# Feedback from the 16th Data Managers Meeting

26-29 March 2017
Marseille, France

Number of participants pre- registered as Data Managers: 122

Number of feedback forms completed

	Valencia	Marseille
Meeting Overview	**30**	**11**
Educational Session	**164**	**381**
EBMT Registry Database (ProMISe) Data Entry Sessions	**13**	**18**
EBMT Registry Database (ProMISe) Data Retrieval Sessions	**18**	**18**
EBMT Registry Database (ProMISe) HLA Data Entry Session	**14**	**17**
EBMT Registry Database (ProMISe) Donor Outcome	**12**	**10**
EBMT Registry Database (ProMISe) Advanced Data Entry	**-**	**5**
EBMT Registry Database (ProMISe) Cell Therapy	**-**	**14**
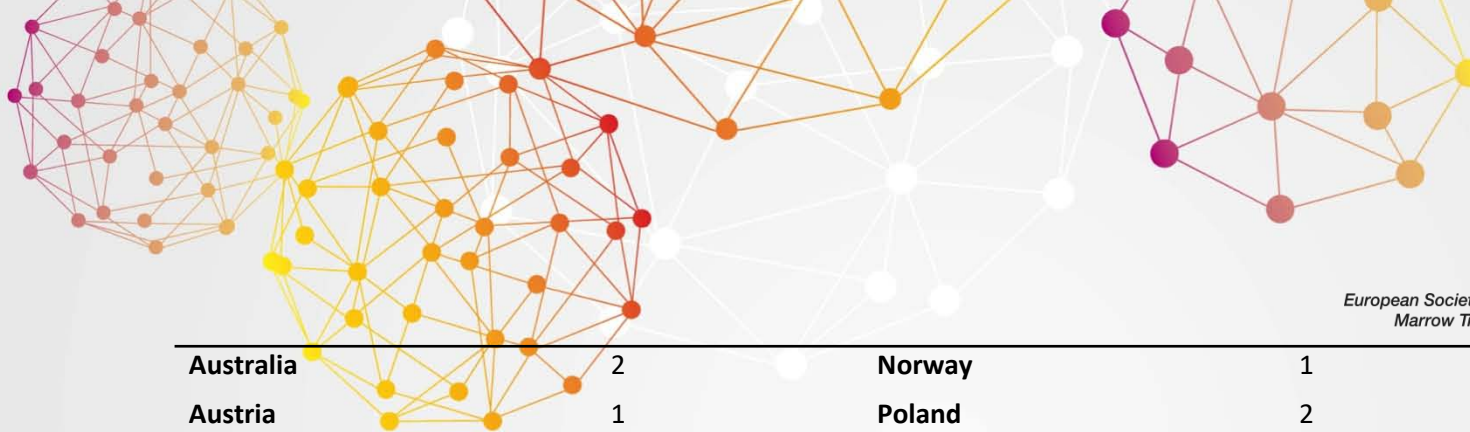
| Country	Count	Country	Count
Australia	2	Norway	1
Austria	1	Poland	2
Belgium	11	Romania	1
Brazil	1	Saudi Arabia	2
Czech Republic	1	South Korea	1
Denmark	2	Spain	1
Finland	4	Sweden	2
France	8	Switzerland	6
Germany	30	Taiwan	2
Hungary	1	Turkey	1
India	2	United Arab Emirates	2
Ireland	3	United Kingdom	12
		United States	9
Israel	4		
Italy	2		
Lithuania	1		
Netherlands	7		

FEEDBACK FOR MEETING OVERVIEW

MEETING OVERVIEW
Number of feedback forms completed: 11
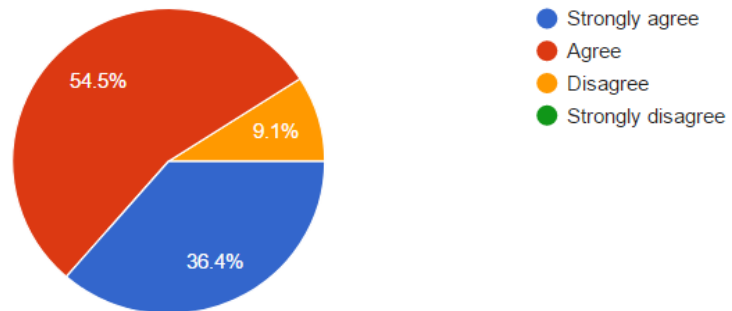

The meeting content was appropriate

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

72.7%
27.3%
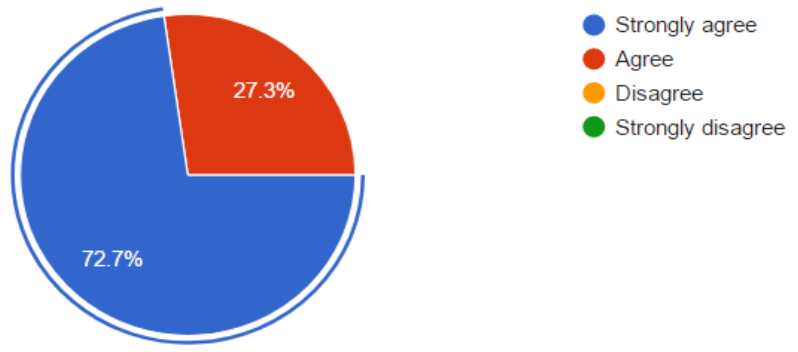
The meeting sessions were presented in a logical order

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

54.5%
9.1%
36.4%

The meeting sessions were interesting

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

54.5%

45.5%
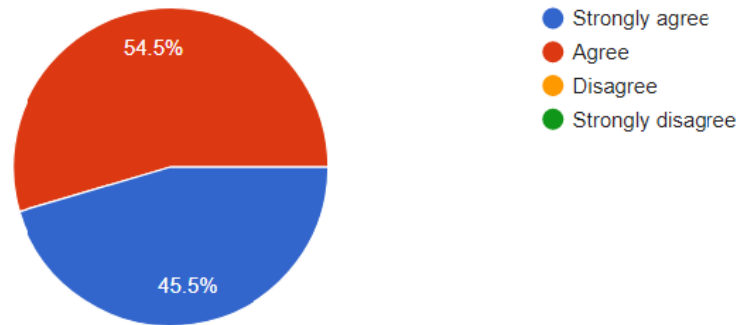
You had the opportunity to ask questions

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

27.3%

72.7%
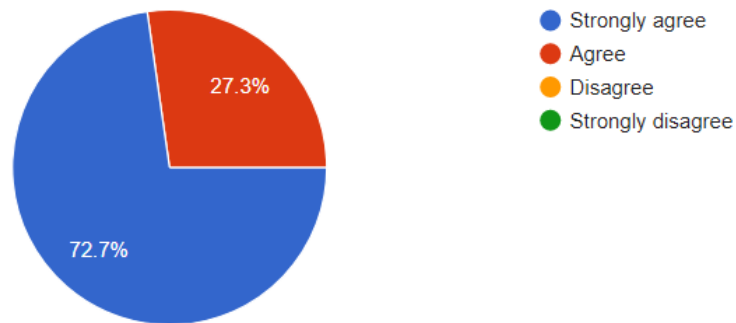
The meeting exposed you to new knowledge

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

54.5%
18.2%
27.3%
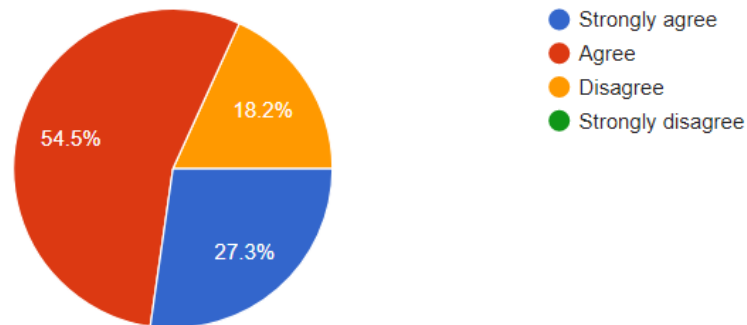
The length of sessions was appropriate

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

54.5%

45.5%
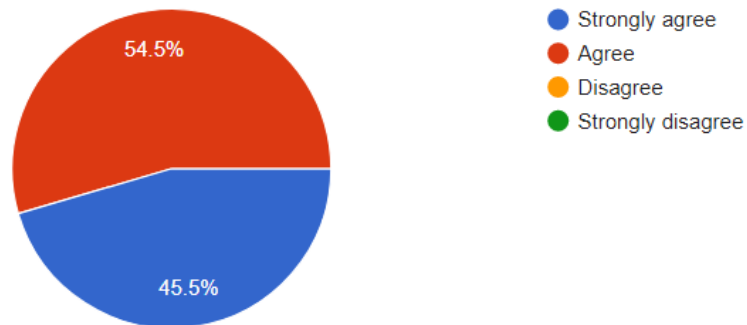
The sessions were clear and easy to understand

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree

72.7%

27.3%
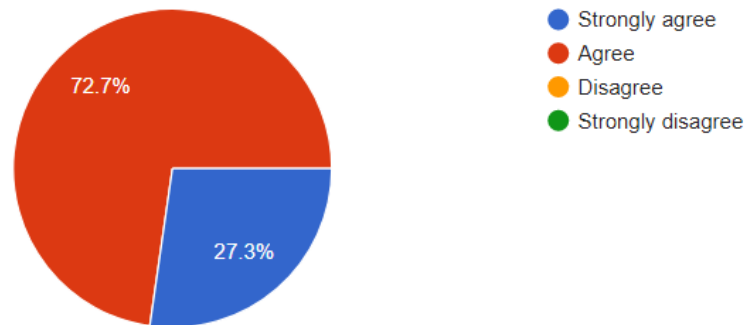
I enjoyed the Data Managers reception

