GUIDE TO PRODUCING DATA QUALITY REPORTS IN THE EBMT REGISTRY DATABASE USING ProMISe

Guide to producing Data Quality Reports in the EBMT Registry Database (November 2010)

Introduction

There are a number of reports, specifically aimed at improving the quality of the data, created within the EBMT Registry Database that we recommend should be run on a regular basis. These, so called, Data Quality Reports will help Centres to check the stored data and to clean up or to manage data in order to ensure accurate and good quality data. Inconsistencies in the data occur when for example changes are made manually or when data is converted to new formats etc. These errors can be minimised by following the usual navigation channels in the database.

This is a basic document to help you to run the basic Data Quality reports. There is more detailed information on Reports in the following document on the EBMT web site - ***Guide to Retrieving Data from the EBMT MED-AB Database (Promise Version 2.2)***.

Overview

The Data Quality Reports which are listed in Table 1 below have been prepared in order to help to address Data Quality issues. Although there are more reports available, for the time being, we recommend only the use of those listed in the Table 1. The Data Quality Reports show, for example: invalid data, missing data, duplicate information, incorrect diagnosis, error messages, conflicting information etc. The reports are useful because they make it easy to see where data is missing or wrongly entered and provide the opportunity to correct the errors. The errors can be edited and corrected within in the Registry database.

Centres who do not enter data directly themselves and whose data are entered by the EBMT Office in Paris can also run Data Quality Reports to check and verify their data. Access can be requested for this using the following form: *Data Entry Application Form* available on the EBMT web site.

If you have a National Registry Office, you may want to discuss with them prior to running these Data Quality Reports as your National Registry may already have set up a Data Quality Report plan/schedule which includes your centre.

We recommend that the reports are run and the corrections are made to the EBMT database regularly – approximately once every 2 – 3 months (depending on the size of the Centre and how many transplants are carried out). By running them regularly, these reports will help to ensure that errors in the data are minimised and that Centres have excellent Data Quality.

