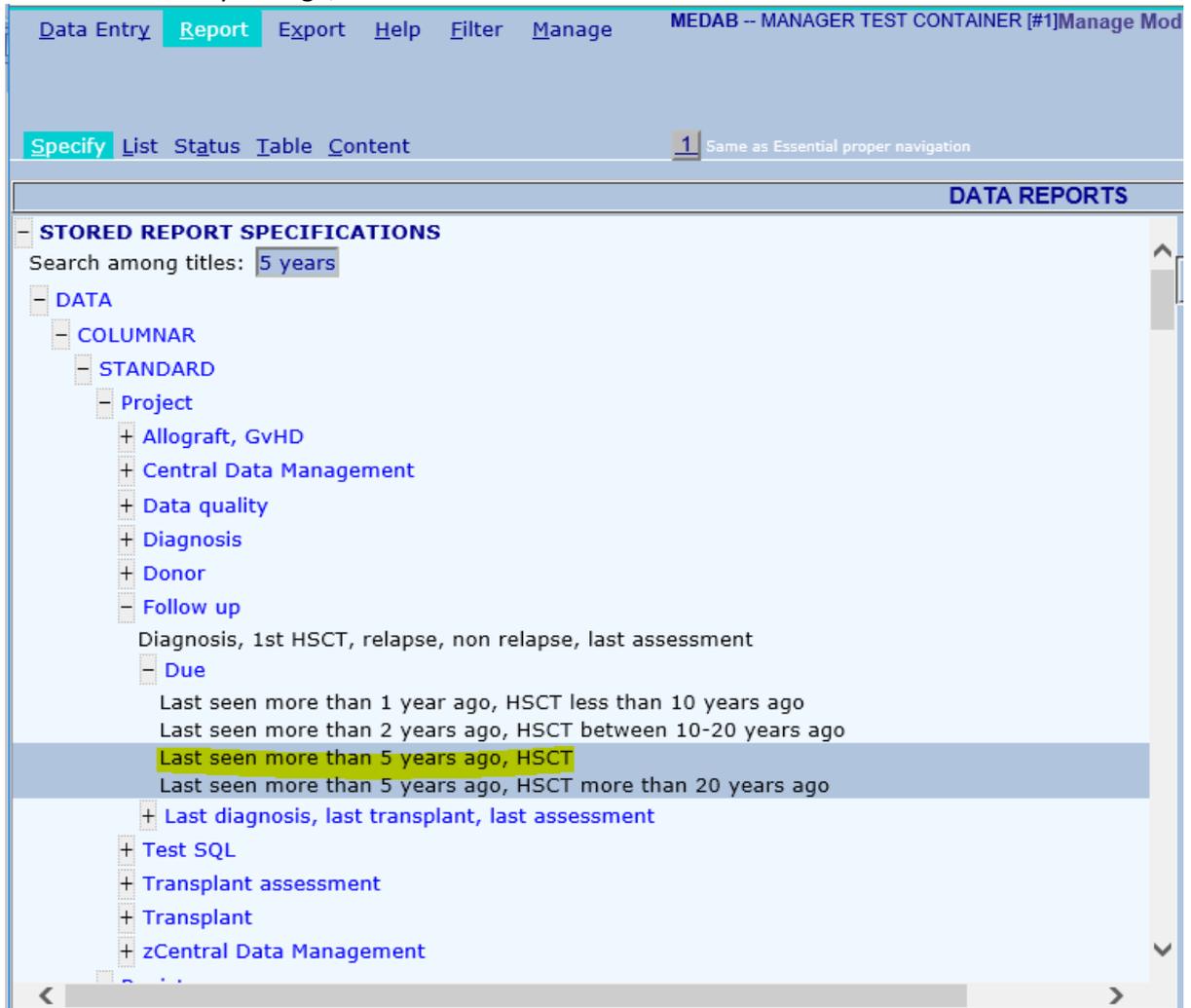


REQUEST FOR 5 YEAR FOLLOW UP: INSTRUCTIONS

Running the report

To obtain a list of patients who have not had a follow up registered for at least 5 years, go to tab [Report] – [Specify] and click this report title (highlighted) in the Stored Report specifications folder:
DATA – COLUMNAR – STANDARD – Project – Follow up – Due –
Last seen more than 5 years ago, HSCT