11 responses

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- DID NOT ATTEND

81.8%
18.2%
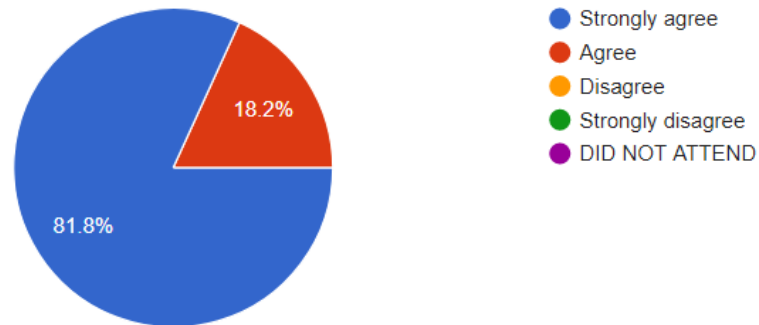
FEEDBACK FOR EBMT REGISTRY DATABASE (ProMISe)
TRAINING SESSIONS
[based on number of feedback forms completed]

DATA ENTRY

Number attended: 38
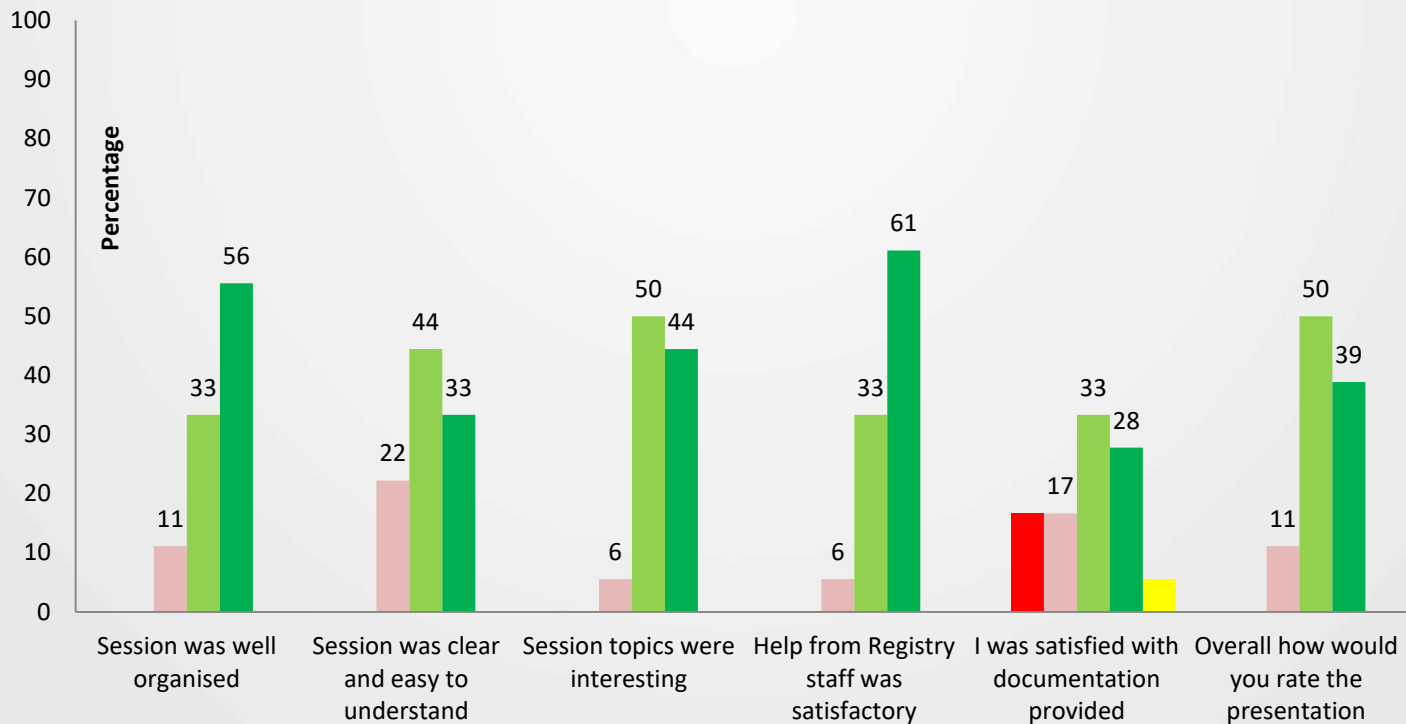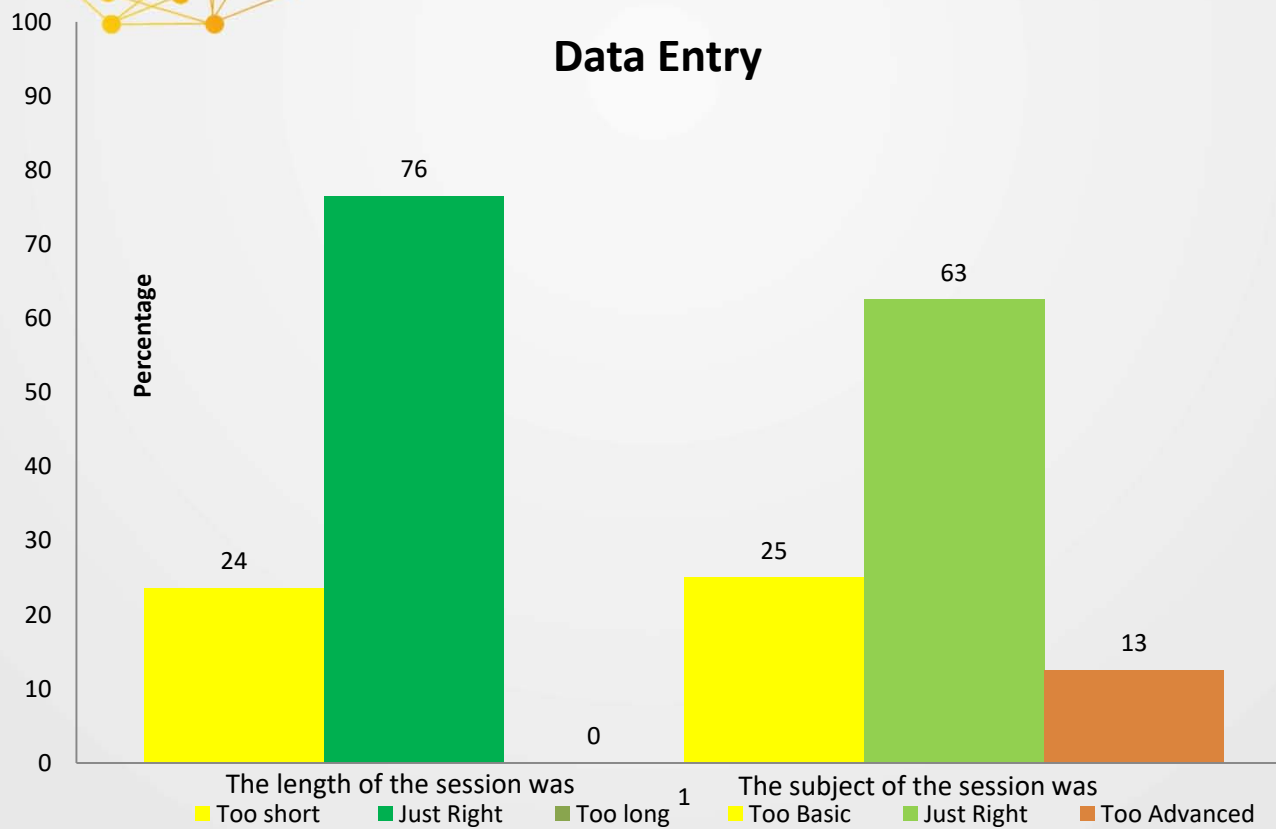**Number of feedback forms completed: 18**

Data Entry

Legend: Strongly Disagree, Disagree, Neither/Nor, Agree, Strongly Agree, Not Applicable (N/A)