End result

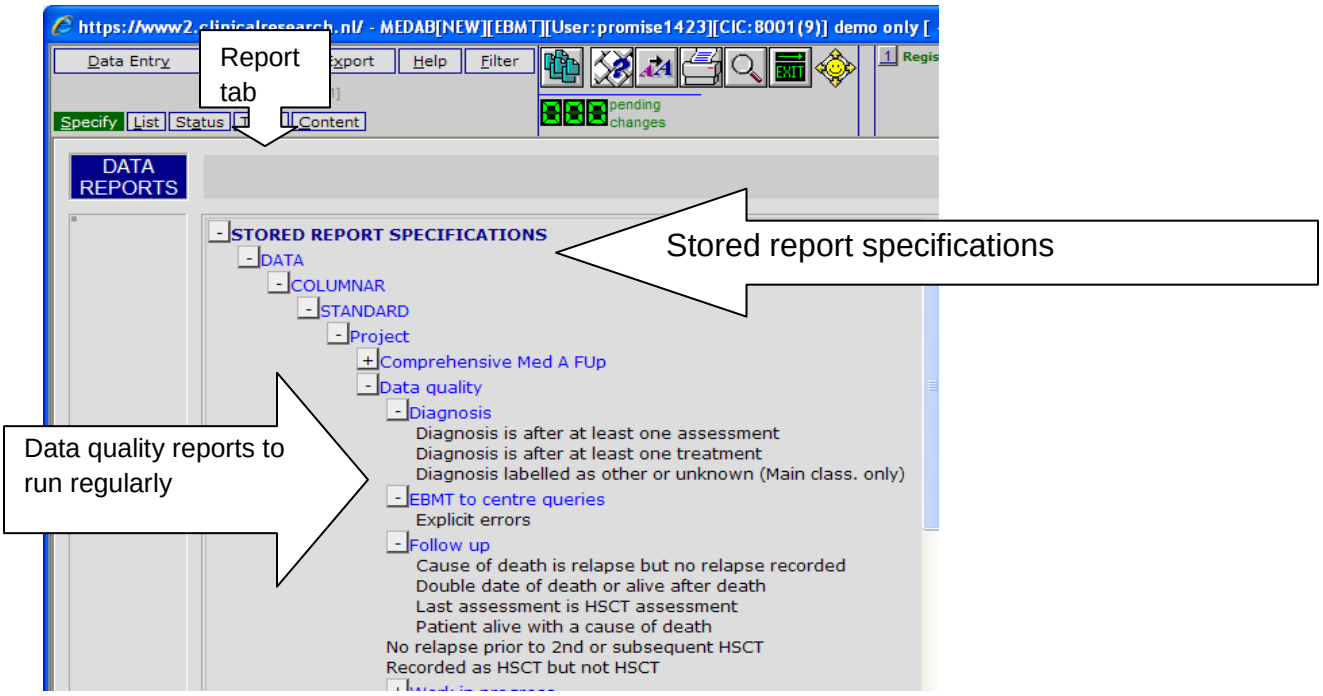
The reports can be used to:-

- Monitor your own data entry (or that of others within your Centre)
- Check on the quality of the data from the Centre(s) for which you have responsibility
- See what data are missing
- Check where data are wrongly entered
- Edit the data directly in the EBMT Registry database
- Make a note of the required amendments and use these to submit the corrections to the EBMT Paris Office or your National Registry via fax or email.

TABLE 1: List of Useful Data Quality Reports to run regularly

The reports specifically aimed at improving the quality of the data are to be found under the general label of **Data Quality** in the Report section of ProMISe, under COLUMNAR/STANDARD/Project. Further Data Quality reports will be added from time to time in the future and we will update you as they become available. You will find a detailed explanation for each report at the end of this document at Appendix 1.

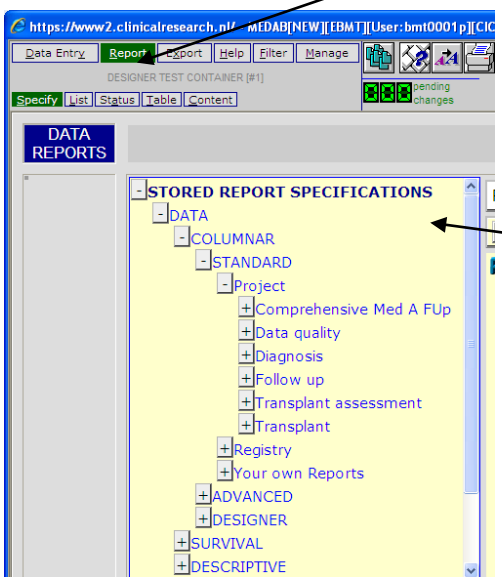
Table 1	
Data Quality Reports	
Diagnosis	Diagnosis is after at least one assessment
	Diagnosis is after at least one treatment
	Diagnosis labeled as other or unknown (Main Classification only)
EBMT to centre queries	Explicit errors
Follow up	Cause of death is relapse but no relapse recorded
	Double date of death or alive after death
	Last assessment is HSCT assessment
	Patient alive with a cause of death
{unlabelled}	No relapse prior to 2nd or subsequent HSCT
	Recorded as HSCT but not HSCT



Summary of Procedure to run the Data Quality Reports:

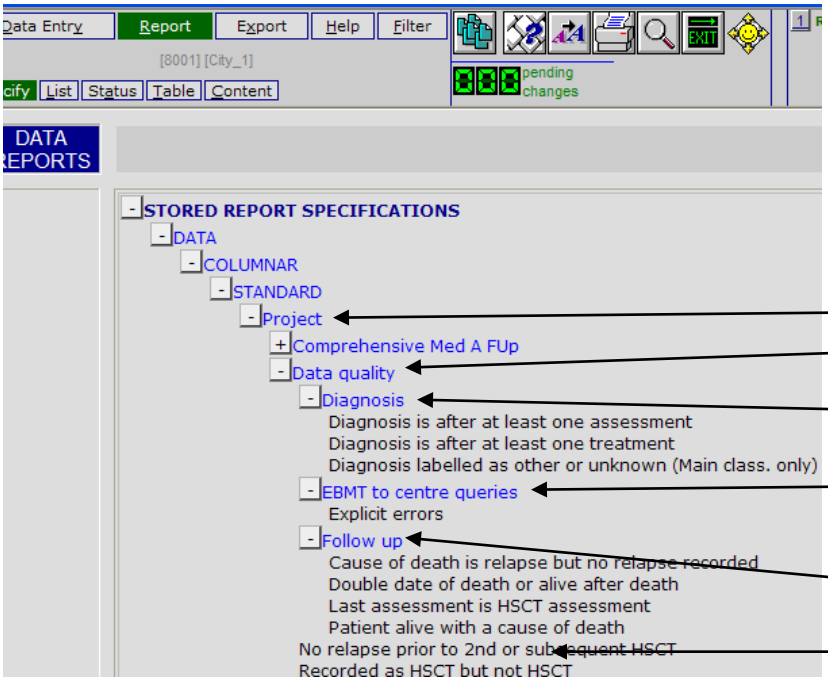
Log into the EBMT Registry database using the ProMISe software in the usual way. If you access more that one CIC, check that you are logged in the correct CIC that you will be working on. If you do not have access, then you can request this using the following form: *Data Entry Application Form* available on the EBMT web site.

