

HLA data entry in the EBMT Registry using ProMISe

The Nomenclature Committee of the World Health Organization (WHO) launched a new system of HLA nomenclature in April 2010. To learn more, visit the following website:

http://hla.alleles.org

where you will find relevant information and links.

EBMT Data Management was modified as follows:

- a. New labelled fields were added to the Registry database. Most of these fields are served by pull down menus to reduce typing errors and improve the quality of the data.
- b. The fields for donor HLA results are in the Donor table (Chapter: Donor HLA: DNA results/Donor HLA: serology results) and the fields for patient HLA results are in the HSCT assessment (Chapter: Patient HLA: DNA results/Patient HLA: serology results).
- c. Whenever possible existing data reported with the old nomenclature has been converted to the new nomenclature.

Understanding HLA data is not easy, we recommend that, if your National Registry provides HLA data entry you should forward the original HLA laboratory results to your collaborating National Registry.

For all the other centres that do data entry of the HLA themselves, the EBMT Registry has prepared these instructions on how to enter these data.

Table of contents

Instruc	ctions for data entry of HLA typing results :	2
1.	Patient	4
	Reducing the size of the HLA DNA drop down menus	4
2.	Donor	6
3.	Ambiguous results (Compressed Allele Lists - CALs)	8
	MAC (multiple allele codes) - previously known as NMDP codes	9
4.	Further recommendations	
5.	Useful links	

Instructions for data entry of HLA typing results as part of data entry of a Med-A or Med-B form

On the laboratory HLA typing results, identify the Donor and the Patient and the HLA results required by the EBMT registry: A, B, C, DRB1, DQB1, DPB1. Some other results, for instance DRB2 are not necessary for the EBMT.

Be careful with the order in which the results appear on the results typing form returned by the laboratory: they will not necessarily be in the same order as they appear in the Med-AB forms and in ProMISe.

If you are adding data retrospectively to an existing registration, please click on the **Donor** in the Record Locator (ensuring you have selected the correct HSCT if the patient had multiple HSCTs **AND** the correct Donor if multiple Donors were used for the same HSCT). Then go to **HLA Laboratory** in the Chapters below to enter the "Laboratory name" and "Technique used for HLA" if available:



After entering "Technique used for HLA", the next field, made necessary purely for proper navigation, will appear:

	2014/03/14 {exact}		
	2014/03/14 {exact}		
4			
	First		
11	Ciclosporin / Cyclosporin / Neoral		Note: Hit the Enter key or Tab to enter the patient
			This is only a navigation field
		0	
	19	Navi	vigation field
	11		11 Ciclosporin / Cyclosporin / Neoral

Press Return or Tab to proceed and the cursor will go to the first field of the Chapter Patient HLA: DNA results

Then the cursor will then move to the Patient record so you can enter the **Patient HLA: DNA results** (stored in the Assessment for the HSCT):