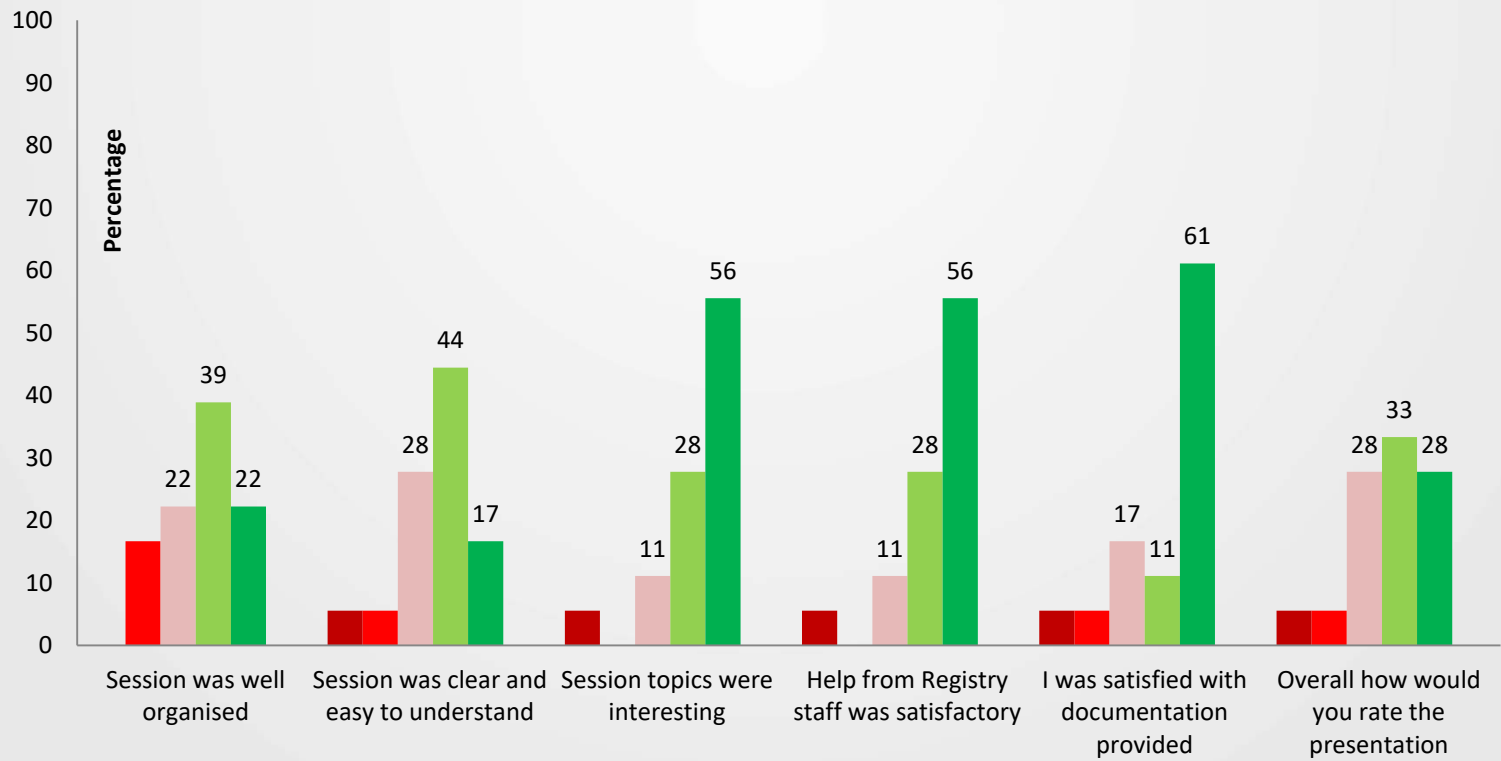| Question	Neither/Nor	Agree	Strongly Agree	Disagree	Not Applicable
Session was well organised	11	33	56		
Session was clear and easy to understand	22	44	33		
Session topics were interesting	6	50	44		
Help from Registry staff was satisfactory	6	33	61		
I was satisfied with documentation provided	17	33	28	17	6
Overall how would you rate the presentation	11	50	39		

Data Entry

DATA RETRIEVAL
Number attended: 23
Number of feedback forms completed: 18

Data Retrieval

Legend: Strongly Disagree · Disagree · Neither/Nor · Agree · Strongly Agree · Not Applicable (N/A)

Question	Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree
Session was well organised		17	22	39	22
Session was clear and easy to understand	6	6	28	44	17
Session topics were interesting	6		11	28	56
Help from Registry staff was satisfactory	6		11	28	56
I was satisfied with documentation provided	6	6	17	11	61
Overall how would you rate the presentation	6	6	28	33	28