Step 1 Click on the [Report tab] at the top of the screen



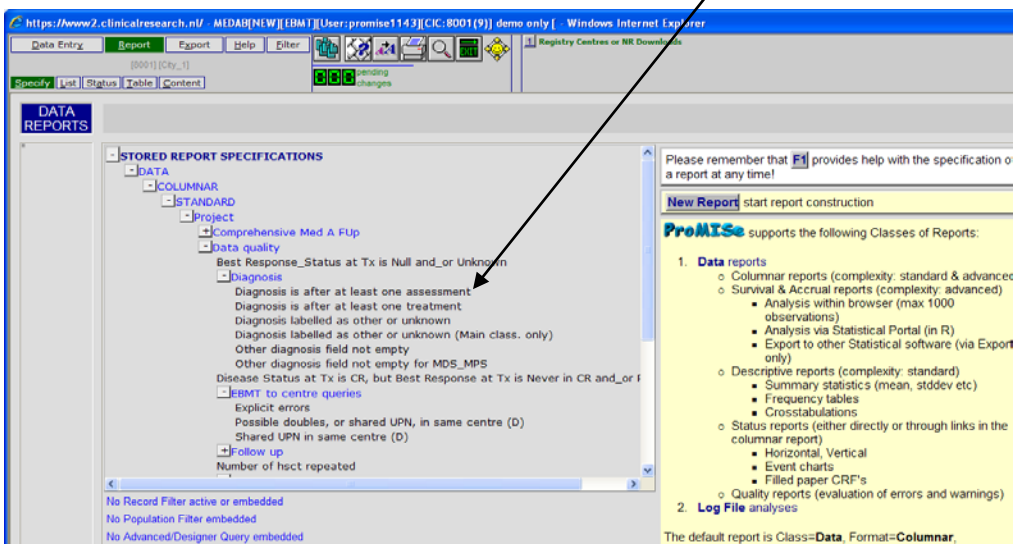
This will open the [Stored Report Specification]

To open the Data Quality Reports, click on the [Data Quality] folder name and open the [foldername] that you need as follows:-

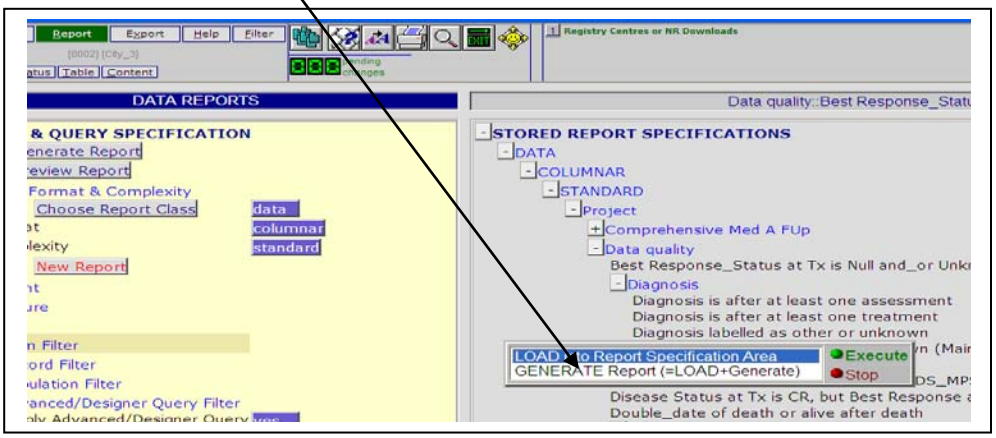


CLICK ON:
[Project]
[Data quality]
and [Diagnosis]
or
[EBMT to centre queries],
or
[Follow up folders
or
report outside subfolder

