Feedback from the 15th Data Managers Meeting

1 – 6 April 2016
Valencia, Spain

Number of participants pre- registered as Data Managers	111

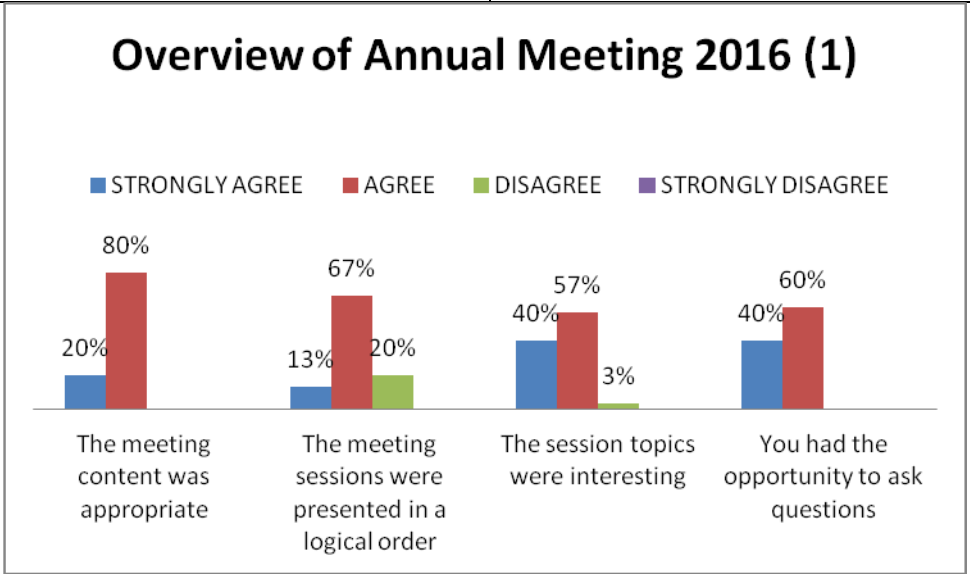
Number of feedback forms completed		
	Istanbul	Valencia
Meeting Overview	20	30
Educational Session	Variable – please see table on page 6 below	164
EBMT Registry Database (ProMISe) Data Entry Sessions	24	13
EBMT Registry Database (ProMISe) Data Retrieval Sessions	25	18
EBMT Registry Database (ProMISe) HLA Data Entry Session	14	14
EBMT Registry Database (ProMISe) Exports and Sharing Reports	n/a	12

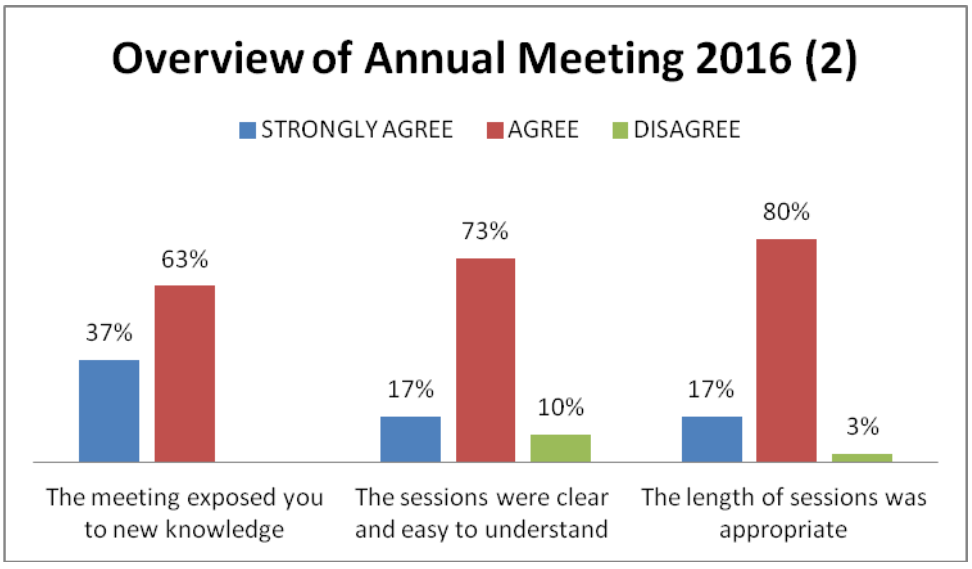
Total number of Data managers registered: 112

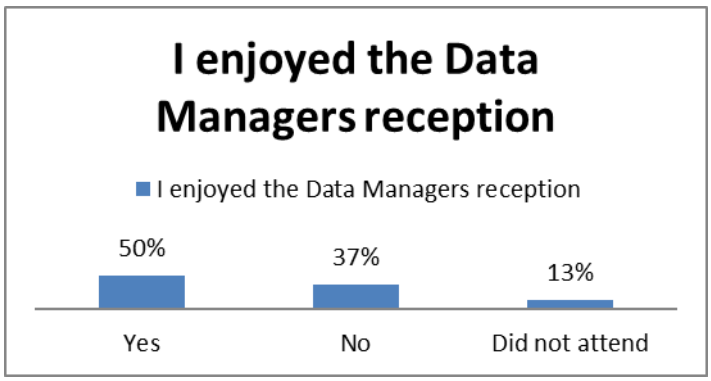
Algeria	1	Japan	2
Australia	1	Jordan	1
Austria	1	Netherlands	4
Belgium	7	Norway	3
Canada	1	Poland	6
		Portugal	1
Columbia	1	Saudi Arabia	1
Czech Republic	2	Switzerland	2
		Taiwan, Province of China	2
Denmark	1		
Finland	5	Turkey	2
France	8	UK	12
Germany	33	USA	8
India	1		
Ireland	1		
Israel	2		
Italy	2		