Data Retrieval
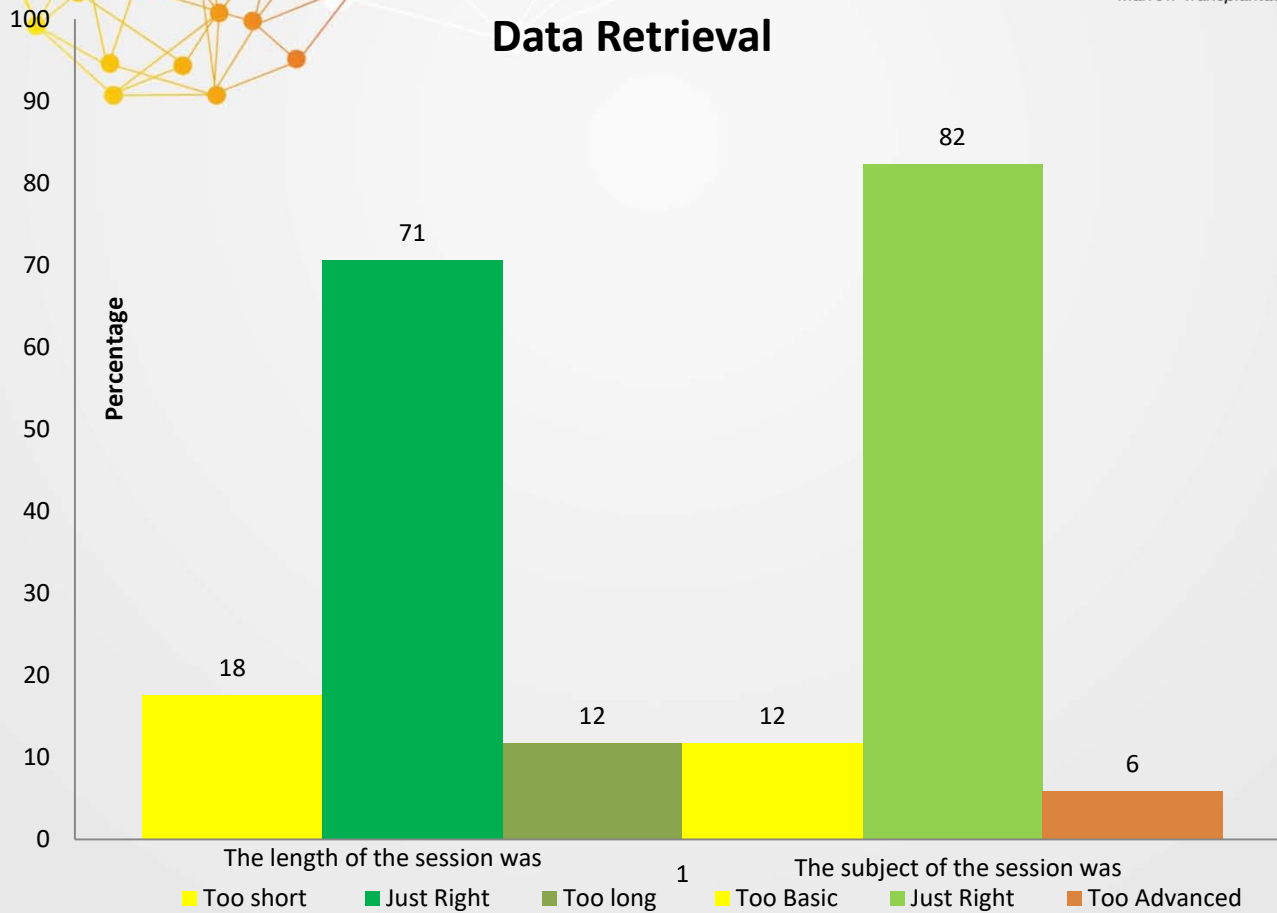
Cell Therapy Data Entry

Number attended: 28
Number of feedback forms completed: 14

Cell Therapy Data Entry
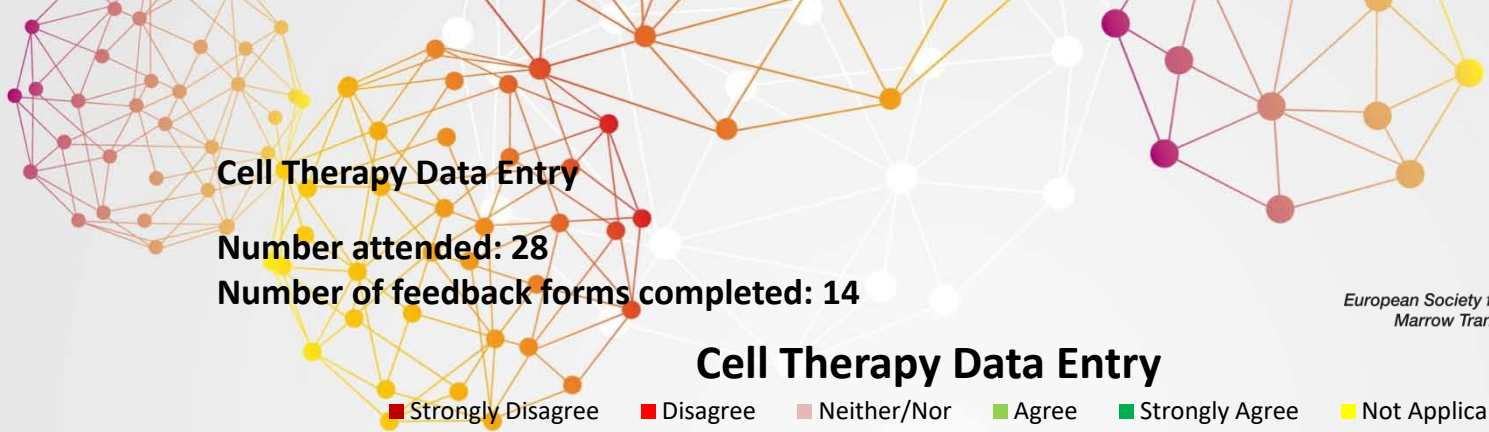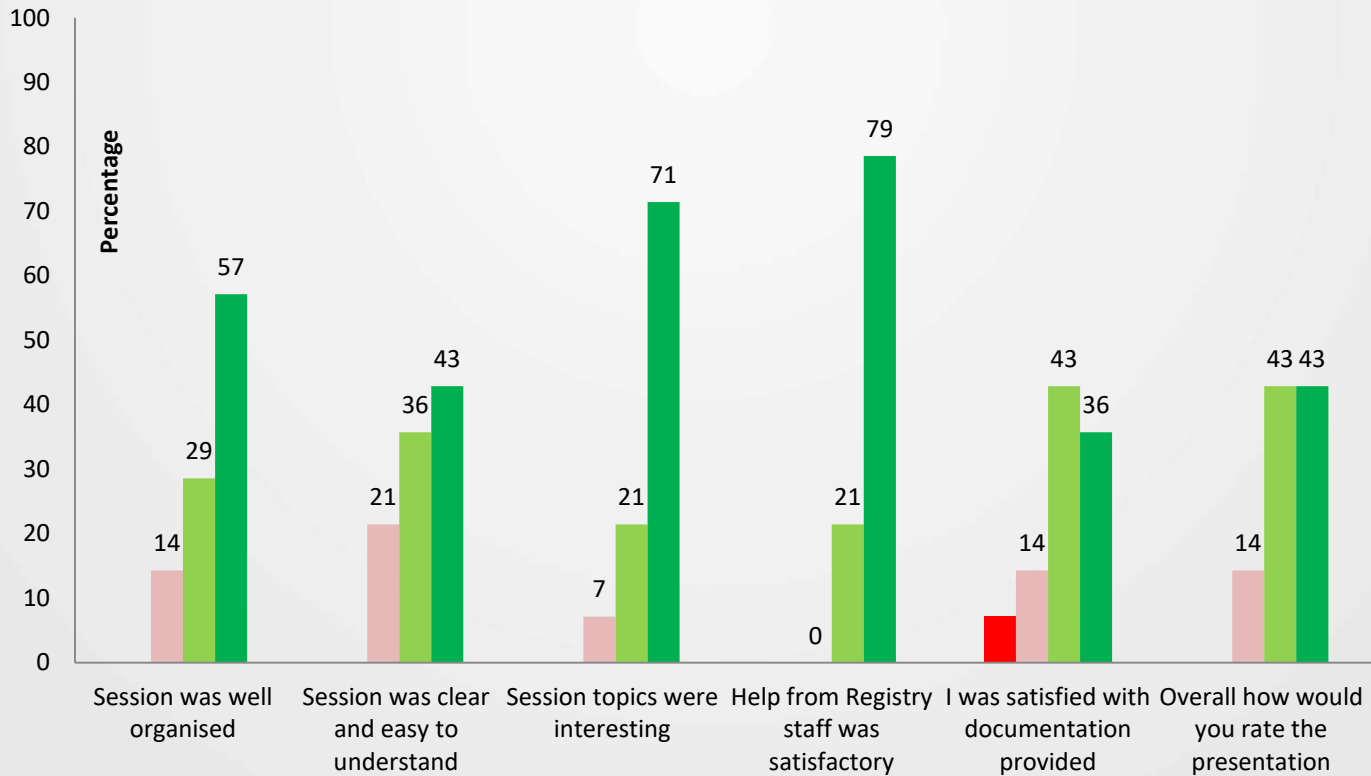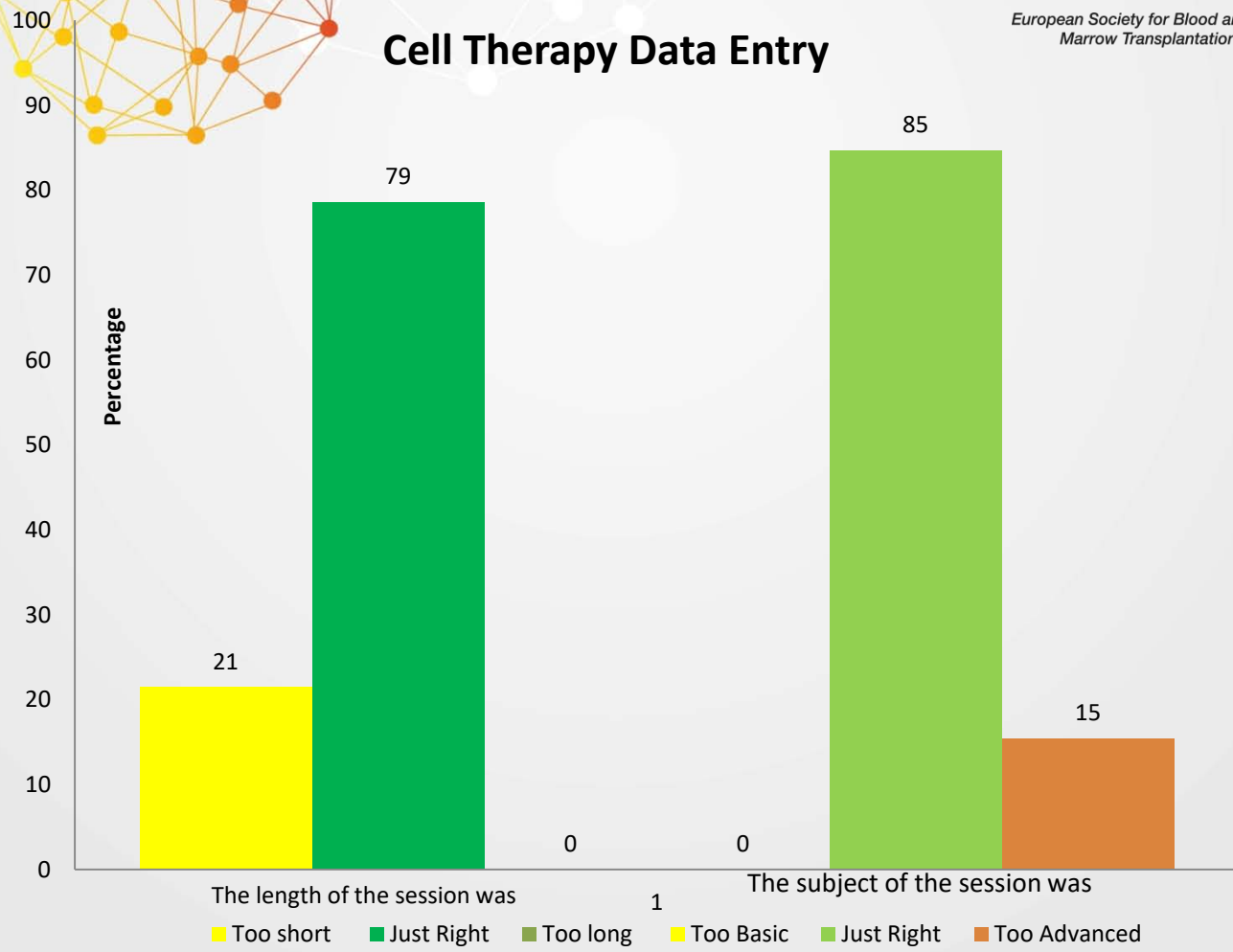
■ Strongly Disagree　■ Disagree　■ Neither/Nor　■ Agree　■ Strongly Agree　■ Not Applicable (N/A)

Category	Neither/Nor	Agree	Strongly Agree	Disagree
Session was well organised	14	29	57	
Session was clear and easy to understand	21	36	43	
Session topics were interesting	7	21	71	
Help from Registry staff was satisfactory	0	21	79	
I was satisfied with documentation provided	14	43	36	7
Overall how would you rate the presentation	14	43	43	

Y-axis: Percentage (0–100)