ata Entry Report Export Help E	lter <u>M</u> anage	MEDAB [8001][DEMO][City_1]	Manage Mode (SQL05)		13:42 so
				Data Entry	Ceneral Info
lex Editor Overview		DynFil:20:Acute leukaemia			
Assessment(1)	value label			+ Actions	
CIC	8001 8001				
atient issessment date	2014/01/22 00:00 2014/01/22 (ex	auth		Form about to be Med-A: Day 100	Create Delete Move/ Copy Save moduleshors Show Ca
atient HLA: DNA results	2014/01/22 00:00/2014/01/22 (ex	Whote: Enter the HLA typing results for the patient		Med-B over Med-A ? UPN 456789	- Record Locator
NA typing done				Date of birth 1981/11/28	- Patient [8001] 1200
LA: DNA typing done		000		Are you adding M ?	Diagn 2013/05/17 [Main indication diagn
A A: DNA in allele 1 of the patient					
LA A: DNA in allele 1 of the patient LA A: MAC code for allele 1 in the patient		HLA: DNA typing done			Asse1 2013/05/17 [Main indication diagr
LA A: MAC code for allele 1 in the patient LA A: DNA in allele 2 of the patient		1 No			- Treat 2014/01/22 [HSCT]
LA A: MAC code for allele 2 in the patient		2 Yes			Drug Ciclosporin / Cyclosporin / Neo
уре В		99 unknown			Drug Fludarabine
A B: DNA in allele 1 of the patient					
A B: MAC code for allele 1 in the patient A B: DNA in allele 2 of the patient					Drug Melphalan
A B: DNA in allele 2 of the patient A B: MAC code for allele 2 in the patient		_			Donor 1
pe C					Asse1 2014/01/22 [HSCT]
A C: DNA in allele 1 of the patient					Asse1 2014/05/02 [Alive]
A C: MAC code for allele 1 in the patient					ASSET SOLADOODS IMMAEL
A C: DNA in allele 2 of the patient					
A C: MAC code for allele 2 in the patient					
A DRB1: DNA in allele 1 of the patient					- Chapters & Sections
A DRB1: MAC code for allele 1 in the patier	ot				+ Investigations identificat & admin
A DRB1: DNA in allele 2 of the patient					+ Assessment record qualifier (manual)
A DRB1: MAC code for allele 2 in the patie	nt				+ Diagnostics
rpe DQB1					+ Diagnostics (cont.)
A DQB1: DNA in allele 1 of the patient A DQB: MAC code for allele 1 in the patient		_			+ Physical examination
A DQB: MAC code for allele 1 in the patient		_			+ History of disease and treatment
A DOB: MAC code for allele 2 in the patient					Patient viral & fungal history
pe DPB1					+ Patient viral & lungal history + Performance
A DPB1: DNA in allele 1 of the patient					
A DPB1: MAC code for allele 1 in the patier A DPB1: DNA in allele 2 of the patient	*				+ Haematopoietic recovery & chimaerism
A DPB1: DNA in allele 2 of the patient A DPB1: MAC code for allele 2 in the patient	-				+ Complications & additional treatment
in the patient of allele 2 in the patient	~				+ Last disease status
					+ Last status
					 Patient HLA: DNA results
					DNA typing done
					Type A
					Type B
					Type C
					Type DRB1
					Type DQB1
					Type DPB1
					+ Patient HLA: serology results
					+ Prognostic scores
					+ Persistence of infused cells dur
					Fields no longer in use
					Heids no longer in use New record creation

The fields to fill in the HLA typing results appear in the order shown below, first for the patient, and then for the donor(s):

Assessment(1)	value	label
CIC	8001	8001
Patient	1200	1200
Assessment date	2014/01/22 00:00	2014/01/22 {exact
Patient HLA: DNA results		
DNA typing done		
HLA: DNA typing done		
Type A		
HLA A: DNA in allele 1 of the patient		
HLA A: MAC code for allele 1 in the patient		
HLA A: DNA in allele 2 of the patient		
HLA A: MAC code for allele 2 in the patient		
Type B		
HLA B: DNA in allele 1 of the patient		
HLA B: MAC code for allele 1 in the patient		
HLA B: DNA in allele 2 of the patient		
HLA B: MAC code for allele 2 in the patient		
Туре С		
HLA C: DNA in allele 1 of the patient		
HLA C: MAC code for allele 1 in the patient		
HLA C: DNA in allele 2 of the patient		
HLA C: MAC code for allele 2 in the patient		
Type DRB1		
HLA DRB1: DNA in allele 1 of the patient		
HLA DRB1: MAC code for allele 1 in the patient		
HLA DRB1: DNA in allele 2 of the patient		
HLA DRB1: MAC code for allele 2 in the patient		
Type DQB1		
HLA DQB1: DNA in allele 1 of the patient		
HLA DQB: MAC code for allele 1 in the patient		
HLA DQB1: DNA in allele 2 of the patient		
HLA DQB: MAC code for allele 2 in the patient		
Type DPB1		
HLA DPB1: DNA in allele 1 of the patient		
HLA DPB1: MAC code for allele 1 in the patient		
HLA DPB1: DNA in allele 2 of the patient		
HLA DPB1: MAC code for allele 2 in the patient		

1. You will be asked to provide, for the patient, the DNA (molecular) results for each locus and allele respectively.

Assessment(1)	value	label
CIC	8001	8001
Patient	1200	1200
Assessment date	2014/01/22 00:00	2014/01/22 {exact
Patient HLA: serology results	1	
HLA: serology typing done		
Serology HLA typing done	· · · · · · · · · · · · · · · · · · ·	(
Туре А		
HLA A: serology in the patient 1		
HLA A: serology in the patient 2		
Type B		
HLA B: serology in the patient 1		
HLA B: serology in the patient 2		
Туре С		
HLA C: serology in the patient 1	· · · · · · · · · · · · · · · · · · ·	
HLA C: serology in the patient 2		
Type DRB1		
HLA DRB1: serology in the patient 1		
HLA DRB1: serology in the patient 2		
Type DQB1		
HLA DQB1: serology in the patient		
HLA DQB1: serology in the patient 2		
Type DPB1		
HLA DPB1: serology in the patient 1		
HLA DPB1: serology in the patient 2		