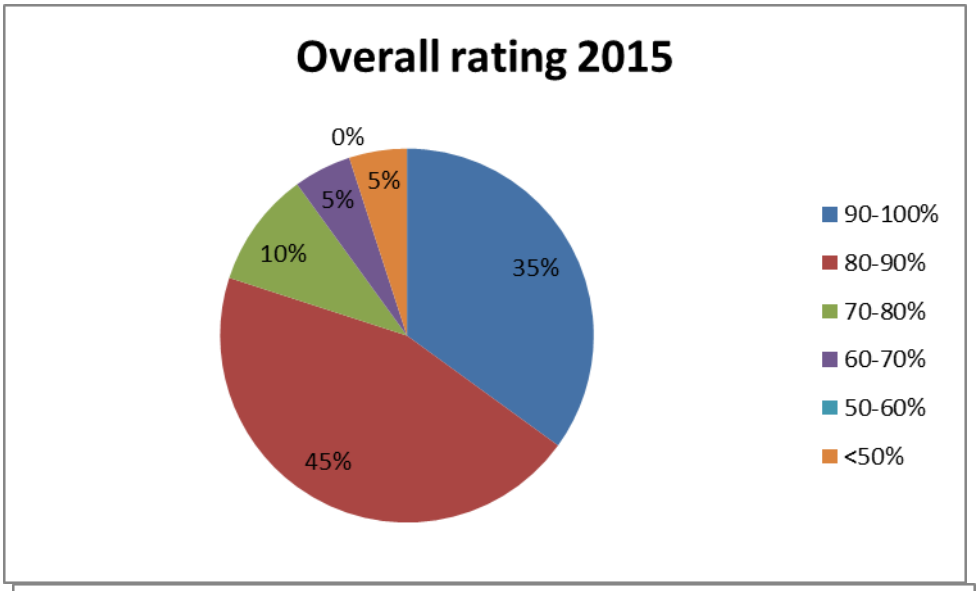
FEEDBACK FOR MEETING OVERVIEW

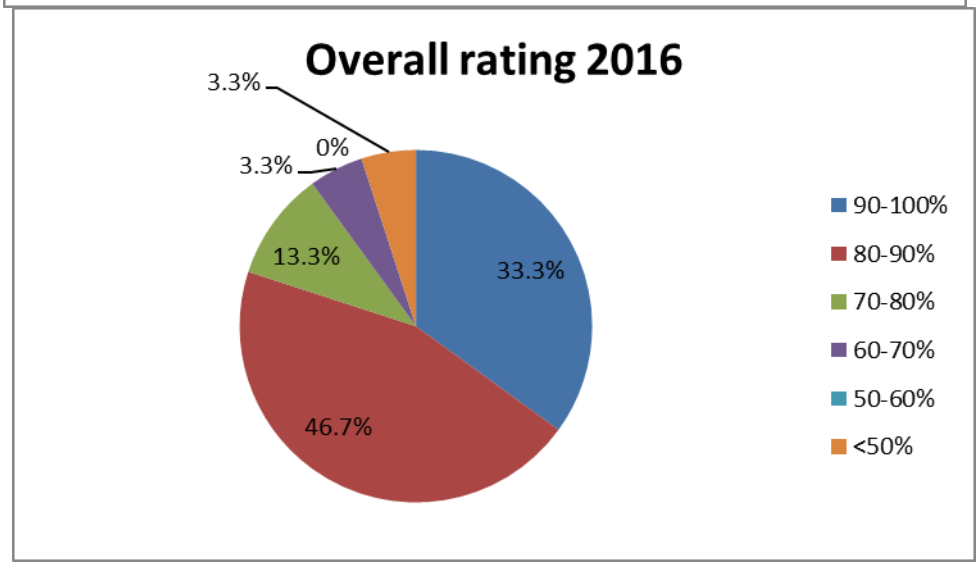
MEETING OVERVIEW	
Number of feedback forms completed:	**30**





