



Dear Data Manager

RE: DATA QUALITY CHECKS – WE NEED YOUR HELP PLEASE!

I am contacting you to ask for your assistance in checking your centre's data before it is transferred from ProMISe into the new system. These Data Quality reports will help to identify some key Data Quality issues - such as invalid data, missing data, duplicate information, incorrect diagnosis, error messages and conflicting information. This is an important exercise as some records may not be transferred to the new system if the data has not been correctly recorded.

- We will send you an **Excel file** very shortly and this will contain a number of Data Quality reports. We would like you to please check the patient data in this spreadsheet. The reports are straightforward to check. Here is a brief summary of what is involved:-
- The file will be password protected and you will receive the password in a separate email
- Below you will find a table with details of what is involved with checking the reports in the Excel spreadsheet.
- When you open the Excel spreadsheet, it will contain a number of sheets – each sheet will represent one of the Data Quality Reports for your Centre
- Please check the patient's details in each of the reports. You should refer to the explanation in the table below. Enter the correct data in the **last column** of each separate sheet.
- Save the document as you go along.
- When you have finished checking all the reports, save the spreadsheet and then email it back to us at: registryhelpdesk@ebmt.org. We will then make the corrections in the database.

When you receive the file, it may look like a large file of queries but please do not be discouraged! – some of them will be very brief and will only take a few moments to check.

Please note, you may not receive all of the reports listed in the *Instructions document* – you will only receive the one where errors have been identified.

We are happy to help you, so if you need any help please contact us on registryhelpdesk@ebmt.org for any further assistance.

So please help us to ensure that your data is as accurate as possible for the forthcoming data transfer. And finally, *THANK YOU – WE REALLY DO APPRECIATE ALL OF YOUR HELP.*

“TIDY UP YOUR DATA”

EBMT REGISTRY DATA QUALITY REPORTS - TO CHECK AND CORRECT THAT YOUR DATA IS ACCURATE AND UP TO DATE

Report name	ProMISe report name	Details of report	Patient’s details	Data for correction – missing data, errors etc	Action required	Amendment required
Diag 3	Diagnosis labelled as other or unknown (Main Classification only)	<p>The main code for the diagnosis has may not have been specified correctly.</p> <p>NB It is not possible for a diagnosis to be “unknown” and it is very rare for a diagnosis to be “uncoded”</p>	<p>The left hand columns show patient’s details (purple heading):</p> <p>CIC no UIC no Patient’s initials DOB</p>	<p>The middle column (orange heading) shows:</p> <p>Diagnosis date Diagnosis</p> <p>Which are blank or coded as “other” or “unknown”</p> <p style="text-align: center;">*****</p> <p>The right hand column (blue heading) contains the Patient’s UPN no.</p>	Check the diagnosis in the patient’s hospital record	<p>Write the correct (full) diagnosis in the last column of the spreadsheet (labelled Correction remarks)</p> <p>Save the spreadsheet.</p>