2. You will be asked to provide, still for the patient, the serologic results for each locus and allele respectively.

- → once all the data for the patient have been completed,
 - 3. You will be invited to fill in the DNA (molecular) HLA typing for the donor
 - 4. You will be invited to fill in the serologic HLA typing for the donor

1. Patient

If DNA typing have been done for the patient, press 'Yes' and enter all relevant data in each locus and each allele.

e, press no to go to serologic result	5.	
2 Yes		
		_
	HLA A: DNA i	n allele 1
	A*01	A*01
	A*01:01	A*01:0
	2 Yes	

 \geq If the **nationt DNA typing has not been done** press (No? to go to serologic results

Please use the drop-down list:

A*01	A*01	
A*01:01	A*01:01	
A*01:01:01	A*01:01:01	
A*01:01:01:01	A*01:01:01:01	
A*01:01:01:02N	A*01:01:01:02N	_
A*01:01:01G	A*01:01:01G	
A*01:01:02	A*01:01:02	
A*01:01:03	A*01:01:03	
A*01:01:04	A*01:01:04	1
A*01:01:05	A*01:01:05	
A*01:01:06	A*01:01:06	
A*01:01:07	A*01:01:07	
A*01:01:08	A*01:01:08	
A*01:01:09	A*01:01:09	
A*01:01:10	A*01:01:10	
A*01:01:11	A*01:01:11	
A*01:01:12	A*01:01:12	
A*01:01:13	A*01:01:13	-
A*01:01:14	A*01:01:14	
A*01:01:15	A*01:01:15	
∆*01·01·16	A*01:01:16	

There are 4 fields in which allelic information can be stored for each locus:

>2 for the 1st chromosome, >2 for the 2nd chromosome.

One of the fields for each chromosome is a coded field such as you can see on this example.

The other field is used to store the MAC multiple allele code which is used for ambiguous results. The use of MACs is explained later in the document

Reducing the size of the HLA DNA drop down menus

Some of the drop-down menus are very long. It is helpful to be able to shorten them and you can do this by typing part of the label. Note, however, that numbers cannot be used for this purpose unless they are preceded by a non numeric character. Therefore if you want to shorten the drop down menu you must always type first either the letters of the loci (A in the example above) or the * that precedes the numeric part or the : that lies between numeric parts.

Useful Tip: Always use that part of the result which is less common when looking for the correct entry. For example, if you have A*01:01:06, use :06 since the number of entries with 06 will be smaller than the number of entries with 01.

Shortcuts examples

Result	Start typing:
A*03:125	:125
A*30:01	*30
Not Evaluated (NE)	no
MAC (Multiple Allele Code)	ma
Only One Value Reported (OOVR)	on
To redisplay full list of labels	?

If Serologic typing has been performed for the patient, press 'yes' and continue with the Patient's HLA serology results.

> If the patient serology has not been studied, press 'no' and go to the next step.

naacaamenii uale	2014/01/22 00.00	2014/01/22 Levari	
Patient HLA: serology results			
HEA: serology typing done			
Serology HLA typing done	2	Yes	
Type A			
HLA A: serviogy in the patient 1			
HLA A: serology in the patient 2		<u></u>	HLA A: serology in the patient 1
Type B			E. E.
HLA B: serology in the patient 1			A1 1
HLA B: serology in the patient 2			A10 10
Tuna C			A11 11

Please use the drop-down list:

010		
HLA B: s	erology in the pa	atient 1
B12	12	
B13	13	\sim
B14	14	
B15	15	
B16	16	
B17	17	
B18	18	
B21	21	
B22	22	
B27	27	
B2708	2708	
B35	35	
B37	37	
B38(16)	38	

There are 2 fields in which serologic information can be stored for each locus:
 1 for the 1st chromosome,
 1 for the 2nd chromosome.

All fields for each chromosome are coded fields such as you can see below.