Cell Therapy Data Entry
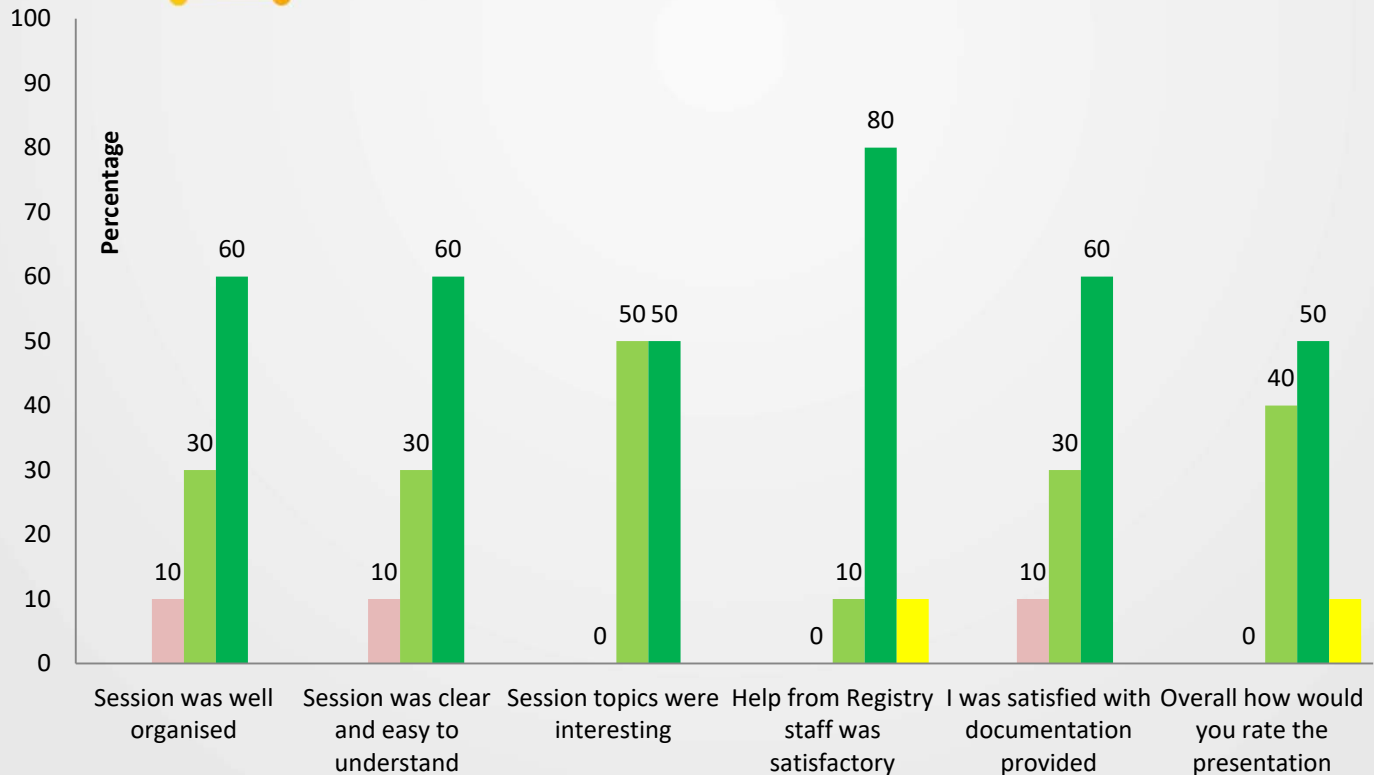
Donor Outcome Data Entry
Number attended: 15
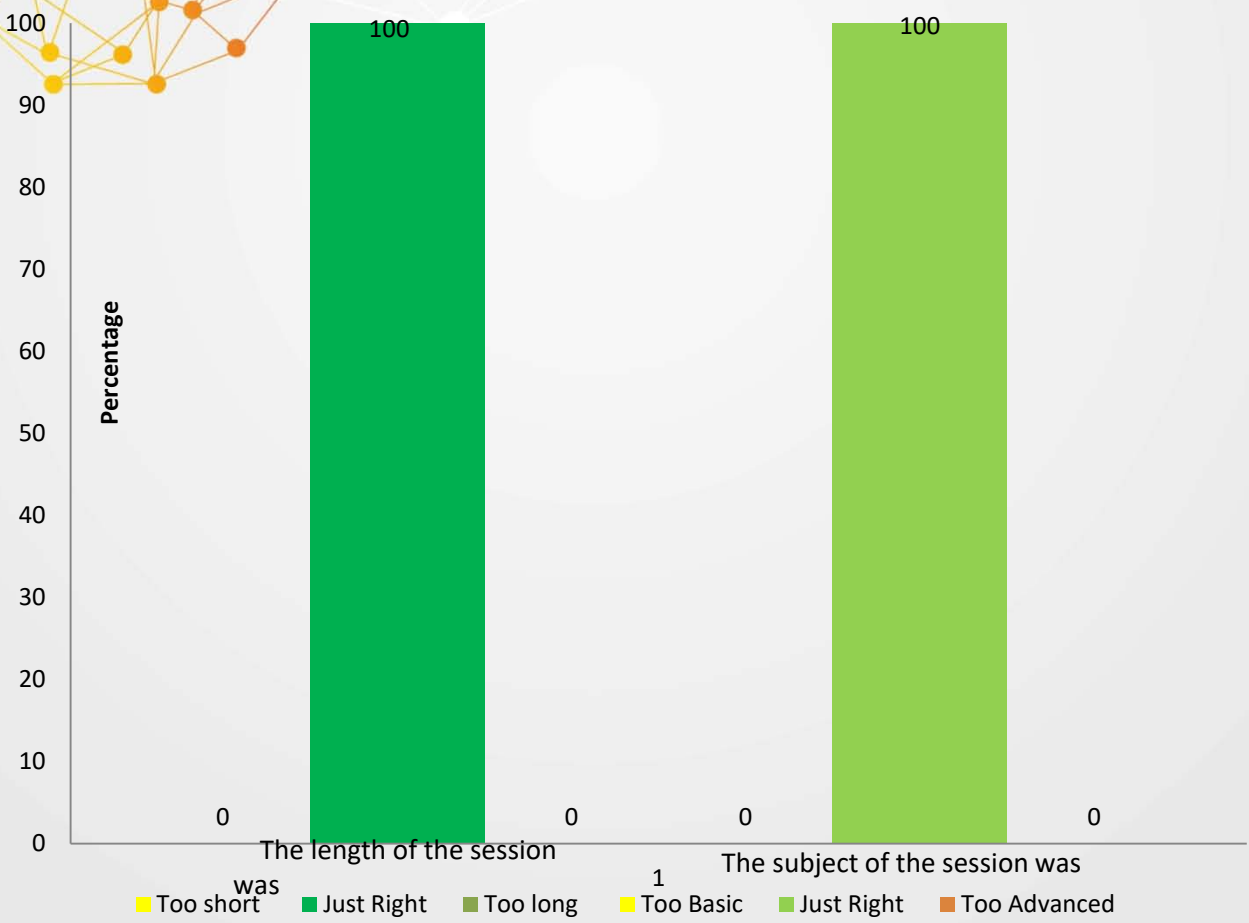**Number of feedback forms completed: 10**

Donor Outcome Data Entry

■ Strongly Disagree ■ Disagree ■ Neither/Nor ■ Agree ■ Strongly Agree ■ Not Applicable (N/A)