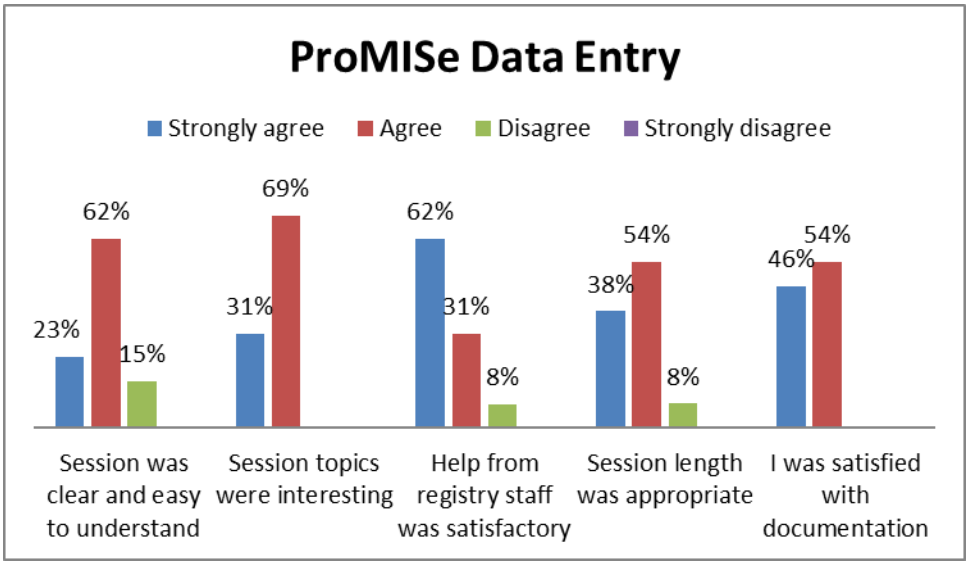

I enjoyed the Data Managers reception
I enjoyed the Data Managers reception
50%
37%
13%
Yes
No
Did not attend


Overall rating 2015
0%
5%
5%
10%
35%
45%
90-100%
80-90%
70-80%
60-70%
50-60%
<50%

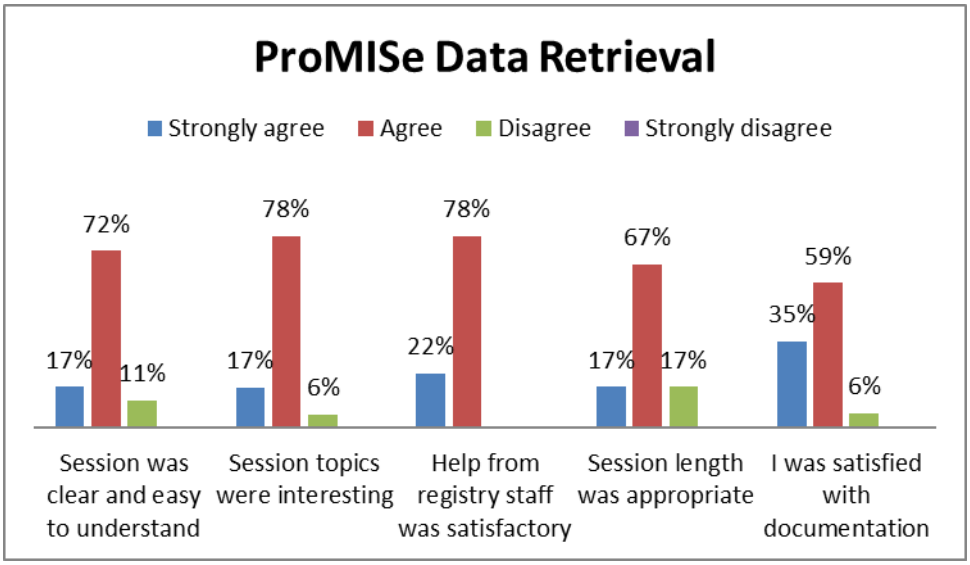

Overall rating 2016
3.3%
0%
3.3%
13.3%
33.3%
46.7%
90-100%
80-90%
70-80%
60-70%
50-60%
<50%

FEEDBACK FOR EBMT REGISTRY DATABASE (ProMISe) TRAINING SESSIONS

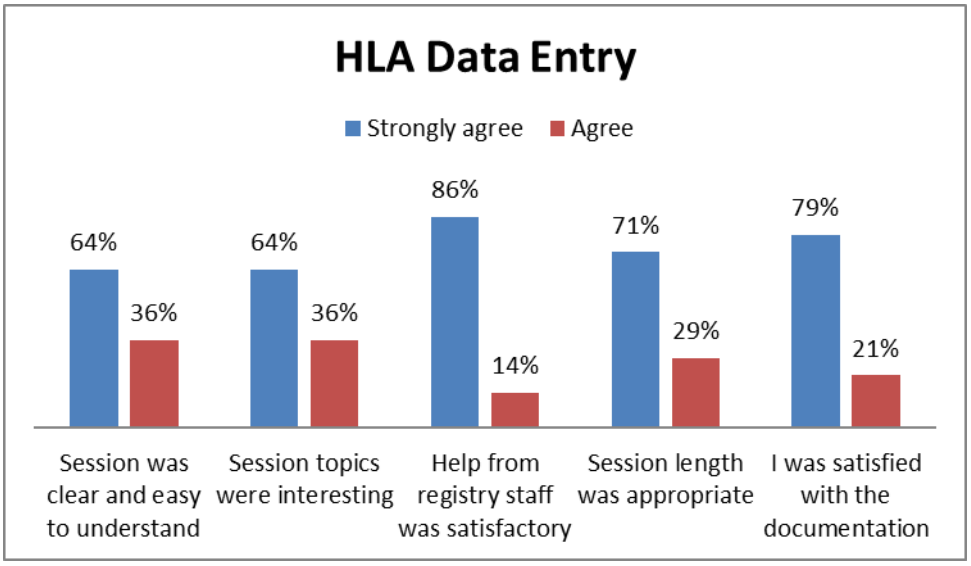
DATA ENTRY			
Number attended:	**26**	**Number of feedback forms completed:**	**13**