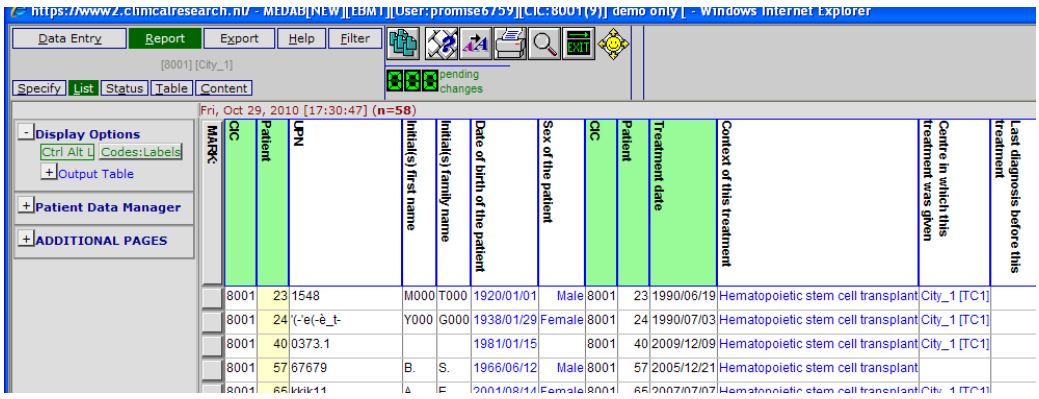
Step 2 Choose the report which you want to run. Click on the [name of that report] in the list.



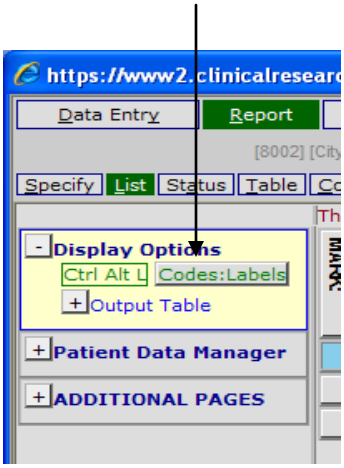
Step 2a Select [Generate Report] →

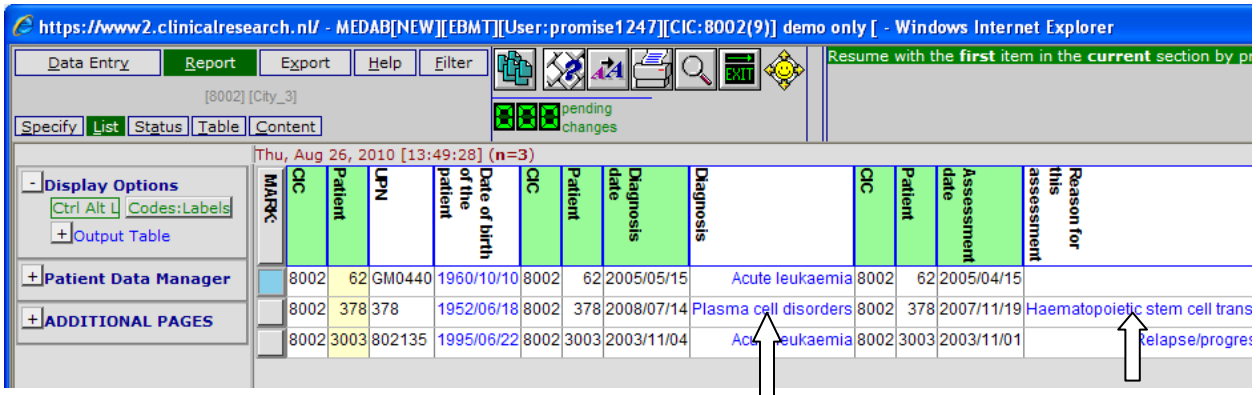


Wait a few moments while your report runs. After a few moments the report will have loaded onto your screen and will look like this:--