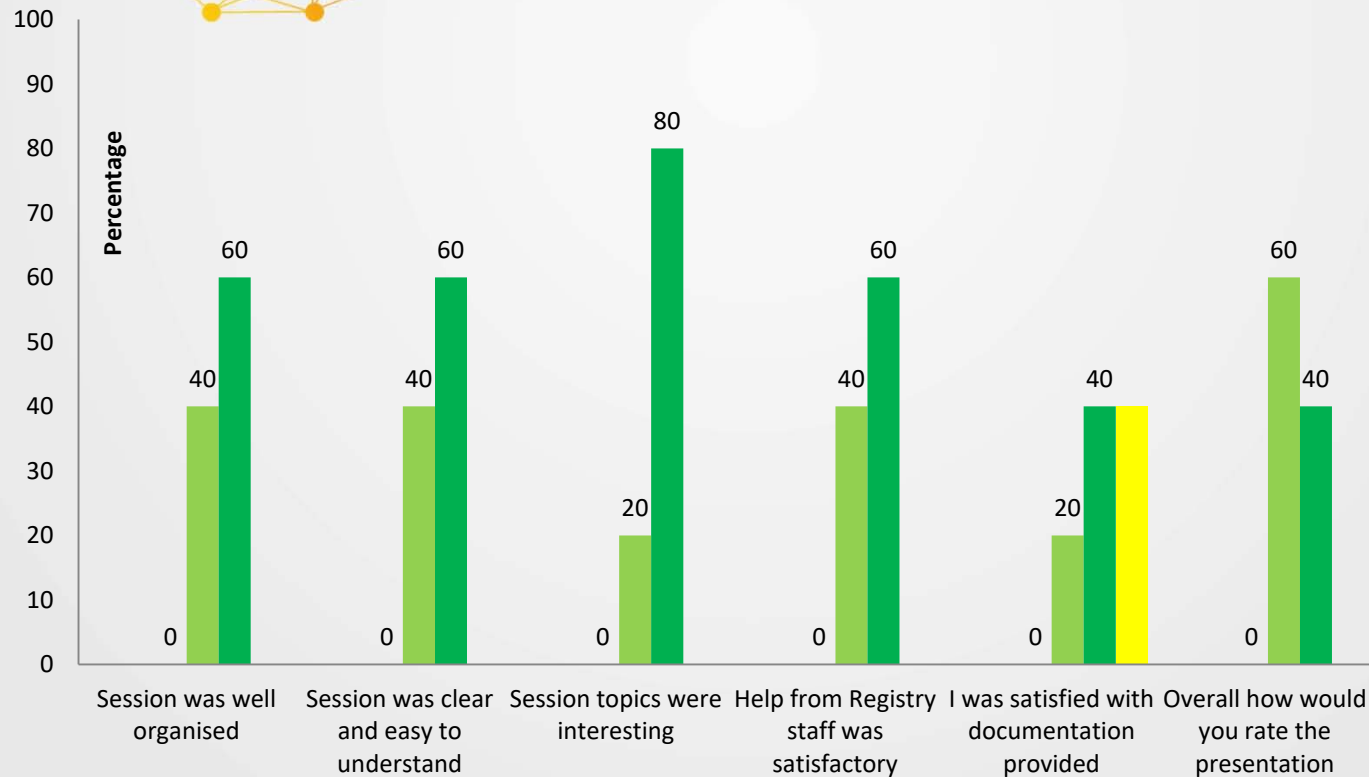**Donor Outcome Data Entry**

Advanced Data Entry

Number attended: 12

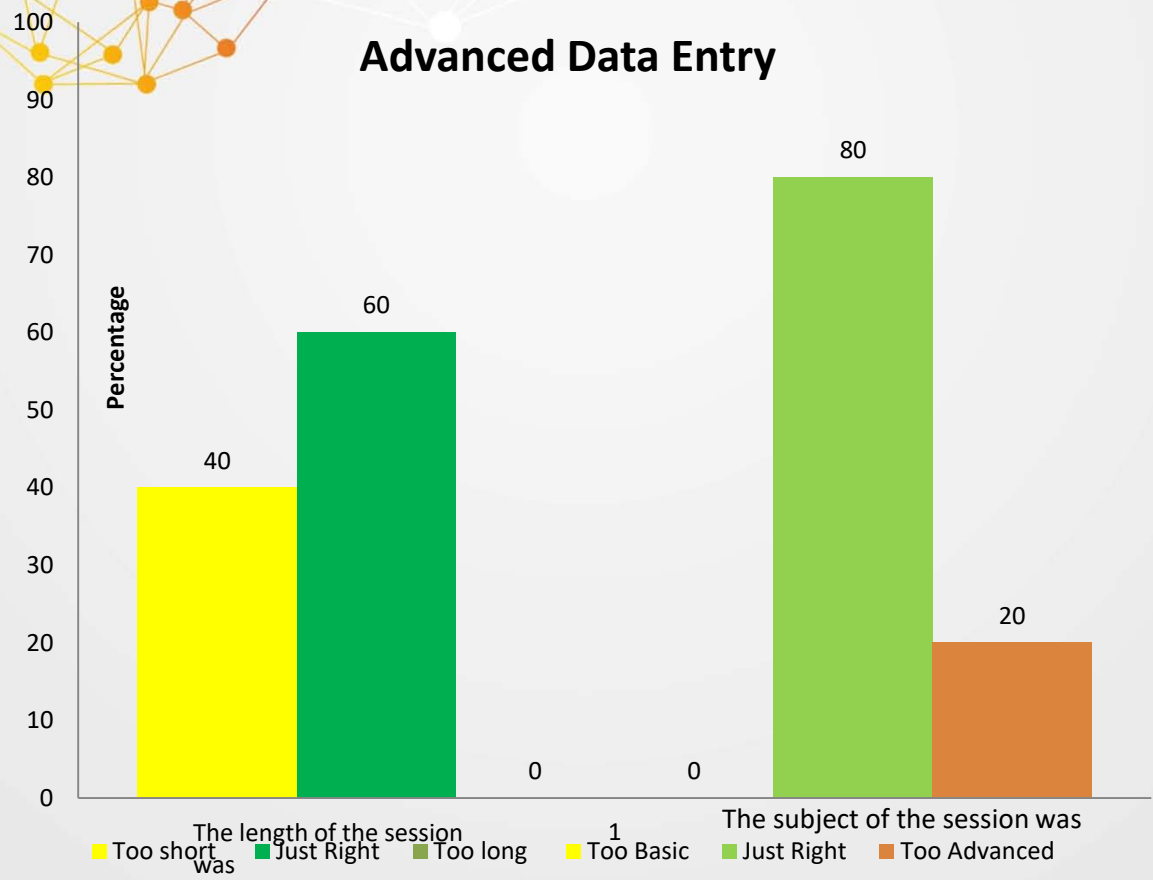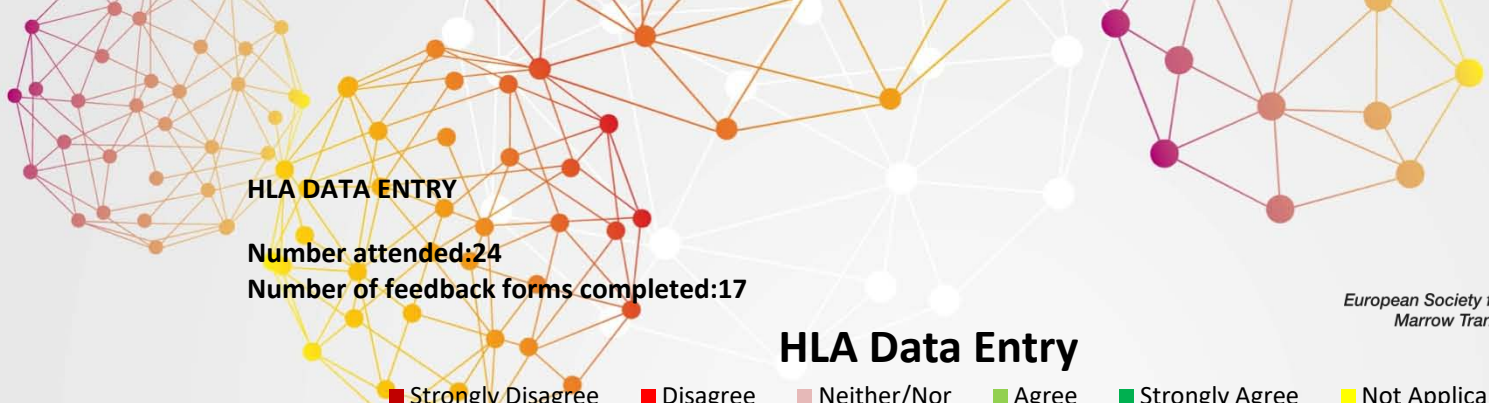**Number of feedback forms completed: 5**

Advanced Data Entry

Legend: Strongly Disagree | Disagree | Neither/Nor | Agree | Strongly Agree | Not Applicable (N/A)

Category	Agree	Strongly Agree	N/A
Session was well organised	40	60	
Session was clear and easy to understand	40	60	
Session topics were interesting	20	80	
Help from Registry staff was satisfactory	40	60	
I was satisfied with documentation provided	20	40	40
Overall how would you rate the presentation	60	40	