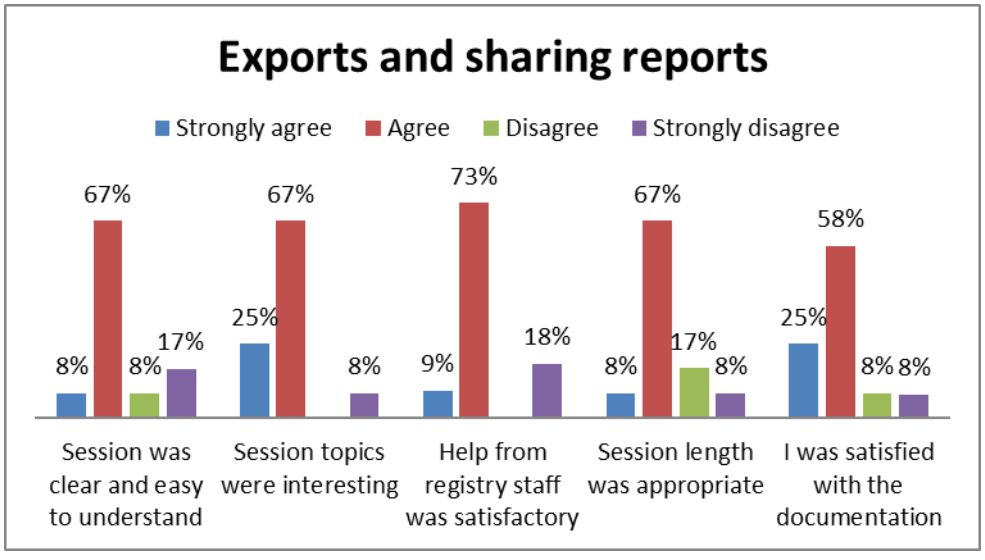
DATA RETRIEVAL			
Number attended:	**28**	**Number of feedback forms completed:**	**18**



HLA DATA ENTRY			
Number attended:	**24**	**Number of feedback forms completed:**	**14**



Exports and Sharing Reports			
Number attended:	**25**	**Number of feedback forms completed:**	**12**



FEEDBACK FOR DATA MANAGEMENT EDUCATION SESSIONS

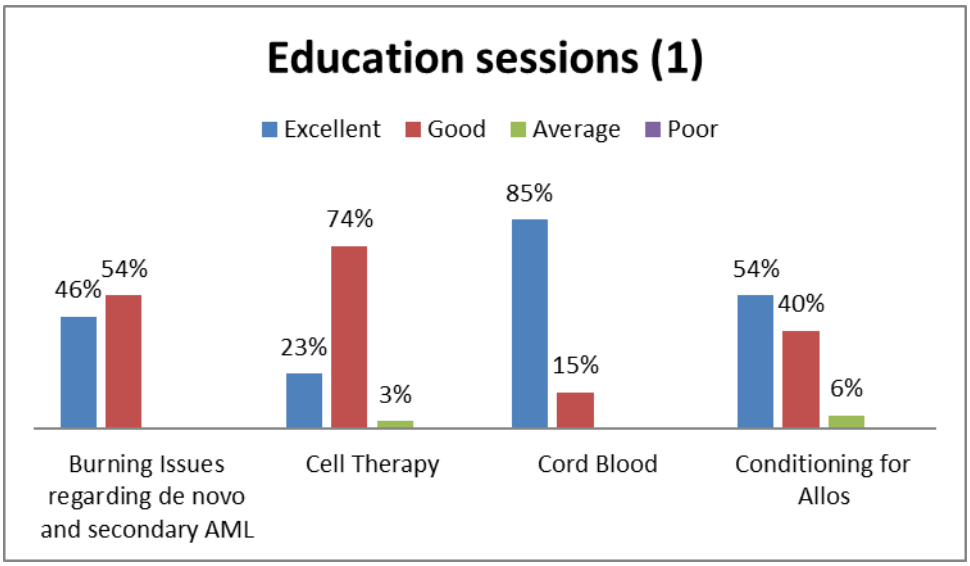
EDUCATION SESSIONS	
Number of feedback forms completed	**258**

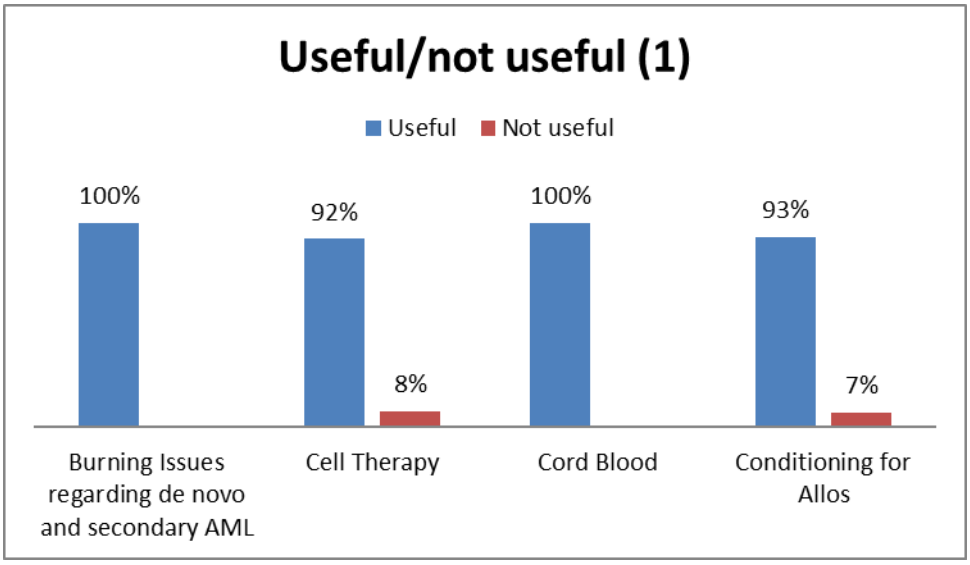
ATTENDANCE AT DATA MANAGEMENT EDUCATIONAL SESSIONS 2016:

