

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

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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 - <u>Guide to Retrieving Data</u> 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: <u>Data Entry Application Form</u> 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.

<u>We recommend</u> 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 2 nd 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: <u>Data Entry Application Form</u> available on the EBMT web site.



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

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

Data Entry Report Export Help Filter [8001] [City_1] [8001] [City_1] Image: Changes Image: Changes	
STORED REPORT SPECIFICATIONS -DATA -COLUMNAR -STANDARD -Project +Comprehensive Med A FUp -Data quality -Diagnosis -Diagnosis -Diagnosis -Diagnosis after at least one assessment Diagnosis is after at least one treatment Diagnosis labelled as other or unknown (Main class. 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 Patient alive with a cause of death No relapse prior to 2nd or subequent HSCT Recorded as HSCT but not HSCT	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.





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.

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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:

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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

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Click on [Report] \rightarrow Click on [Stored Report Specifications] \rightarrow Click on Data \rightarrow Columnar \rightarrow Standard \rightarrow Project \rightarrow 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 <u>registryhelpdesk@kcl.ac.uk</u>. 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	 To check that the date of the diagnosis and/or an assessment have been entered 	This report shows patients in which an assessment has been entered <u>before</u> the first diagnosis record.	ACTION: Verify the patient's details. Check both dates and amend the data as applicable.				
	 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 	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.	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	1)	To check that the date of the	This report shows patients in which	ACTION: Verify the patient's details. Check
treatment		diagnosis and/or of a treatment	a treatment has been entered	both dates and amend as necessary.
		have been entered correctly.	before the first diagnosis record.	
				NB Please remember – the diagnosis may
	2)	A patient should always have	The report shows a list of patients	have a related <u>Treatment</u> record, in which
		the diagnosis first and any	with a column on the left [Diagnosis	case, if it is the date of diagnosis that is
		treatment date should be <u>after</u>	date] indicating the date of their	incorrect, the date must be changed in both
		or <u>the same</u> as the diagnosis	diagnosis and a column on the right	the diagnosis record and the corresponding
		date.	[Treatment date] showing the	<u>Treatment</u> Record. The diagnosis may also
			treatment date that has been	have a related <u>Assessment</u> record which
	3)	If the date of the treatment is	recorded before the diagnosis date.	also needs to be changed.
		before the diagnosis, there is	This is incorrect.	
		an error in one of these dates		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	The report shows a list of patients with a column on the right side [Type of diagnosis] indicating the	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 Description of the right of the sector of the right of the sector of the right of the sector o
	report**.	main diagnosis.	patient's Record Locator on the right side
	1) This report will show patients for whom the diagnosis code has not been specified correctly or fully for	Other columns are: [Diagnosis] [Disease classification]	Form about to be 1 Are you adding L 7 UM 531 Date of birth of 2001/09/01 Are you adding M 7
	the diagnosis for the HSCT.	The [Diagnosis field] has been left	Second Locator and Second Locator and Second Locator Second Locato
	2) It is very rare for a diagnosis to be "uncoded"	blank or the diagnosis has not been completely specified.	Olagn 2006/99/15 [Main indication diagnosis] OTreat 2007/02/15 [HSCT] ODoor 1 OAsse1 2007/02/15 [HSCT]
	3) It is not possible for a diagnosis to be "unknown".		Click on [Diagnosis Classification] in the
		ACTION: If completely coded, erase the entry in the [Other	click on the relevant disease.
		diagnosis, specify] field.	Chapters & Sections Diagnosis identification & administr Diagnosis record qualifier (manuar)
		If the diagnosis is truly "uncoded" please inform the Registry.	 Diagnosis: classification Diagnosis: main classification teukaemias tuymphomas
		Note: It is acceptable to use	Plasma cell disorders Solid tumours Grade and staging Multi-industrial multiplicative
		"uncoded" if there are two diseases diagnosed simultaneously (very	+ Non malignatics + Other diagnosis & secondary disease + Global subclassification
		rare). In these cases, this should be explicitly stated in the [Other	Lick on the [Diagnosis box]in the patients
		diagnosis, specify] field, and both	record which will open up on the left part of the screen.
		their respective subclassifications.	Data Entry Beport Export Help Filter [8002] [Chy_3] [8002] [Chy_3] [8002] [Chy_3] [8002] [Chy_3] Jex Edit Overview [1000] [Chy_3]
			Orignosis Value Jabel CIC 8002 City_3 (TC3) Patient Patient 1755 1755 Descenders
		Enter the correct code. Save the changes made.	Diagnosis classification Diagnosis: main classification Diagnosis: main classification Diagnosis Ana et his diagnosis
		Click on the [Report tab] at the top of the screen to	Arge a truits diagnosis Interval from last transplant to this diagnosis
		continue checking the patients' records	7 Bone marrow failure 8 inherted disorders 9 Histocytic disorders 10 Auto-Immune diseases
			11 Bringgbingstilles 88 Pragaest 99 Junknown