When this field appears again:

New record creation				
New record creation				
C: Index date for new record	2014/03/14 00:00	2014/03/14 {exact}		
C0: Index code for new donor	1	First		
C2: Index code for new drug/agent	11	Ciclosporin / Cyclosporin / Neoral	 Image: A start of the start of	Note: Hit the Enter key or Tab to enter the donor HLA
Data entry help Trt				This is only a navigation field
Navigation field	1			
			Nav	vigation field
				- Sector Hold

Press Return or Tab to proceed

2. <u>Donor</u>

(If you are adding data retrospectively to an existing registration, the fields for the Donor HLA results are in the **Donor** table. Please go to this record, ensuring you have selected the correct HSCT if the patient had multiple HSCTs **AND** the correct Donor if multiple Donors were used for the same HSCT).

https://www3.clinicalresearch.nl/ - MEDAB[NEW][EBMT][5][promise8001ak][CIC 8001/9]	(Med-A8: Al - Internet Explorer		- 0 ×
Data Entry Report Export Help Eliter	[8001][DEMO][C8y_1] [13:12 /	=
Resume with the first item in the current section by pressing Tab (or dick on Index Editor Overview	any other Rem) Cycl 202 Acids Induseria	Link fory Lower Leven	*
Index Click Overgine GO Overgine Value http://doi.org/10.0016/0016 Go Overgine 2014/0016 00016 Tradinated atter 2014/013 (pace) Laborationy fields 2 2 Laborationy fields 1 1 Traditional date 2014/013 (pace) Laborationy fields 1 1 Laborationy fields 1 1 Technique used for HLA 1 1		Image: Section	loxan n / Neoral

The data entry for the donor is similar to that described for the patient with one more possibility; that of copying the patient data to the donor record when the HLA results are identical:

a Entry Report Export Help Fil	ter <u>M</u> anage	MEDAB [8001][DEMO][City_1]	Manage Mode (SQL05)		13:53
					ă₩ĦQ o ≈₽ ♣
ex Editor Overyiew		DynFili20:Acute leukaemia			
	value label			# Actions	
ient	8001 8001 1200 1200	_			
atment date	2014/01/22 00:00 2014/01/22 (exac	at		Form about to be Med-A: Day 100	Create Delete Movel Save pending Show
nor	11	<u></u>		Med-B over Med-A ? UPN 456789	- Record Locator
or HLA: DNA results		Whote: Enter the HLA typing results for this donor		Date of birth 1981/11/28	- Patient (8001) 1200
A: DNA typing done				Are you adding M ?	
A HLA typing done		000			Diagn 2013/05/17 [Main indication dia
e A A DNA in allele 1 of the donor		DNA HLA typing done			Asse1 2013/05/17 [Main indication dia
A A: MAC code for allele 1 in the donor		1 No			- O Treat 2014/01/22 [HSCT]
A A: DNA in allele 2 of the donor		2 Yes			
A A: MAC code for allele 2 in the donor		2 Yes 3 Yes, identical, Copy results from patient			Drug Ciclosporin / Cyclosporin / Ne
e B		3 Yes, identical. Copy results from patient 99 unknown			Drug Fludarabine
A B: DNA in allele 1 of the donor		33/00/00/00			Drug Melphalan
A B: MAC code for allele 1 in the donor A B: DNA in allele 2 of the donor					Donor 1
B: MAC code for allele 2 in the donor					
e C					Asse1 2014/01/22 [HSCT]
C: DNA in allele 1 of the donor		-			Asse1 2014/05/02 [Alive]
C: MAC code for allele 1 in the donor					
C: DNA in allele 2 of the donor					- Chapters & Sections
C: MAC code for allele 2 in the donor		_			
e DRB1 DRB1: DNA in allele 1 of the donor					+ Donor identification & administratio
DRB1: DNA in allele 1 of the donor DRB1: MAC code for allele 1 in the donor		-			+ Donor
A DRB1: DNA in allele 2 of the donor					+ Legacy Donor harvest or collection
A DRB1: MAC code for allele 2 in the donor					+ Cell products
e DQB1					+ Cord blood processing at Bank
A DQB1: DNA in allele 1 of the donor		_			+ Cord blood cryopreservation at Bank
A DQB1: MAC code for allele 1 in the donor A DQB1: DNA in allele 2 of the donor		_			+ Cord blood counts/viability at Bank
A DQB1: DNA in allele 2 of the donor A DQB1: MAC code for allele 2 in the donor		-			+ HLA laboratory
e DPB1					- Donor HLA: DNA results
A DPB1: DNA in allele 1 of the donor		-			HLA: DNA typing done
DPB1: MAC code for allele 1 in the donor					Type A
DPB1: DNA in allele 2 of the donor					Type B
DPB1: MAC code for allele 2 in the donor					
					Type C
					Type DRB1
					Type DQB1
					Type DPB1
					+ Donor HLA: serology results
					+ Ex vivo manipulation of donor cells
					+ Donor cell infusion method
					+ Cells infused
					+ Donor milestones
					+ Fields no longer in use I
					+ Fields no longer in use II
					+ New record creation
					T New record creation

If DNA typing has been done for the donor and the results are different from that of the patient, press 'Yes' and enter all relevant data in each locus and each allele.