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Diag 4	Diagnosis sub classification labelled as other or unknown	The diagnosis <u>sub classification</u> has not been completely specified or some data are missing	The left hand columns (purple heading) show patient's details: CIC no UIC no Patient's initials DOB	The middle (orange heading) columns show: Diagnosis date Diagnosis sub-classification which is blank or incorrectly coded coded as "other" or "unknown" ***** The right hand column (blue heading) contains the Patient's UPN no.	Check the diagnosis in the patient's hospital record We would appreciate if you could check this list – however it is possible that it includes genuine "other" diagnosis. For more info please download: List of disease classifications	Write the correct (full) sub classification of the diagnosis in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet.
Dis Stat 1	Best Response_Status after HSCT is Null and_or Unknown	The <u>response status</u> of the patient after HSCT (day 100) has not been entered	The left hand columns show patient's details (purple heading): CIC no UIC no Patient's initials UPN no DOB	Data has not been entered in the right hand column (orange heading) "Best Response" – or it has been recorded as "unknown"	Check the correct "Best response" for this HSCT in the patient's hospital record. For more info please download: Summary of Disease status and Response by disease	Write the "Best Response after HSCT" (day 100) in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Dis Stat 2	Disease status at HSCT is Null and_or Unknown	The disease status of the patient at HSCT has not been entered	The left hand columns show patient's details (purple heading): CIC no UIC no UPN no Patient's initials DOB	Data has not been entered in the right hand column (light blue heading) "Disease status at HSCT" – or it has been recorded as "unknown"	Check the correct status of "Disease status at HSCT" in the patient's hospital record. The column "Assessment date" indicates the date of the relevant HSCT For more info please download: Summary of Disease status and Response by disease	Write the correct Disease Status at HSCT in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet
Dis Stat 3	Missing number of this Disease status at HSCT	The number of the Disease status at HSCT (e.g. CR: 1 st , 2 nd , 3 rd ?) has been left blank	The left hand columns show patient's details (purple heading): CIC no UIC no Patient's initials DOB	The Number of the Disease status at HSCT has not been recorded in the "Disease status" column in the Assessment section (green section).	Check the number of the "Disease status at HSCT" (e.g. CR 1 st , 2 nd , 3 rd) for this HSCT in the patient's hospital record. The column "Assessment date" indicates the date of the relevant HSCT	Fill in the number (1,2,3..)of the Disease status in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Dis Stat 4	No relapse prior to 2 nd or subsequent HSCT	A 2 nd or subsequent HSCT has been registered. The disease status indicates that there must have been a relapse/progression between transplants. However relapse has not been indicated in the record	The left hand columns show patient's details (purple heading): CIC no UIC no UPN no DOB Patient's initials	The middle (orange heading) columns show: HSCT date ***** The right hand column (blue heading) contains the second or subsequent HSCT data.	No details of a relapse have been recorded	Write the date of the relapse between transplants in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet
Foll_up 1	Cause of death is GvHD but no GvHD recorded	The cause of death has been recorded as GvHD. However no details relating to GvHD have been recorded in the patient's record.	The left hand columns show patient's details (purple heading): CIC no UIC no Treatment date DOB Patient's initials Cause of death is marked as GvHD	The Assessment columns "Chronic graft" and "Extent of GvHD" (orange section) are blank or unknown	Check cause of death Check and confirm the details of GvHD <ul style="list-style-type: none"> • No • Yes – 1st episode • Yes before this date • Yes recurrence • Continuous since last HSCT • Resolved • Unknown Grade <ul style="list-style-type: none"> • Limited • Extensive • Resolved • Unknown Date of onset Date of resolution	Confirm details of the GvHD in the last column of the spreadsheet (labelled Correction remarks): Save the spreadsheet

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Foll_up 2	Cause of death is relapse but no relapse recorded	The cause of death has been recorded as relapse. However there are no details relating to relapse in the patients record.	The left hand columns show patient's details (purple heading): CIC no UIC no Patient UPN no DOB Patient's initials ***** Middle column: Treatment date (orange section)	The Main cause of death has been recorded as "Relapse or progression of original disease" (light blue section). However, no relapse/progression data are recorded after the HSCT in the patient's record.	Check & confirm cause of death is "relapse" Check & confirm the date of the <u>first relapse after transplant.</u> For Leukemias: Please also include date of cytogenetic and/or molecular relapse	Confirm that cause of death is "relapse". Write the date of the first relapse after transplant and/or assessment dates for Leukaemias in the last column of the spreadsheet: labelled Correction remarks) Save the spreadsheet
Foll_up 3	Last assessment is HSCT assessment	Follow up data has not been provided – although HSCT was performed more than 100 days ago.	The left hand columns show patient's details (purple heading): CIC no UIC no Patient's initials DOB ***** The middle column (orange heading) shows the details of the Treatment	In the right hand column (light blue section) no follow up data 100 days after HSCT has been recorded	Follow up data is required at 100 days and then <u>annually</u>	Complete a Med A follow up form (page 18) and fax it through to EBMT Registry office: <i>Fax:+44 (0)20 71 88 84 11</i> Please mark the last column in the spreadsheet: FU sent Save the spreadsheet