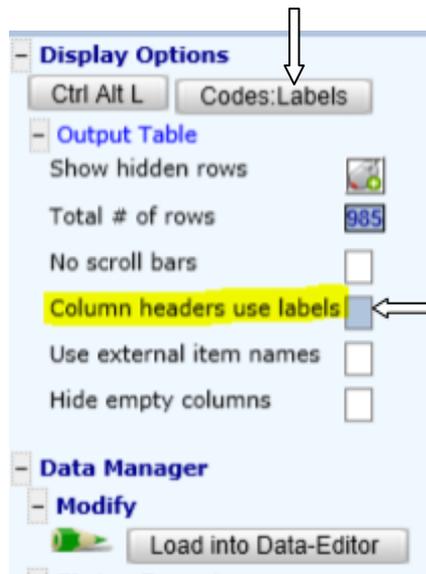


Select [Generate report]

You should obtain a list of transplants in the [List] tab

You can translate the codes to labels using the [Codes:Labels] button

To translate the headers to text, mark the option “Column headers use labels”:



You can transfer the list to Excel using the Print icon (or there is an Excel icon below the results).

Main questions asked in the MED-A [annual follow up form](#):

- GvHD status (allo)
- additional disease treatment since last report
- secondary disease
- first relapse after each transplant
- disease presence
- pregnancy after transplant
- survival status
- cause of death

If you are truly unable to obtain information on the patient, for example they moved to another country and you have completely lost contact, please see further instructions below in point 4, “Lost to follow up”.

Instructions

- 1. Run the report directly in Promise as above.**
- 2. Load the patient directly from the report by right-clicking on the patient ID number.**
- 3. Please enter a new follow up report directly in ProMISe:**

In the first question (Form about to be entered) enter the code for MED-A follow up (code 3) or a MED-B follow up (code 6). You may have to re-enter this same code again and again whenever you have new follow up data

Data Entry Report Export Help Filter MEDAB -- [8001][DEMO][City_1]

Index Editor Overview

Patient	value	label
CIC	8001	8001
Patient	1103	1103

Form information

Form about to be entered

Patient information	value	label
Name of unit or team for the HSCT or Cell therapy	Coquelicot	Coquelicot
Type of unit or team for the last HSCT or Cell therapy	1	Haematology
Contact person for the last HSCT or Cell therapy	anne durand	anne durand
Area code where patient lived at time of HSCT or Cell therapy		
Date of the last report	2016/06/23	2016/06/23
Patient in nat / international study / trial		
Unique Patient Number/code given by hospital	1103	1103
Initial(s) first name	M	M
Initial(s) family name	R	R
Date of birth of the patient	1955/09/20	1955/09/20

Note: Use codes 4, 5 or 6 for

3 Med-A: Follow up

Form about to be entered

1	Med-A: Day 0
2	Med-A: Day 100
3	Med-A: Follow up
4	Med-B: Day 0
5	Med-B: Day 100
6	Med-B: Follow up
9	Cell Therapy Med-A registration

You will be asked the date the follow up data was collected (Date of the last report), whether the patient is in a study and then the cursor will move straight to "Date last contact" where you enter the date the patient was last seen, or the date of death, and you can continue with the follow up entry

4. **If your patient is "lost to follow up"**: please enter the date the patient was last known to be alive in the "date of last contact". Note that this is not the date that you decided the patient was lost to follow up, we need the last date alive. Enter as much data as possible (we understand much of it will be unknown) then put the survival status as "lost to follow up". (This patient will now be excluded from the follow up due reports. If the patient ever comes back into contact again, you will still be able to enter a new follow up report in the future).

If you receive a warning that the last date of contact is too recent, please check it is genuine and contact registryhelpdesk@ebmt.org

For any other registration that does not appear in this list, we would like to remind you of the rules adopted by the EBMT regarding follow up update:

- every year if the patient was transplanted less than 10 years ago,
- every 2 years if the patient was transplanted between 10 and 20 years ago,
- every 5 years if the patient was transplanted more than 20 years ago

We would also like to remind you that one of the requirements for EBMT membership is to report all consecutive haematopoietic stem cell transplants since joining, including follow-up data.

If you have any questions about the follow up questions or the entry in ProMISe please contact us on the [Helpdesk](#)

Thank you very much for your help with the registrations and follow up updates.

EBMT Registry