Advanced Data Entry

HLA DATA ENTRY

Number attended:24
Number of feedback forms completed:17

HLA Data Entry
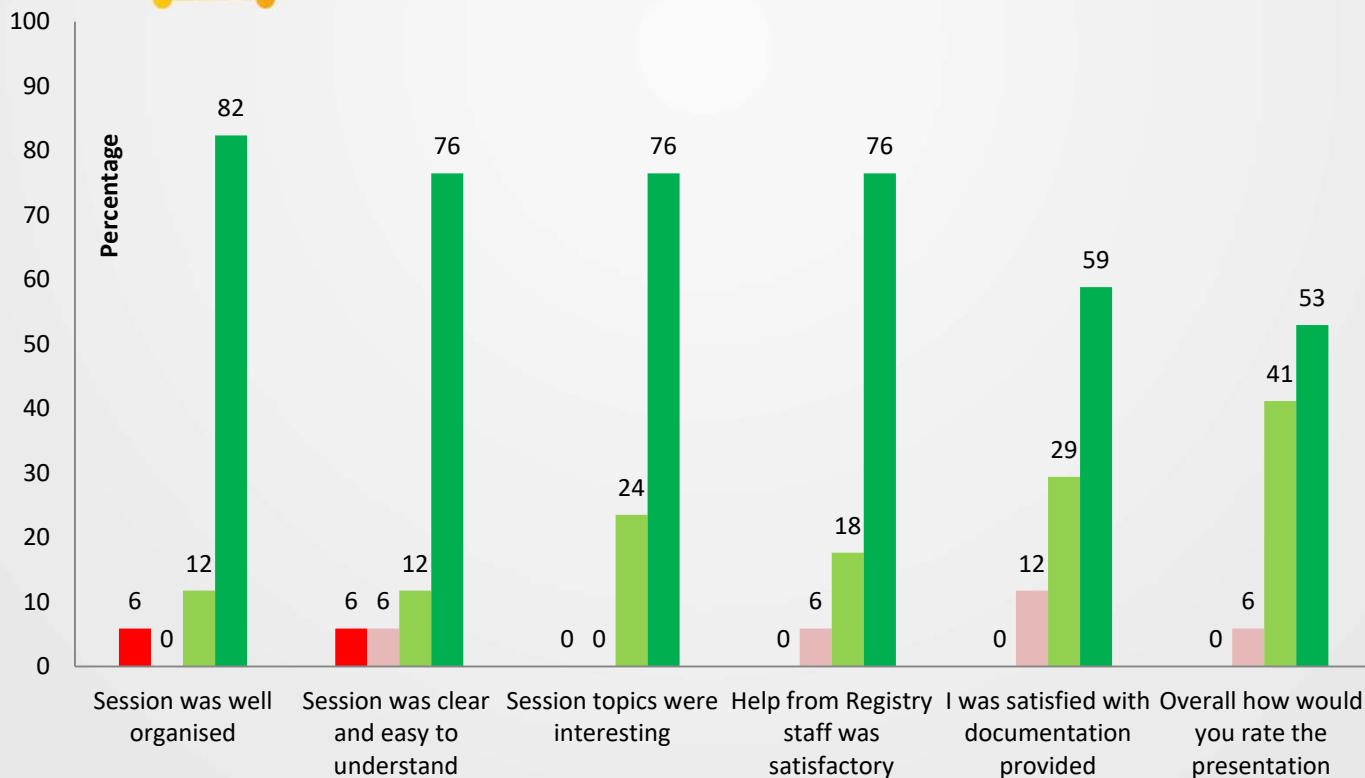
HLA Data Entry
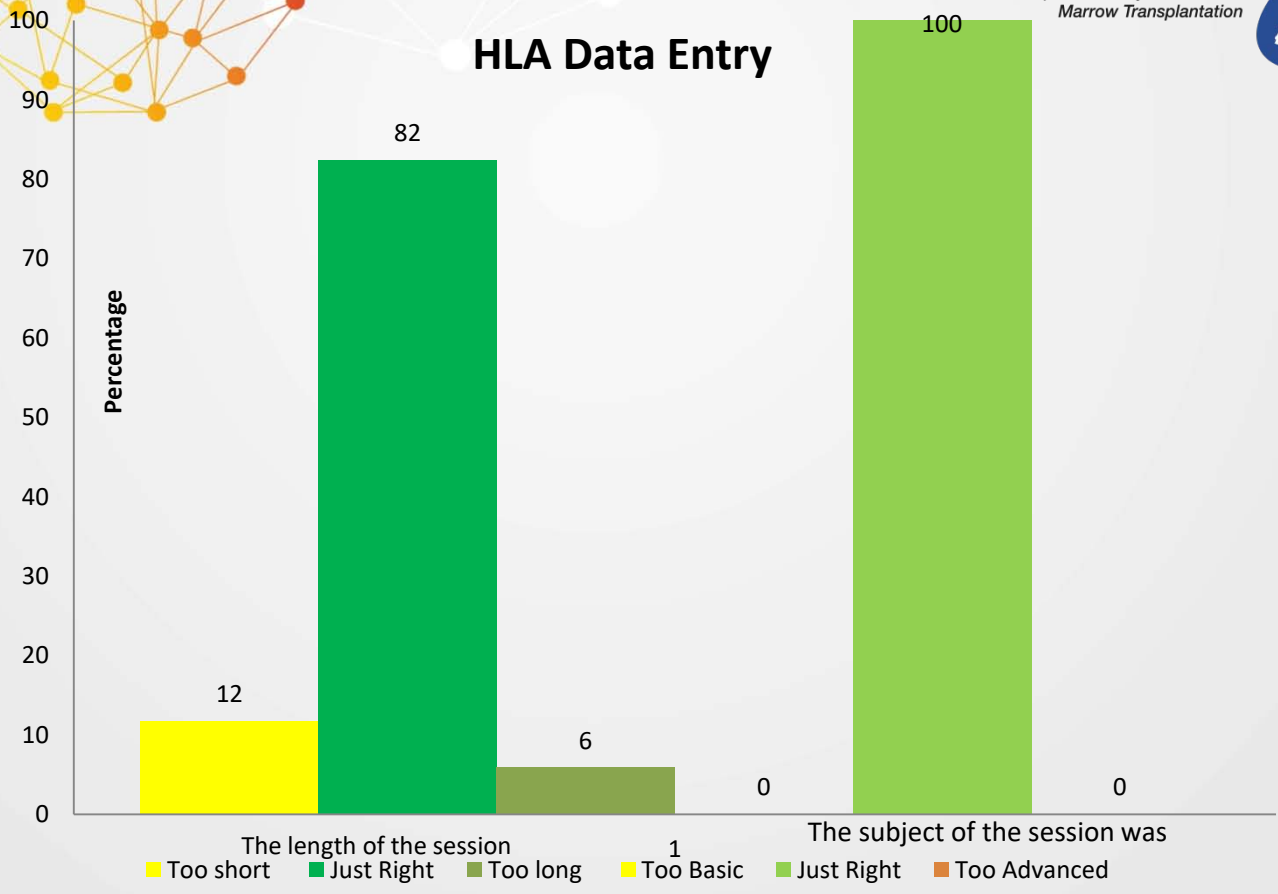
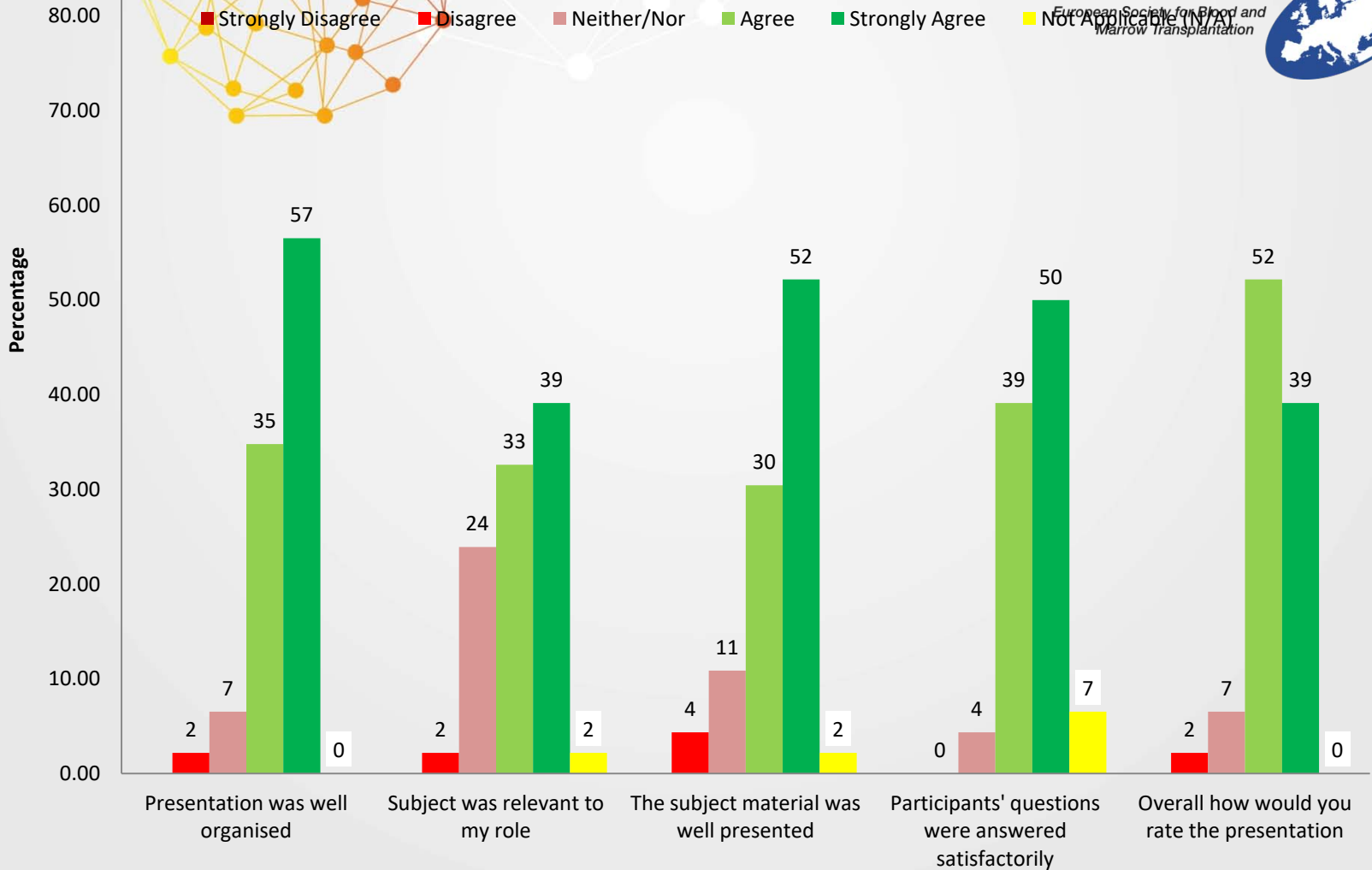**FEEDBACK RECEIVED FOR DATA MANAGEMENT EDUCATION SESSIONS**

EDUCATION SESSIONS
Number of feedback forms completed: 381

ATTENDANCE FIGURES AT DATA MANAGEMENT EDUCATIONAL SESSIONS 2017:

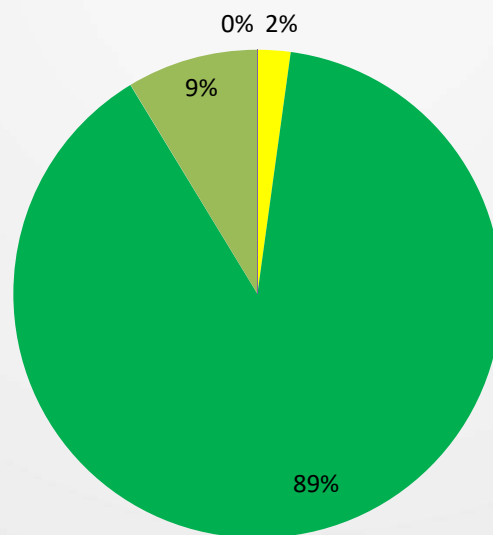| Session Name	total forms	total attended
CAR-T cells: basics, applications and data reporting	46	100
Over 40,000 transplants in Europe each year: The latest trends and developments from the EBMT Transplant Activity Survey	48	80
"Haplo identical" transplants	30	120
How to document complicated patient histories	30	75
Centre Presentation on how new Med-A form has affected working practices in centres	23	40
Chronic GvHD	38	48
Immunosuppressive Treatments in Aplastic Anaemia: current practice. RACE trial update and training	17	39
Med-A form: Discussion forum	19	44
Data protection	22	33
Long-term survivors	24	27
How is HLA data in the registry database being used by EBMT?	27	45
Myelodysplastic syndromes (MDS)	30	38
Cytogenetics (with a focus on Med-A)	25	37

CAR-T cells

Legend: Strongly Disagree, Disagree, Neither/Nor, Agree, Strongly Agree, Not Applicable (N/A)

Percentage (y-axis: 0.00 to 100.00)