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Foll_up 4	Patient alive with a cause of death	A cause of death has been recorded in “cause of death field”. However patient status in the last assessment record is “alive”	The left hand columns show patient's details (purple heading): CIC no UIC no Patient's initials DOB Main cause of death has been recorded	In the middle (orange) section patient status is “alive” or Treatment data (light blue section) has been recorded after the cause of death.	One of the fields has been wrongly entered.	Confirm if patient is alive or dead. Provide the date of death or most recent date of follow up if patient alive Write the correct details in the last column of the spreadsheet: (labelled Correction remarks) Save the spreadsheet
Ident 2	Hospital or Unit unique patient number (UPN) missing	The patient has not been given a UPN (Unique Patient Number – Hospital Identity Number)	The left hand columns show patient's details (purple heading): CIC no UIC no Patient's initials DOB	In the middle (orange) section the column “UPN for this patient” has been left blank	This is incorrect – the patient should have one <u>unique</u> UPN (Unique Patient Number) or Hospital Identity Number	Confirm the correct UPN in the last column of the spreadsheet (labelled Correction remarks) Save the spreadsheet

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Ident 3	Hospital unique patient number (UPN) shared by two patient records	<p>Details for two different patients appear side by side. The field names end in 1 or 2 for each patient (DOB1, DOB2, for example).</p> <p>Both patients have been given the same UPN no (Unique Patient Number / Hospital Identity Number).</p>	<p>The left hand columns show patient's details (purple heading):</p> <p>CIC no UIC no Patient's initials DOB</p>	<p>This is incorrect – each patient should have their own <u>unique</u> UPN (Unique Patient Number/ Hospital Identity Number)</p> <p>It is possible that the entry is a duplicate: same patient reported twice. Please, check to see if this is the case.</p>		<p>Confirm the correct UPN in the last column of the spreadsheet (labelled Correction remarks) for each of the patients.</p> <p>If the entry is a duplicate, check the details (date of birth, initials) and let us know which are the correct ones.</p> <p>Save the spreadsheet</p>
Ident 4	Patient date of birth missing	The patient's date of birth has not been recorded	<p>The left hand columns show patient's details (purple heading):</p> <p>CIC no UIC no Patient's initials DOB - no date has been entered</p>	This is incorrect – the patient's date of birth is required		<p>Advise the correct date of birth in the last column of the spreadsheet (labelled Correction remarks)</p> <p>Save the spreadsheet</p>

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Ident 5	Possible duplicate entry of same patient	<p>Details for two different patients appear side by side. The field names end in 1 or 2 for each patient (DOB1, DOB2, for example).</p> <p>The patient's details are the same or very similar to each other.</p>	This may be a duplicate entry for the same patient	Check to see if the two patients are the same individual.		<p>If applicable, please advise us that it is a duplicate and tell us which UPN would be the correct one.</p> <p>If the records refer to two different individuals, let us know so we can remove them from the query.</p> <p>Write this information in the last column of the spreadsheet labelled Correction remarks)</p> <p>Save the spreadsheet</p> <p>We can then make the necessary amendments to the database.</p>

Report name	ProMiSe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Donor 1	Allogeneic HSCT without a donor	Donor details have not been recorded – the data are missing	The left hand columns show patient's details (purple heading): CIC no UIC no DOB	Check the patient's details. Check if transplant is allo or auto. Confirm donor details. Forward HLA report to EBMT Registry Office		<p>Confirm the details in the last column of the spreadsheet (labelled Correction remarks)</p> <p>Confirm type of transplant Allo or Auto. If Allo, confirm the following donor details: Source of stem cells, HLA match, donor ID, sex, ex-vivo manipulation yes/no.</p> <p>Send HLA typing report to EBMT Registry Office</p> <p>Complete "Cover sheet for HLA report". Fax this together with the HLA Laboratory report to EBMT Registry Office:</p> <p><i>Fax:+44 (0)20 71 88 84 11</i></p>

Report name	ProMISe report name	Details of report	Patient's details	Data for correction – missing data, errors etc	Action required	Amendment required
Transplant 02	Source of stem cells missing	The stem cell source is blank		Source of stem cells missing	Check the details in the patient/donor record for stem cell source.	Enter the stem cell source(s) e.g. BM, PB, Cord Blood Save the spreadsheet

When you have finished checking all the reports, save the Excel spreadsheet and then email it back to us at: registryhelpdesk@ebmt.org. We will then make the corrections in the database.

Thank you very much for your help