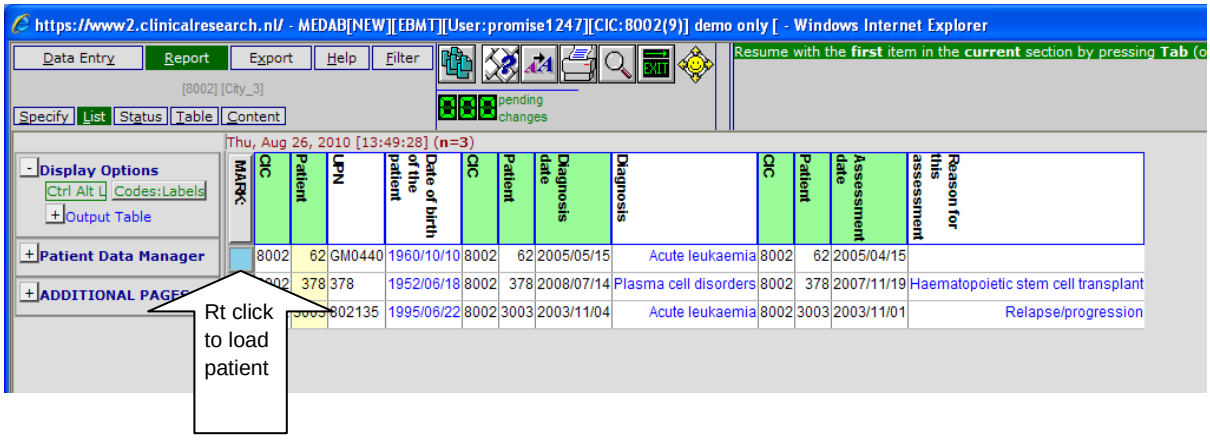
Step 3 **To translate the codes into labels** so that you can see the meaning of the codes for all the fields, go to the top left corner and left click on the [Codes: Labels] tab :-



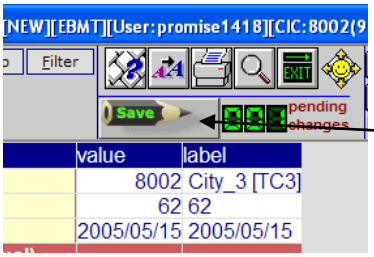


This will display the meaning in all the fields as shown here.

Step 4 You are now ready to check through the report to see which data are missing, wrongly entered etc. To make the necessary amendments, right click on the “mark” box to load the patient – in the same way as you would usually load a patient in the Data Entry index screen.

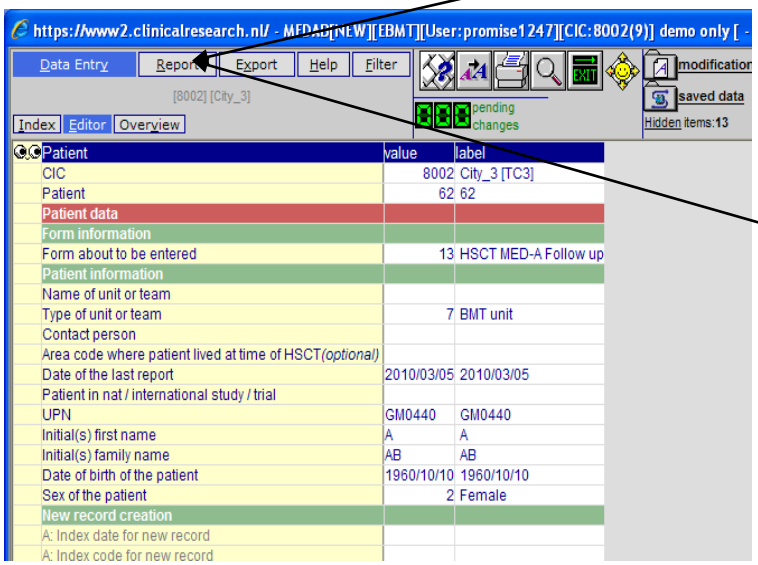


Step 4a Amend the details in the patient's record as required. Please see Appendix 1 for further instructions on making these amendments. Save the changes to the patient's record.



Don't forget to save the changes that you make to the patient's record.

Step 5 To move on to the next patient, return to the Data Quality Report to load the next patient and continue with the checking. To do this: Click on the [Report button] at the top of the screen:

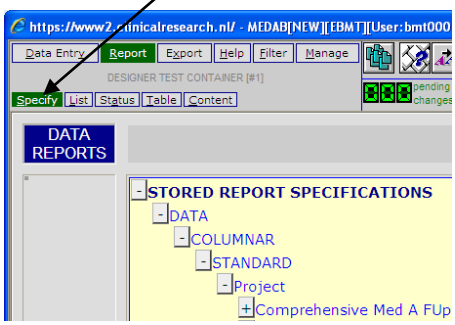


Click on the report button to move between the report and the patient's record

In the Data Quality Report, right click on the "mark" box for the next patient and load the patient – as already illustrated in Step 4 above.