Donor HLA: DNA results				
nLA: DNA typing done				
DNA HLA typing done	2 Yes			
Type A				
HLA A: DNA in allele 1 of the donor				
HLA A: MAC code for allele 1 in the donor				
HLA A: DNA in allele 2 of the donor		HLA A: DNA in	allele 1 of the dono	or
HLA A: MAC code for allele 2 in the donor		A*01	A*01	
Туре В		A*01:01	A*01:01	^

- If the donor DNA typing has been done and the results are the same as that of the patient, press 'Yes, identical. Copy results from the patient'. The data from the patient HLA fields will be copied to the corresponding fields in the donor record.
- > If the donor DNA typing has not been done, press 'No' to go to serologic results.
- > The cursor will then take you to the serologic results.

https://www3.clinicalresearch.nl/ - MED	DABINEW/EEMIIIS promue8001ak CICB	001(9/) [Med-A8: Al - Internet Explorer	Contraction and Resident	_	- 0 ×
Data Entry Report Export	Helo Filter	[8001][DEMO][City_1]			13:59
		A second s			
Resume with the first item in the cu	arrent section by pressing Tab (or cli	ick on any other item)	A. (- (-)	6 6480054	
and a second second					
Index Editor Overview				to see the second se	
Q Donor	value label		Actions		8AVE 001 63
CIC	8001 8001		Visibility		
Patient	1600 1600		Apply Item Fil		pending modifications
Treatment date	2014/11/13 00:00 2014/11/13 (exact)		No DynFilters	Record Locator	
Donor Donor HLA: serology results	2 2		Show Names	Patient [8001] 1600	
HLA: serology typing done			Hide Values	Diagn 2014/	08/19 [Main indication diagnosis]
Serology HLA typing done		00	RecLoc at Ivi=	-2	
Type A			Keep Chp&Se	c closed	clophosphamide / Endoxan
HLA A: serology in the donor 1	14 11	Serology HLA typing done	RecLoc 100%	visible	closporin / Cyclosporin / Neoral
HLA A: serology in the donor 1 HLA A: serology in the donor 2		1 No.	History always	s visible	
Type B		2 Yes 3 Yes, identical. Copy results from patient	Trace always	VISIDIE	
HLAB: serology in the donor 1	1	3 Yes, identical. Copy results from patient	+Cancel,Change		G or ALG (ATS or ALS)
HLA B: serology in the donor 2		99 unknown	+ ClipBoard		cophenolate mofetil
Type C		AND A CONTRACTOR OF A CONTRACTOR OFTA CONTRACT		Oonor 1	
HLA C: serology in the donor 1			Form about to be	HSCT MED-A registration Donor 2	
HLA C: serology in the donor 2			Are you adding i. Centre identific Q-Q	2 City_1 (TC3)	
Type DRB1				778899 @Asse1 2015/0	02/08 [Alive]
HLA DRB1: serology in the donor	1		Date of birth of	1979/12/21	
HLA DRB1: serology in the donor	2		Are you adding M	2	
Type DQB1				Chapters & Sections	Frank and a second
HLA DQB1: serology in the donor				+Donor identification 8	s administratio
HLA DQB1: serology in the donor				+ Donor	
2				+ Legacy Donor harves	st or collection
Type DPB1				+ Cord blood processin	no at Bank
HLA DPB1: serology in the donor 1	1			+ Cord blood cryoprese	
HLA DPB1: serology in the donor 2	2			+ Cord blood counts/via	
					ability at barn
				+HLA laboratory	
				+ Donor HLA: DNA res	
				Donor HLA: serology	results
				HLA: serology typ	ping done
				Type A	
				Type B	
				Type C	
				Type DRB1	
				Type DQ81	
				Type DPB1	
				+ Ex vivo manipulation	of donor cells
				+ Donor cell infusion	
				+ Donor milestones	
				+ Fields no longer in us	
				+ New record creation	

If serologic typing has been performed for the donor, press 'yes' and proceed with the Donor's serology.