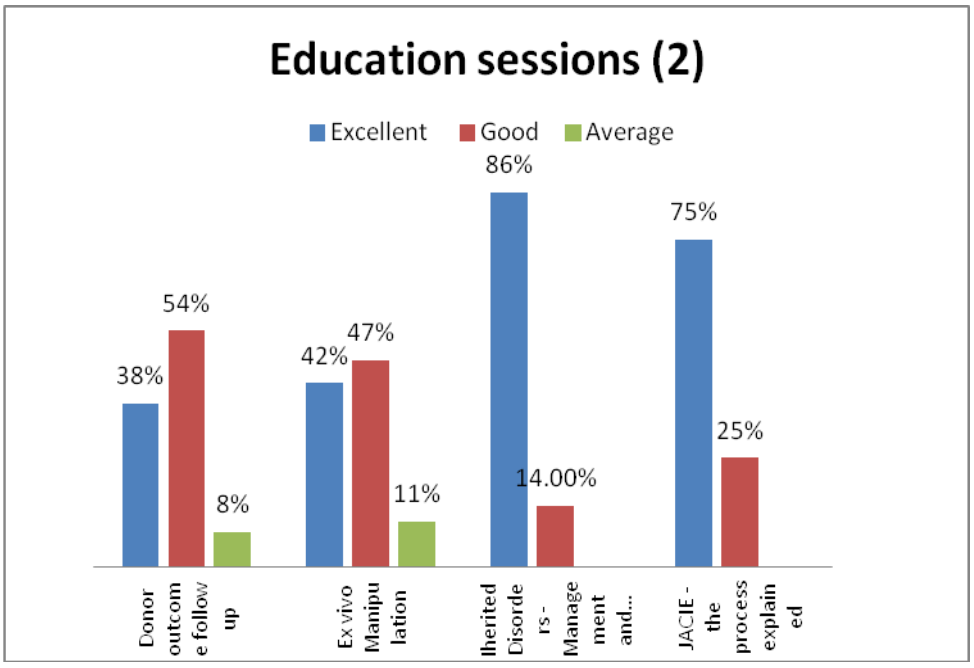
	total forms	total attended
Burning Issues regarding de novo and secondary AML	24	45
Cell Therapy	31	42
Cord Blood	20	35
Conditioning for Allos	35	45
Donor outcome follow up	24	35
Ex vivo Manipulation	19	35
Inherited Disorders - Management and follow up	7	25
JACIE - the process explained	16	40
Myeloma - how to evaluate response to treatment and relapse case studies	16	30
Optimising Data collection at a BMT Unit*	-	30
Performing a study: from study proposal to publication	27	40
The changes to the Med-A	17	100
The comorbidity Index	22	35

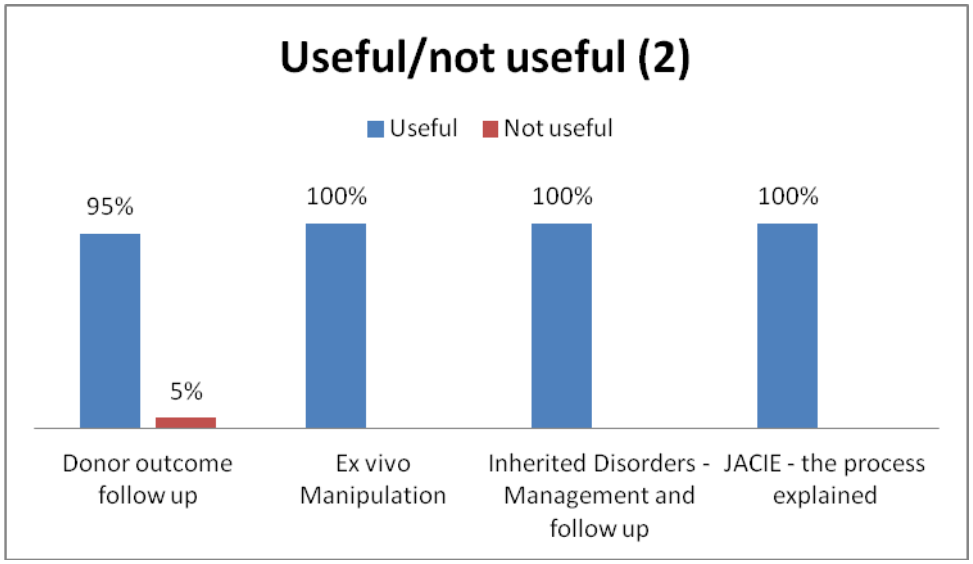
*Unfortunately, due to an error, no feedback forms were collected at this session.