		11 /	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.	The report provides a list of the patients where there is an <i>EBMT to centre query – error or omission.</i>	ACTION: Make a note of the query detailed in the Data Quality Report. Load the patient's details.
	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	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	Verify the patients details against the query listed in the <i>Explicit errors</i> field. Check the details and update the patient's record accordingly.
	 3) A query message is placed in the <i>EBMT to centre</i> field in patient's records noting the inconsistency found. 		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.
	4) A warning message appears the next time you go into that patient's record.		If required, at any moment during data entry, the query can be viewed in the patient's record as follows: -
	We recommend that you run this report regularly – monthly.		Click on the first field available during data entry: [Form about to be entered] field. This will make the query to pop-up. https://www.elimicalresearch.nl/ YEVAU(NEW][EMAT][Use Reta Entry Report Export Help Filter Retained Retained to the last report Value Click Editor Overview Patient data Form about to be entered 1: Patient Information Form about to be entered 1: Patient Information Retained to the last report Patient Information Area code where patient lived at time of HSCT(optional) Date of the last report Patient Informational study / trial UPN
			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	 The cause of death for the patient has been recorded as <i>relapse</i>, however no details relating to the relapse have been recorded, or, alternatively, the relapse box has been entered as <i>no</i>. The details of the patient's <i>relapse</i> should always be recorded when the <i>cause of death</i> has been recorded as <i>relapse</i>. Alternatively, the <i>cause of death</i> may have been wrongly recorded as <i>relapse</i> 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 <i>empty</i> or <i>No</i> has been recorded. <u>If the patient has relapsed</u> , ensure the relapse assessment exists with the correct date. If the patient has <u>not</u> 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	 The patient's status has been recorded as dead on more than one date. There may be additional assessment records created after the date of death which should be impossible. 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 <i>Survival status on this date</i> 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.	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.].	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.
	2) Ensure the patient has an <u>annual</u> follow up appointment and that the follow up data is entered annually.	You may need to use the blue horizontal scroll bar at the bottom of the screen to view all the details on the right.	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.
		The date is the same for the HSCT treatment and the assessment – no follow up data has been provided for these patients.	
Patient alive with cause of death	1) Cause of death field has been recorded in the patient's record.	The report shows the list of patients with the column in the centre showing main cause of death.	Action: Load the patient (right click on the fist box – <i>marker box</i>). Verify the patient's details.
	2) The patient status is alive.	There is a column on the right which shows the survival status	If patient is alive, delete cause of death.
	3) This is incorrect and one of these fields has been wrongly entered.	which has been recorded as alive or left blank.	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 2 nd or subsequent HSCT	 There is a period of over 100 days between HSCT1 and HSCT2. Diagage status at 2nd HSCT 	The report shows a column on the left [Treatment date] indicating the date of the first HSCT and a column on the right [Treatment data] with	ACTION: Verify the patient's details. If the patient has relapsed, enter the relapse assessment record, between transplants, with
	compared with response to 1 st HSCT indicates there must have	the date of the second HSCT.	If the patient has <u>not</u> relapsed, correct the
	been a relapse/progression between HSCTs.	Other columns are 1 st HSCT: Best Response 2 nd HSCT: Best Response &	necessary data for disease status and/or response. Save the changes made.
	 This relapse / progression assessment record is missing. 	Disease Status.	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	The transplant field has been filled	ACTION: Load the patient's record. To make
	been correctly entered.	in – shown in output as cell therapy	any amendments, click on the [Treatment_date
	2) In some cases the treatments	HSCT)	the right side
	have been labeled as HSCT (code		
	7) - however there is no information		Patient [8001] 80
	on stem cells, only donor		Diagn 2005/11/03 [Main indication diagnosis] Asse1 2005/11/03 [Main indication diagnosis]
	lymphocyte infusion DLI or other		Invol Nodes below diaphragm
	type of cell therapy.		Treat 2005/12/21 [Non graft treatment]
	3) There is a query as to whether		Drug CD20(rituximab,mabthera)
	this is really a transplant.		Treat 2006/02/07 [HSCT]
			Treat 2007/06/27 [Non graft treatment] Drug DHAP
	4) If yes, then the transplant record		Treat 2007/10/17 [HSCT] Assel 2007/10/17 [HSCT]
	needs to be filled in properly. If not,		
	then the record needs to be		To enter the correct code(s), go to the
			[Chapters and Sections] section at the bottom
			of the screen. Click on the [] reatment record
			patient's record which requires amendment
			-Chapters & Sections
			 treatment identification & administr Treatment record qualifier (man al)
			Date precision
			+ General
			+Transplant and cell source specifics + Ex-vivo graft manipulation
			- Main treatment
			General
			Total body irradiation, details
			Total body irradiation, continued Other modalities
			+Hospital admin (STABMT) +Supportive treatment in the patient
			+Cellular therapy (non HSCT)