Index <u>E</u> ditor Over <u>v</u> iew	6		
Q. Donor	value	label	
CIC	8001	8001	
Patient	1600	1600	
Treatment date	2014/11/13 00:00	2014/11/13 {exact}	
Ponor	2	2	
Donor HLA: serology results			
HLA: serology toping done			
Serology HLA twing done	2	Yes	
Type A			
HLA A: serology in the donor 1			
HLA A: serology in the donor 2		10.	HLA A: serology in the donor 1
Туре В			
HLA B: serology in the donor 1			A1 1
HLA B: serology in the donor 2			A10 10
Type C			A11 11
HLA C: serology in the donor 1			A19 19
HLA C: serology in the donor 2			A2 2
			A203 202

- > If the donor serologic typing has been done and the results are the same as that of the patient, press 'Yes, identical. Copy results from the patient'. The data from the patient HLA fields will be copied to the corresponding fields in the donor record.
- > If the **donor serology** has not been studied, press 'no' and go to the next step.
- > The cursor will then take you to the next step.

Follow instructions as for 1. Patient above.

3. Ambiguous results (Compressed Allele Lists - CALs)

Some results are not completely precise: we know they can be something and we know they cannot be something else, but there are still options among which we cannot make a decision. For example, we could have a result that could be 01:04 or 01:06 but not anything else, or perhaps it can be 02:03 or 03:07. Ambiguities are represented with slashes separating all the possibilities. In these examples, the first one would be represented as 01:04/06 and the second as 02:03/03:07. These types of results are also known as CAL - Compressed Allele Lists.

The ambiguity of the results has to do with the type of antibodies used and it varies a lot.

To deal with this problem, the NMDP (National Marrow Donor Program[®]) has come up with a series of codes that are known as MACs (Multiple Allele Codes - Previously known as "NMDP codes"). Unfortunately, these codes cannot be added to the labels of the EBMT registry because there are too many (>80,000 different codes) and they represent entries that can have over 600 characters. If you encounter results that contain "/", they should be dealt with using MACs.

At the end of all pull down menus for all DNA results, you will see the code MAC. If you cannot enter the result because it is ambiguous, use this code.

	A 14.21	A 14.21	
	A*74:28	A*74:28	
	A*80	A*80	
	A*80:01	A*80:01	
	A*80:01:01:01	A*80:01:01:01	
	A*80:01:01:02	A*80:01:01:02	
	A*80:01:01G	A*80:01:01G	
	A*80:01P	A*80:01P	
	A*80:02	A*80:02	
	A*80:03	At00:03	
$\boldsymbol{<}$	MAC	MAC (old NMDP code)	>
	NE	Not evaluated	
	OOVR	Only one value reported	~

On selecting this code, the cursor will move to the next field where an entry reflecting the MAC code (see further down in the document on how to find it), can be entered for that particular case. The entry should be a maximum of 10 characters long for A, B & C and 14 characters long for DRB, DQB & DPB values:

Donor HLA: DNA results		
HLA: DNA typing done		
DNA HLA typing done		2 Yes
Туре А		
HLA A: DNA in allele 1 of the donor	MAC	MAC (old NMDP code)
HLA A: MAC code for allele 1 in the donor	A*31:RBWU	A*31:RBWU
HLA A: DNA in allele 2 of the donor	A*32:08	A*32:08
HLA A: MAC code for allele 2 in the donor		
Type B		

So if the first field of each pair (*line 1*) contains **MAC**, the cursor will go to the next field for the MAC code to be entered (*line 2*).

<u>But</u> if the first field of each pair (*line 3*) contains an exact result (*A**32:08 in the example above), the next field will be skipped and should remain empty (*line 4*).

> MACs (Multiple Allele Codes) /previously known as NMDP codes/

<u>NOTE</u> Do not use the MACs for a result which is precise but which does not appear in the pull down menus. See below for instructions on what to do in this case.

> P & G codes

Do not use the MAC Lookup tool (MAC Service UI) for results showing a P or G suffix. These are alleles that encode for identical peptide binding domains ('P') and alleles that share identical nucleotide sequences for the exons encoding the peptide binding domains ('G'). These notations are accepted by the NMDP but they are not included in the allele codes. The P and G groups have been added to the drop-down list of labels in ProMISe, so you can select them from here and enter them in the same way as you would an exact result.