Step 6 To download further Data Quality Reports

Go back to **Step 1** above.
Click on **[Specify]** to start again



Click on [Report] →
Click on [Stored Report Specifications]→
Click on Data → Columnar → Standard → Project → Data Quality and etc. and run the next report.

Step 7 Running Reports

WE DO RECOMMEND That all of the Data Quality Reports listed below at Appendix 1 are run regularly – every 2 – 3 months (in accordance with your centre size/National Registry) – by checking your data regularly your Data Quality will be of the highest standard

REMEMBER - If you need any assistance, contact the help desk (registryhelpdesk@kcl.ac.uk) or your National Registry Office and we will do our best to assist you.

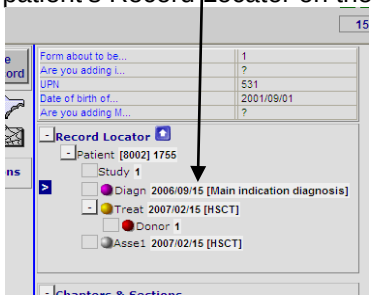
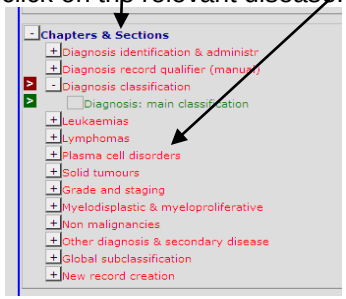
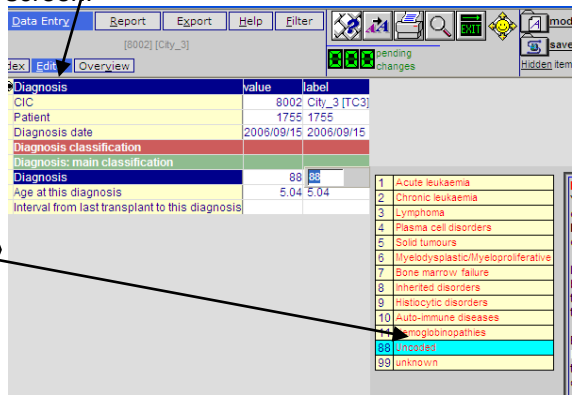
We are keen to hear your views regarding this document. Please let us know what you think by emailing registryhelpdesk@kcl.ac.uk. Please let us know if you found the document to be helpful? too difficult? complicated to follow? too simplistic? Your feedback will help us to improve our Data Quality!.

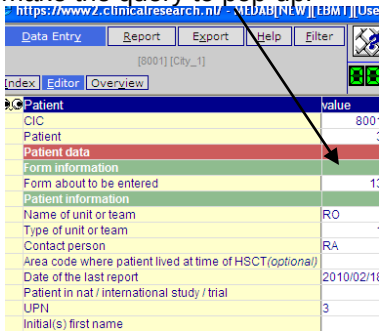
APPENDIX 1 – EXPLANATION OF DATA QUALITY REPORTS

Below a list of the reports which are available with a brief explanation of their potential uses. There are more Data Quality reports in the EBMT Registry database stored under "Work in progress". For the time being, we recommend that you use only those detailed below. Further reports will be added from time to time in the future and we will update you as these become available.

Name of report	Rationale of report	Details of report	Action or amendment required
DATA QUALITY REPORTS: Diagnosis			
Diagnosis is after at least one assessment	1) To check that the date of the diagnosis and/or an assessment have been entered correctly. 2) A patient should always have the diagnosis first and any assessment date should be <u>after</u> or <u>the same</u> as the diagnosis date. 3) If the date of the assessment is before the diagnosis, there is an error in one of these dates	This report shows patients in which an assessment has been entered <u>before</u> the first diagnosis record. The report shows a list of patients with a column on the left [Diagnosis Date] indicating the date of their diagnosis and a column on the right [Assessment date] showing the assessment date that has been recorded before the diagnosis date. This is incorrect.	ACTION: Verify the patient's details. Check both dates and amend the data as applicable. **NB Please remember – the diagnosis may have a related <u>Assessment</u> record, in which case, if it is the date of diagnosis that is incorrect, the date must be changed in both the <u>Diagnosis</u> record and the corresponding <u>Assessment Record.</u>** Save the changes made. Click on the [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients' records.