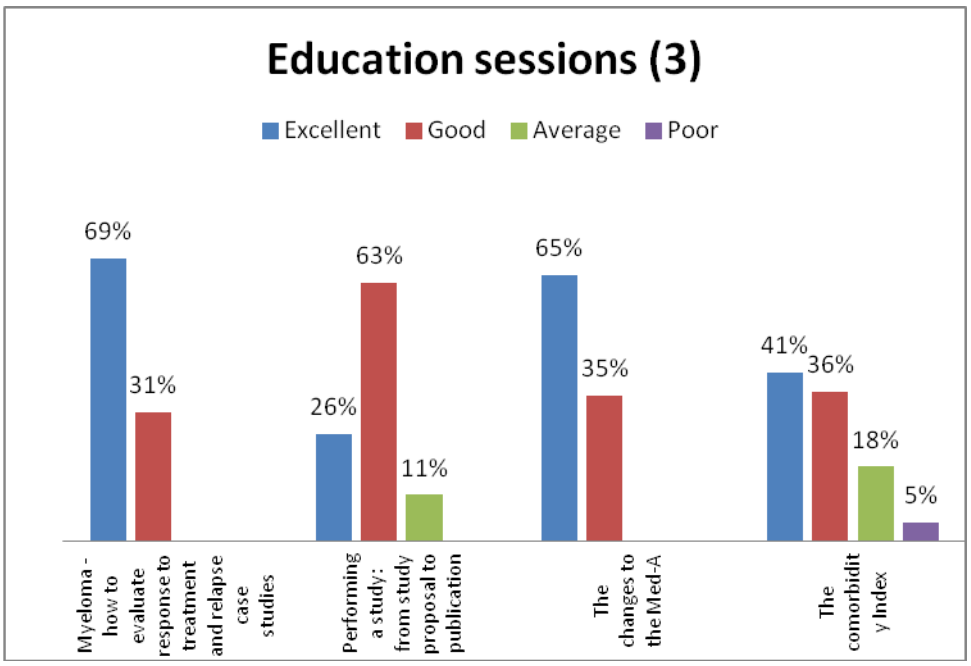
FEEDBACK FROM DATA MANAGEMENT EDUCATION SESSIONS 2016

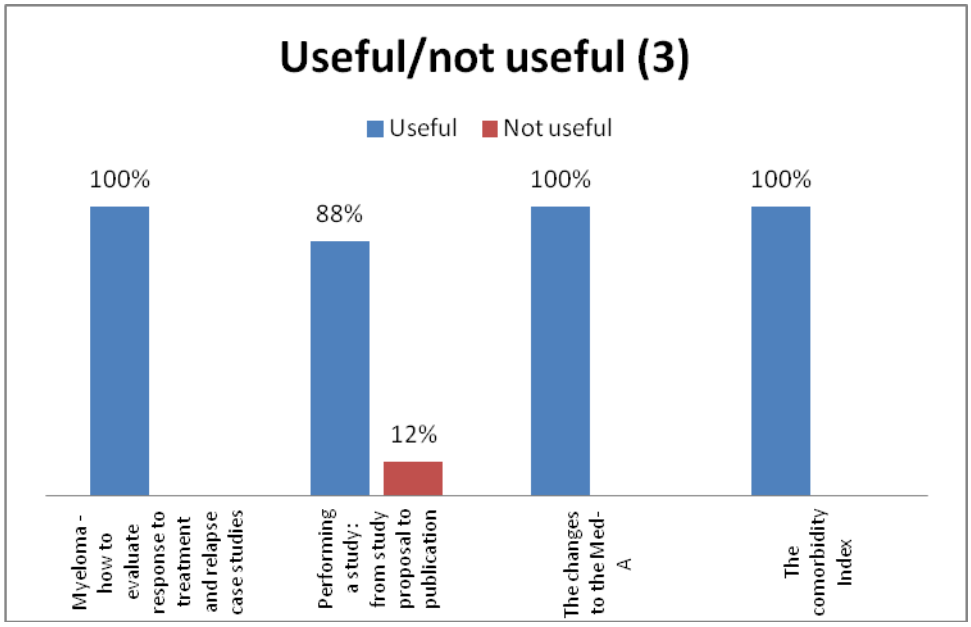





Education sessions (2)
Excellent
Good
Average
38%
54%
8%
42%
47%
11%
86%
14.00%
75%
25%
Donor outcome follow up
Ex vivo Manipulation
Inherited Disorders - Management and...
JACIE - the process explained


Useful/not useful (2)
Useful
Not useful
95%
5%
100%
100%
100%
Donor outcome follow up
Ex vivo Manipulation
Inherited Disorders - Management and follow up
JACIE - the process explained


Education sessions (3)
Excellent
Good
Average
Poor
69%
31%
26%
63%
11%
65%
35%
41%
36%
18%
5%
Myeloma - how to evaluate response to treatment and relapse case studies
Performing a study: from study proposal to publication
The changes to the Med-A
The comorbidity Index


Useful/not useful (3)
Useful
Not useful
100%
88%
12%
100%
100%
Myeloma - how to evaluate response to treatment and relapse case studies
Performing a study: from study proposal to publication
The changes to the Med-A
The comorbidity Index

EBMT ANNUAL MEETING 2016
REVIEW OF DATA MANAGENT SESSIONS

Khrystyna Valkiv
EBMT Data Manager

The 15th Meeting of the Data Management Group was held at the EBMT Annual Meeting in Valencia in 2016 and once again proved to be a very enjoyable event.

There was a good attendane with **112** Data Managers attending from a variety of different countries from all over Europe and from as far afield as Australia, Canada, India, Saudi Arabia and Taiwan.