In all other cases when the result is not precise, use the MAC Lookup tool (MAC Service UI) at:

https://hml.nmdp.org/MacUI/

Too look up an allele list to find MAC:

- Select IMGT HLA DB Release. Choose the version number of the IMGT allele database release that was used for the allele list generated. If you don't know, use the highest release number.
- Type whatever result (CAL Compressed Allele list) you have, for example B*18:01/18:17N. You can enter between 1 50 different CALs or GL strings into the Encode Input box. Each CAL or GL string must be on its own line. The UI will assign a number to the CAL or GL string. This number will be used in the Encode Result box to link the request list and MAC together.
- Click the Look Up button. All MAC results for the CALs or GL strings entered will be displayed in the Encode Result box.

Select IMGT HLA DB	Release: 3.26.0
Encode/Look up Input	Enter a CAL or GL string to find a MAC for the list. Look up does not assign a new MAC. Encode assigns a new MAC if one has not been assigned.
1. B*18:01/18:17N	
Look Up Encode Examples CAL:DRB1*13: 02/13:36/13:67/13:96 GL String: HLA-DRB5*01:01/HLA-DR	
Encode/Lookup Resul	t:

The result will be the letter identifying the [locus*] followed by a code of up to 7 characters, here B*18:RRG, which is universally accepted.

Type this entry exactly as shown in the corresponding MAC field in the EBMT database. You can also highlight the entry and copy/paste it into the corresponding field.

<u>Note</u>: lab results prior to 2010 will show the old nomenclature without : in between the digits (see example below).

If the MAC doesn't exist for the entered result (CAL or GL string) you will get the following message:



In that case you need to **encode** a new MAC with an allele list. After you entered your result(s) in the 'Input' window click the Encode button. It will generate new MAC(s) and return them in the Encode Result box.

If the entry is not valid you will get an error:

Encode/Lookup Result: 1. Invalid allele: 'HLA-A*14:04' at 1

Please recheck your data.

More help and information on the MAC Lookup tool (MAC Service UI) can be found here: <u>https://hml.nmdp.org/MacUI/static/instructions.html</u> Another way to recheck your data is to do a search of all the known NMDP codes in existence. The webpages:

https://bioinformatics.bethematchclinical.org/HLA/alpha.v3.html https://bioinformatics.bethematchclinical.org/HLA/numeric.v3.html

have all the MACs in alphabetical or numerical order with their corresponding allelic codes. You can use standard "find" shortcuts (Ctrl-F for English keyboards) to find the ambiguous code you are interested in. In the above example, you can search for "18:01/18:17N".

IMPORTANT NOTE - DONOR and PATIENT IDENTIFICATION

The <u>Donor ID</u> is an important part of the donor questions in the MED-AB forms and Donor Outcome forms and is used by the Donor Registries. PLEASE MAKE SURE TO FILL IT IN!

Another identification item that has been added in 2016 is 'Patient ID given by the Donor Registry or the Cord Blood Bank'. It is an Identification given by the Donor Registry or the Cord Blood Bank to the recipient. Although, this is currently an optional field, it is extremely important information, which helps in identifying the correct set of data. It is always the best practice to collect all possible unique identifications.

<u>NOTE</u>: The CIBMTR and NMDP have requested that the donor ID given by the registry, which we store in the field "*Identification of donor given by donor registry*" be entered as a number only, but retaining the leading zero if it exits.

Please do not enter dashes between numbers, nor add "NMDP" or other characters to the beginning of the donor id, and do not drop leading zeroes.

We provide some examples as illustration:

As it is now	As it should be	
0257-8376-2	025783762	No dashes between numbers
NMDP0323-4119-0	032341190	No additional characters, no dashes between numbers
81706343	081706343	Keep leading 0's
US033941345	033941345	No additional characters
0699-30685	069930685	No dashes between numbers

The reason for this is to facilitate the identification of the donor when EBMT forwards the data to the CIBMTR for those centres that have requested it and ensure data integrity.

Donor Identification: Cord Blood

In addition to the ID for Donor Registries, we have a specific ID field for Cord Blood banks. "*Identification of the CBU given by the cord blood bank*". Note that this field is be used exclusively for the identification of cord blood units. Please only fill for Cord Blood. The navigation in Promise should skip this field for other sources of cells (BM, PB). If you notice any problems please contact the EBMT Registry Helpdesk.

PLEASE REFER TO OUR MED-AB FORMS MANUAL UNDER THE SECTION "*DONOR AND STEM CELL SOURCE*" FOR FURTHER INFORMATION ON DONOR REGISTRIES, HLA MATCH TYPE, ETC.