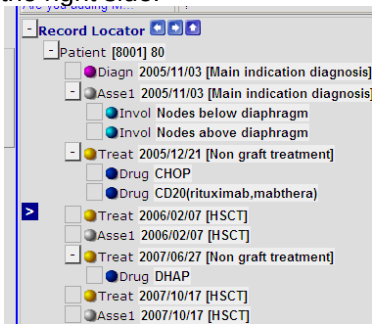
Name of report	Rationale of report	Details of report	Action or amendment required
Diagnosis is after at least one treatment	1) To check that the date of the diagnosis and/or of a treatment have been entered correctly. 2) A patient should always have the diagnosis first and any treatment date should be after or the same as the diagnosis date. 3) If the date of the treatment is before the diagnosis, there is an error in one of these dates	This report shows patients in which a treatment has been entered before the first diagnosis record. The report shows a list of patients with a column on the left [Diagnosis date] indicating the date of their diagnosis and a column on the right [Treatment date] showing the treatment date that has been recorded before the diagnosis date. This is incorrect.	ACTION: Verify the patient's details. Check both dates and amend as necessary. **NB Please remember – the diagnosis may have a related Treatment record, in which case, if it is the date of diagnosis that is incorrect, the date must be changed in both the diagnosis record and the corresponding Treatment Record. The diagnosis may also have a related Assessment record which also needs to be changed.** Save the changes made. Click on the [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients' records

Diagnosis labeled as other or unknown (Main class. only)*	**** NB Ensure you are logged on to the whole database using MEDAB- All diseases to run this report**.** 1) This report will show patients for whom the diagnosis code has not been specified correctly or fully for the diagnosis for the HSCT. 2) It is very rare for a diagnosis to be “uncoded” 3) It is not possible for a diagnosis to be “unknown”.	The report shows a list of patients with a column on the right side [Type of diagnosis] indicating the main diagnosis. Other columns are: [Diagnosis] [Disease classification] The [Diagnosis field] has been left blank or the diagnosis has not been completely specified. _____ ACTION: If completely coded, erase the entry in the [Other diagnosis, specify] field. If the diagnosis is truly “uncoded” please inform the Registry. **Note:** It is acceptable to use “uncoded” if there are two diseases diagnosed simultaneously (very rare). In these cases, this should be explicitly stated in the [Other diagnosis, specify] field, and both diagnosis should be fully coded in their respective subclassificati ns. Enter the correct code. Save the changes made. Click on the [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients’ records 11	ACTION: Check the diagnosis against the patient’s records. Load the patient. To amend the diagnosis, click on the [Diagnosis tab]in the patient’s Record Locator on the right side  Click on [Diagnosis Classification] in the Chapters and Sections part of the screen and click on the relevant disease:  Click on the [Diagnosis box]in the patients record which will open up on the left part of the screen.  Enter the correct code. Save the changes made. Click on Report at the top of the screen to return to the DQ Report to continue checking the patients’ records.

Name of report	Rationale of report	Details of report	Action or amendment required
EBMT TO CENTRE QUERIES			
Explicit errors	1) To check if there are queries for your Center from EBMT Registry or Working Parties. 2) EBMT registry staff have noticed some data missing on the paper forms which they have received or they have detected inconsistencies in the stored data. 3) A query message is placed in the *EBMT to centre* field in patient's records noting the inconsistency found. 4) A warning message appears the next time you go into that patient's record. **We recommend that you run this report regularly – monthly.**	The report provides a list of the patients where there is an ***EBMT to centre query – error or omission.*** The report shows the list of patients with a column on the right [Outstanding query] providing details of the query or inconsistencies in the data.	ACTION: Make a note of the query detailed in the Data Quality Report. Load the patient's details. Verify the patients details against the query listed in the *Explicit errors* field. Check the details and update the patient's record accordingly. Save the changes made. Click on [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients' records. If required, at any moment during data entry, the query can be viewed in the patient's record as follows: - Click on the first field available during data entry: [Form about to be entered] field. This will make the query to pop-up.  **After you have actioned, please inform the Registry Helpdesk so that the query can be removed**