Once agin, we are extremely grateful to all of our speakers at the Data Management Education sessions who generously shared their expertise and gave us the benefit of their knowledge. **Thank you** therefore to: Andrea Velardi, Andrew Gennery, Anja van Beizen, Camilla Roepstorff, Cora Knol, Chiara Bonini, Eoin McGrath, Herman Einsel, Jane Apperley, Jordi Esteve, Jörg Halter, Heidi Petersen, Laurent Garderet, Roberto Raimondi, Tuula Rintala, Vanderson Rocha. **Thanks also** to the trainers for the ProMISE courses: Asterios, Emmanuelle, Henk-Jan, Lucas, Tunde and Shelley.

Finally thanks to all the staff from registries, centres and EBMT offices who helped with chairing or supporting all of these sessions: Marie, Paul, Richard, Leila, Asterios, Lucas, Nicole, Helga, Franziska, Mathilde, Beate, Cora, Helene, Henk-Jan, Jude and many others. We are indeed very fortunate to have so many able and willing assistants.

Special thanks to MCI who organised the conference for their help and support and to the local conference centre staff who were very helpful.

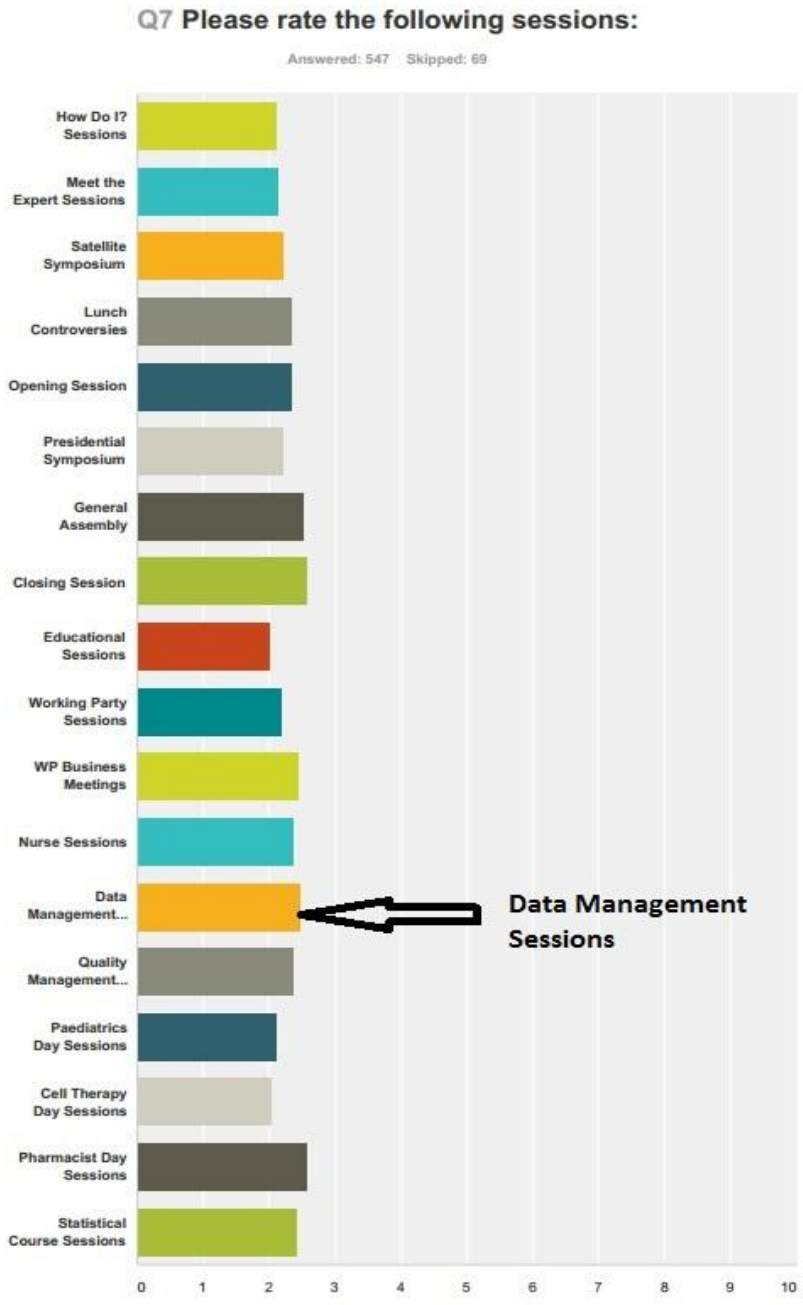
Most of the presentations are available to download on:
http://www.ebmt.org/Contents/Data-Management/Helpdesk/Pages/Helpdesk.aspx

We are editing the ProMISe training recordings and these will be added in the same location as the user guides on www.ebmt.org - [Data Management] – Data Submission

We are always pleased to receive any ideas or suggestions for topics for future Data Management sessions. Please let us know what you think - contact: registryhelpdesk@ebmt.org

The Data Management sessions scored highly in the general survey to all delegates

SURVEY



	Excelent	Very Good	Good	Fair	Poor	N/A	Total	Weighted Average

ANNUAL MEETING VALENCIA 2016
COMMENTS FROM FEEDBACK FORMS

SUMMARY OF COMMENTS FROM FEEDBACK FORMS
Valencia 2016

STRENGTHS
It was very nice that drinks have been provided also for the audience during the data management presentations.
Very interactive, lots of new things to learn. Really, appreciate hearing the science from the experts.
Note: The downloaded .exe file is around 800MB size. When it is downloaded you double click on it and follow instructions for installing it. A second file which has the .txt extension contains the serial number which is required to activate SPSS.
It is always useful to understand that other centers are experiencing problems I see in day-to-day practice.
The speakers for the education sessions were generally very interesting and presented their topics very well

WEAKNESSES
One or two talks were too long, not enough time for the Med A changes.
I do not attend all the sessions as I mix physician type sessions with data management so I cherry pick sessions. Therefore hard to identify weaknesses.