4. Further recommendations

1) If results have not been provided by the laboratory for a certain locus (both alleles), please use the code NE (Not evaluated):

URD1 10.32	URD1 10.32	
DRB1*16:33	DRB1*16:33	
DRB1*16:34	DRB1*16:34	
DRB1*16:35	DRB1*16:35	
DRB1*16:36	DRB1*16:36	
DRB1*16:37	DRB1*16:37	
DRB1*16:38	DRB1*16:38	
DRB1*16:39	DRB1*16:39	
DRB1*16:40	DRB1*16:40	
DRB1*16:41N	DRB1*16:41N	
DRB1*16:42	DRB1*16:42	
DRB1*16:43	DRB1*16:43	
DRB1*16:44	DRB1*16:44	
MAC	MAC (old NMDP code)	
NE	Not evaluated	
OOVR	Only one value reported	Ť

2) Where only one result is reported for a certain loci (possible homozygous), you should enter the reported result in the 1st chromosome.

For the 2nd chromosome, use code **OOVR** (only one value reported):

0.10.01.010	U" 18.01.01G	
C*18:01P	C*18:01P	
C*18:02	C*18:02	
C*18:03	C*18:03	
C*18:04	C*18:04	
C*18:05	C*18:05	
C*18:06	C*18:06	
C*18:07N	C*18:07N	
C*18:08	C*18:08	
C*18:09	C*18:09	
C*18:10	C*18:10	
MAC	MAC (old NMDP code)	
NE	Not evaluated	
OOVR	Only one value reported	~

3) If the result is precise but the code cannot be found in the pull down menu, this may have two different explanations: New HLA codes are being discovered continuously and they may not have been added to the labelsets as yet; alternatively, the results may contain typing errors and they would need to be corrected at source. Therefore, you should check for its existence. To do this, access the website pages:

http://hla.alleles.org/alleles/class1.html for loci A, B and C http://hla.alleles.org/alleles/class2.html for loci DRB1, DQB1 and DPB1

- If you cannot find the code, contact the centre or laboratory from where the data originates and seek an explanation or correction.
- If you find the code, contact the Registry helpdesk at <u>registryhelpdesk@ebmt.org</u> requesting that the code be added to the drop down menu.
- 4) Never derive serologic results from allelic results. If serology typing has not been done, this should be explicitly stated by answering "No" to the question **Serology HLA typing** done, and all the serology results fields will be left empty.
- 5) Sometimes, we can have DNA/molecular results (identified by a *) with 2 digits only. For instance, Cw*08 is a partial code of the set C*08:02:01, C*08:02:02, etc. because sometimes the whole matching is not done. In that case, enter this result as C*08 in the DNA fields.
- 6) In DNA results if a code with 4 or more digits cannot be found, it is acceptable to enter the first 2 digits while awaiting further clarification. For example, if you did not find B*07:113, then B*07 could be entered in the meantime.

- 7) If you have more than one type of result, which one should be entered?
 - a) Generic and allelic (generic A*26:KDSK / allelic A*26:01, generic B*18:PZEN / allelic B*18:01, generic C*07:RGFU / allelic C*07:01) : we recommend entering the allelic, as it provides us with information about both the antigen and the allele.
 - b) An exact result (03:01) and an MAC (A*03:AXTK): please enter the exact result (03:01) as this is the specific allele rather than a range of allele options.
 - c) Between "A*02:XX1" and "A*02:KTUC", please choose the MAC option, as it provides us with a range of options, as opposed to the first one, which gives us only the antigen and not the allele.
 - d) Between 2 MACs, please type both of them in the <u>MAC lookup tool</u> and choose the shortest of the 2 options, as this will give you the narrowest range of allele options.

Only enter data when you are sure they are correct. For any problem, please contact the EBMT / National Registry.

5. <u>Useful links</u>

Full list of alleles: http://hla.alleles.org/alleles/class1.html http://hla.alleles.org/alleles/class2.html

MAC Lookup tool (MAC Service UI): <u>https://hml.nmdp.org/MacUI/</u> Ambiguous codes: MAC (previously known as NMDP codes) Allele Code List in Alphabetical Order: <u>https://bioinformatics.bethematchclinical.org/HLA/alpha.v3.html</u> in Numerical Order: <u>https://bioinformatics.bethematchclinical.org/HLA/numeric.v3.html</u>

G and P codes: http://hla.alleles.org/alleles/g_groups.html http://hla.alleles.org/alleles/p_groups.html