Name of report	Rationale of report	Details of report	Action or amendment required
FOLLOW UP			
Cause of death is relapse but no relapse is recorded	1) The cause of death for the patient has been recorded as *relapse,* however no details relating to the relapse have been recorded, or, alternatively, the relapse box has been entered as *no.* *2)* The details of the patient's *relapse* should always be recorded when the *cause of death* has been recorded as *relapse.* 3) Alternatively, the *cause of death* may have been wrongly recorded as *relapse* and needs to be corrected.	The report shows a list of patients with a column [Relapse or progression after transplant] on the right side. This field has been left *empty* or *No* has been recorded. If the patient has relapsed, ensure the relapse assessment exists with the correct date. If the patient has not relapsed, correct the cause of death.	**ACTION**: Load the patient (right click on the fist box – *marker box*). Verify the patient's details. If the patient has relapsed, enter the correct assessment date for relapse. To do this, enter a [follow up form] using date of death or date last seen, and follow the normal navigation.
Double date of death or alive after death	1) The patient's status has been recorded as dead on more than one date. 2) There may be additional assessment records created after the date of death which should be impossible. 3) One or more of the dates is incorrect and/or the patient's status has been incorrectly entered.	The report shows the list of patients with the column in the centre showing *Survival status on this date* as dead. There is a column on the right which shows a further assessment record at a later date (i.e. after the date of death).	**Action**: Load the patient (right click on the fist box – *marker box*). Verify the patient's details. If patient is alive, change the status for the record in which it has been coded as "dead" to "alive". If there are two dates of death, and patient is dead, amend the relevant assessment record, or delete the incorrect record. NB - Always check the data registered in the assessment records involved in the corrections. You may need to copy data from one record to another to ensure there is no loss of information on deletion of one record.

Name of report	Rationale of report	Details of report	Action or amendment required
FOLLOW UP			
Last assessment is HSCT assessment	1) Follow up data has not been provided for these patients. And yet HSCT was performed more than 100 days ago. 2) Ensure the patient has an annual follow up appointment and that the follow up data is entered annually.	The report shows the list of patients with the column on the right showing the [Assessment date]. There is a column on the left with the [Treatment date.]. You may need to use the blue horizontal scroll bar at the bottom of the screen to view all the details on the right. The date is the same for the HSCT treatment and the assessment – no follow up data has been provided for these patients.	ACTION: Verify the patient's details. Enter the patient's follow up details. To do this, enter a [follow up form] using date last seen or date of death and follow the normal navigation. Save the changes. Click on the [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients' records.
Patient alive with cause of death	1) Cause of death field has been recorded in the patient's record. 2) The patient status is alive. 3) This is incorrect and one of these fields has been wrongly entered.	The report shows the list of patients with the column in the centre showing main cause of death. There is a column on the right which shows the survival status which has been recorded as alive or left blank.	**Action**: Load the patient (right click on the fist box – *marker box*). Verify the patient's details. If patient is alive, delete cause of death. If patient is dead, amend the relevant assessment record, or add the date of death. To do this, enter a [follow up form] using date of death or date last seen, and follow the normal navigation.
No relapse prior to 2nd or subsequent HSCT	1) There is a period of over 100 days between HSCT1 and HSCT2. 2) Disease status at 2nd HSCT compared with response to 1st HSCT indicates there must have been a relapse/progression between HSCTs. 3) This relapse / progression assessment record is missing.	The report shows a column on the left [Treatment date] indicating the date of the first HSCT and a column on the right [Treatment date] with the date of the second HSCT. Other columns are 1st HSCT: Best Response 2nd HSCT: Best Response & Disease Status.	ACTION: Verify the patient's details. If the patient has relapsed, enter the relapse assessment record, between transplants, with the necessary information. If the patient has not relapsed, correct the necessary data for disease status and/or response. **Save** the changes made. Click on the [Report tab] at the top of the screen to return to the DQ Report to continue checking the patients' records

Name of report	Rationale of report	Details of report	Action or amendment required
Recorded as HSCT but not HSCT	1) To check that the HSCT field has been correctly entered. 2) In some cases the treatments have been labeled as HSCT (code 7) - however there is no information on stem cells, only donor lymphocyte infusion DLI or other type of cell therapy. 3) There is a query as to whether this is really a transplant. 4) If yes, then the transplant record needs to be filled in properly. If not, then the record needs to be correctly labeled.	The transplant field has been filled in – shown in output as cell therapy fields. Check if truly a transplant (HSCT)	ACTION: Load the patient's record. To make any amendments, click on the [Treatment_date HSCT] tab in the patient's Record Locator on the right side.  To enter the correct code(s), go to the [Chapters and Sections] section at the bottom of the screen. Click on the [Treatment record qualifier (manual)] tab to locate the field in the patient's record which requires amendment