SUGGESTIONS FOR IMPROVEMENTS OR TOPICS TO BE INCLUDED
A session regarding definition Haplo Identical - and maybe explaining the problems associated it (i.e. with the definition?)
The talks by data managers on "their experiences" were very useful, would like more of those.
Additional training on comorbidity index maybe? Session on statistics - what outcome measures are used & what data is essential for them (e.g. date of relapse for EFS)
The new Med-A session was very good - a good chance to ask questions and it showed some of the different problems that Centres have. More sessions like this would be helpful.
Chromosome analysis, immunophenotyping, molecular markers: background, meaning for diagnosis and treatment, practical session
Unknown, unclear, too many complications …. How to document complicated patient histories. Interactive – send in anonymized reports in advance.

ADDITIONAL COMMENTS
The meeting room for the data managers was very nice this year (not so far away from the rest of the conference like in previous years)
It was very nice to meet Data Managers from other centres

ProMISe Training Courses

Data Entry
Support for the theoretical part could be provided
Speaker needs to speak louder
Questions not always answered adequately Promise is crashing. We need help to do it right.
Repeat the question that was asked. Questions cannot be heard sometimes.
The length of the session could be all day. It is so interesting and the only place where I can learn this.
More information on how to document Med-B, GVHD, infections and allo patients.
Data Retrieval
Too long, too slow.
Not satisfied with the export session.
I missed the introduction of who you are and where you are from. Maybe more background information. Why and when you want to use Report/Export. Can you see all data or only for you CIC. Can you modify someone else's Report/Filter.
HLA Data Entry
A bit more background information would have been nice. Otherwise clear, Thank you!
Great!
Exports and Sharing reports
Not clear at all!
Sometimes a little bit too fast just to follow the explanation. Possible would be worthwhile to practice the exports, spss etc.

EDUCATION SESSIONS

Burning Issues regarding de novo and secondary AML
-

Cell Therapy
Too long.
Good explanations of gene therapy, very clear and comprehensive.
Go more into detail about CAR-T cell therapy for ALL for example.

Cord Blood
The start with the Med-B forms was too long
It is very good to go through the Registry form

Conditioning for Allos
Conditioning for allo: This session just gave a general overview. I hoped to get more details on specific conditioning regimes for specific diseases and the most common non myeloablative conditioning regimes.
Too general, well known information – seemed not to show anything new The slides were quite old!

Good speaker, but content-wise not interesting (for me).
No information on chemotherapy itself, too basic, need more information in depth on drug doses, drug targets.
It was too low level, more concrete details would be better.
Very interesting talk, very clear.
Very clear presentation and very useful for Data Managers and Promise.
Are there any plans to include “MA” and “RIC”, “Non MA” options on the Med-A?
Too long

Donor outcome follow up
Not as interesting as I had expected, but ok. It would have been informative to see several outcome results (areas of interest: early donation problems, late effects? Summary of publications – is it safe to donate?) of what is known from unrelated donors. I would also have been interested in a parallel session on how to create queries on the donor data that we collect in Promise.
Too long.
Do I need to fulfill the Donor follow-up in Promise?
Demonstrated that HSCT can have a negative impact on donors and highlights risks they take.
Very thought provoking.

Ex vivo Manipulation
The content of the session ex vivo manipulation was not at all adapted to the public. The topic is rather complex and I was hoping to learn from scratches. It was not the case. I would be great to have another session next year "for beginners".
Is the boost and ex-vivo manipulation? The question is not really answered: how do we know what is ex-vivo manipulation?
Very hard to understand. Very specific.

Inherited Disorders - Management and follow up
Interesting talk, giving insight in a small area of the wide field of inherited disorders Very good speaker; it was a pleasure to listen to him.

JACIE - the process explained
JACIE: This session was very informative and helped a lot!
I am currently in JACIE Inspection and I did not know I am an active part of the Inspection!
Although I am familiar with the process, it was a good reminder!

Myeloma - how to evaluate response to treatment and relapse case studies
Excellent!
Thank you very much!

Optimising Data collection at a BMT Unit
Good, very practical example of how to organize everyday data collection work. I also thought it was a good idea to check one's own measures … trying to document improvement in data collection, completeness of data.

Performing a study: from study proposal to publication
I liked the use of two screens.
When you send out a big file for a study, it is very important to provide explanations for each column, explain exactly which data was requested.

The changes to the Med-A
This session wasn't useful to dispel the aversion of many data managers against the new Med A.
It was very interactive and in this respect good, but it should have been better prepared. It also showed that there still needs to be done some revision work and documentation in the MED-AB manual. Maybe it would even be worth to have a MED-A- manual. As we do now have so much space on the paper forms it would also be possible to give some explanations there.
Should have been longer, too many questions necessary for the time planned!
The time was too short. For the next session with this content, it will be helpful to plan more time.
Excellent for discussion and voicing problems with new Med-A.
Too short.

The comorbidity Index
There was a lot of text in the slides.
Referred to the old Med-A.
HCT-Ci only asked for a few diseases on Promise Med-B.