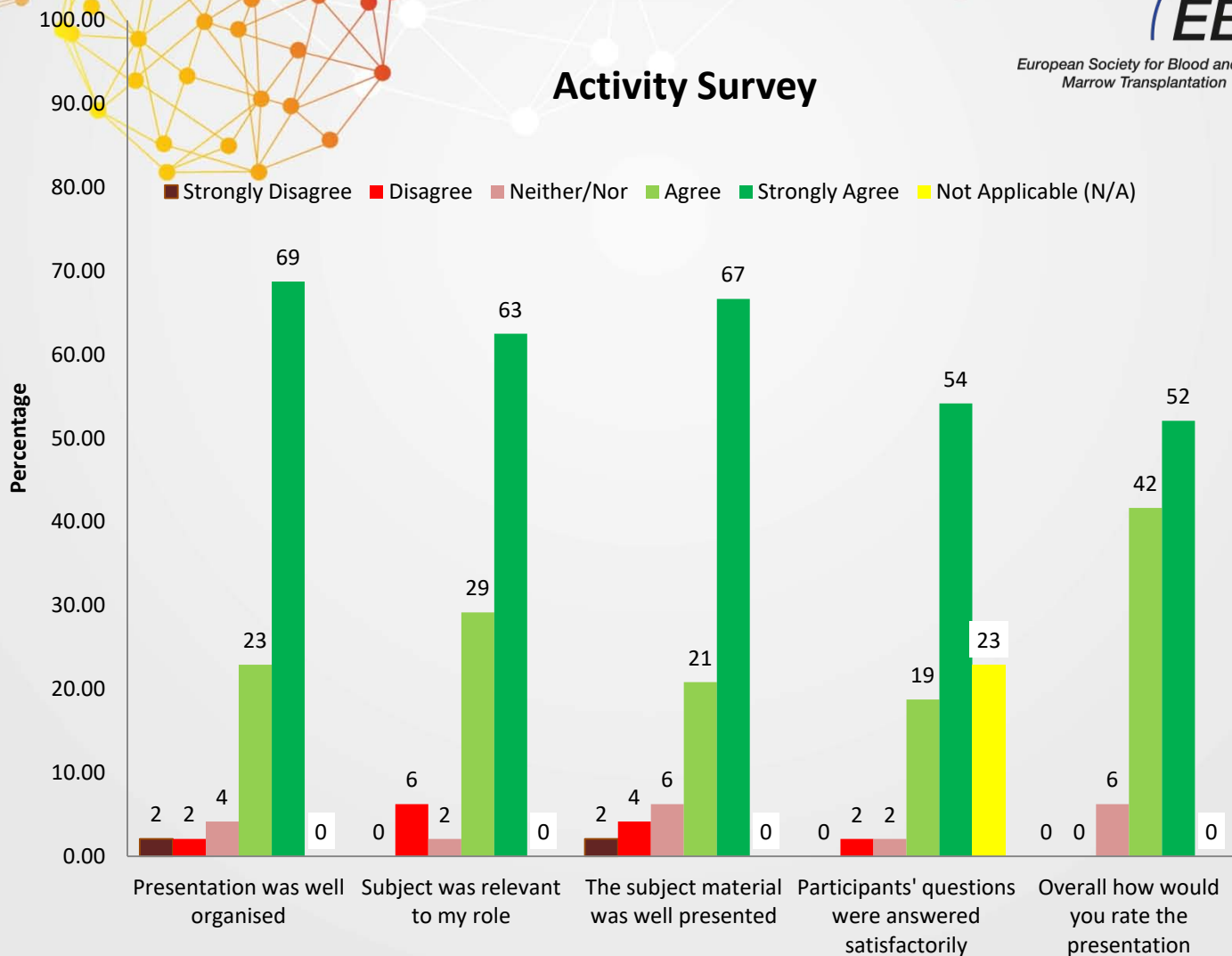| Question	Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree	Not Applicable
Presentation was well organised		2	7	35	57	0
Subject was relevant to my role		2	24	33	39	2
The subject material was well presented	4		11	30	52	2
Participants' questions were answered satisfactorily	0		4	39	50	7
Overall how would you rate the presentation		2	7	52	39	0

CAR-T Cells

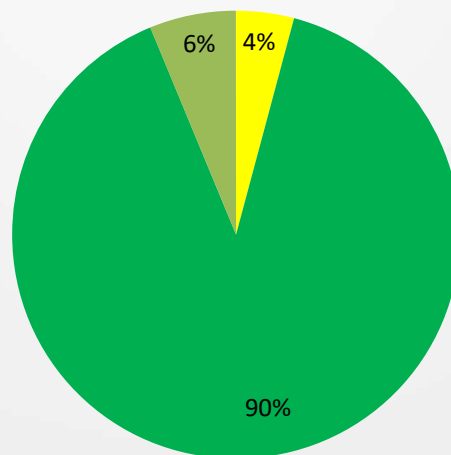■ Too Basic ■ Just Right ■ Too Advanced

Activity Survey
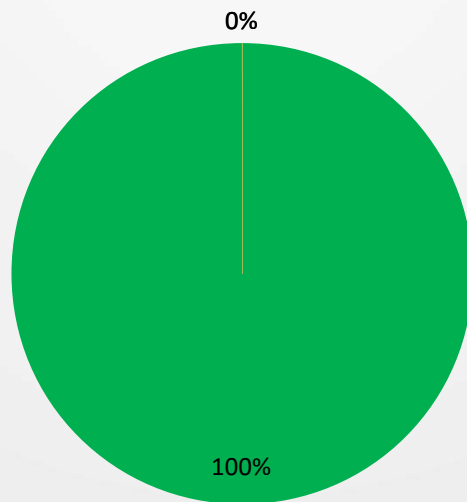
Activity Survey

Too Basic Just Right Too Advanced
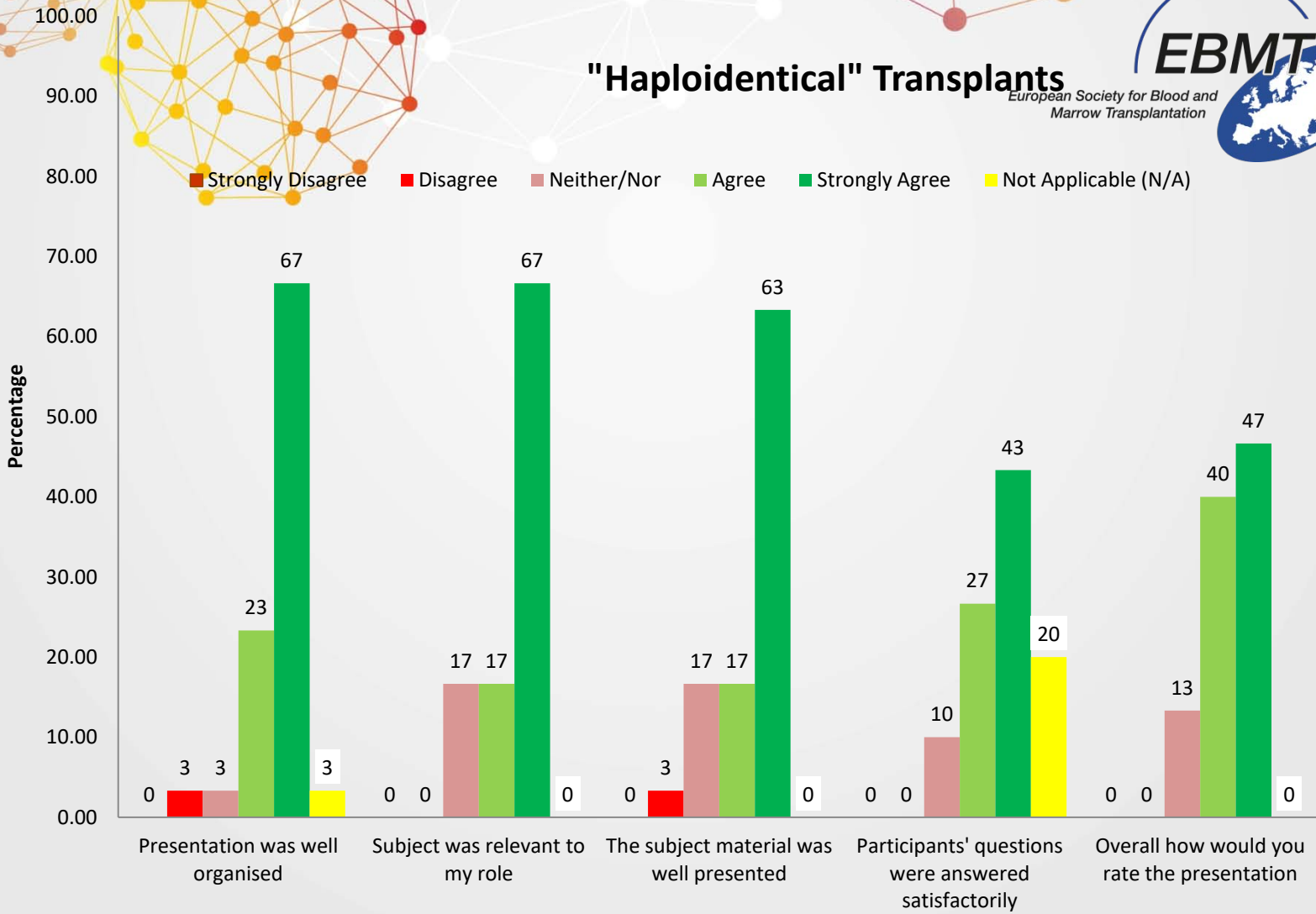
6% 4%

90%

"Haploidentical" Transplants

"Haploidentical" Transplants

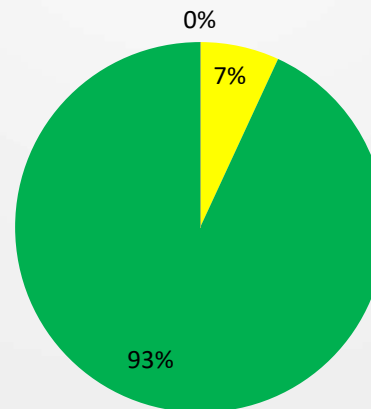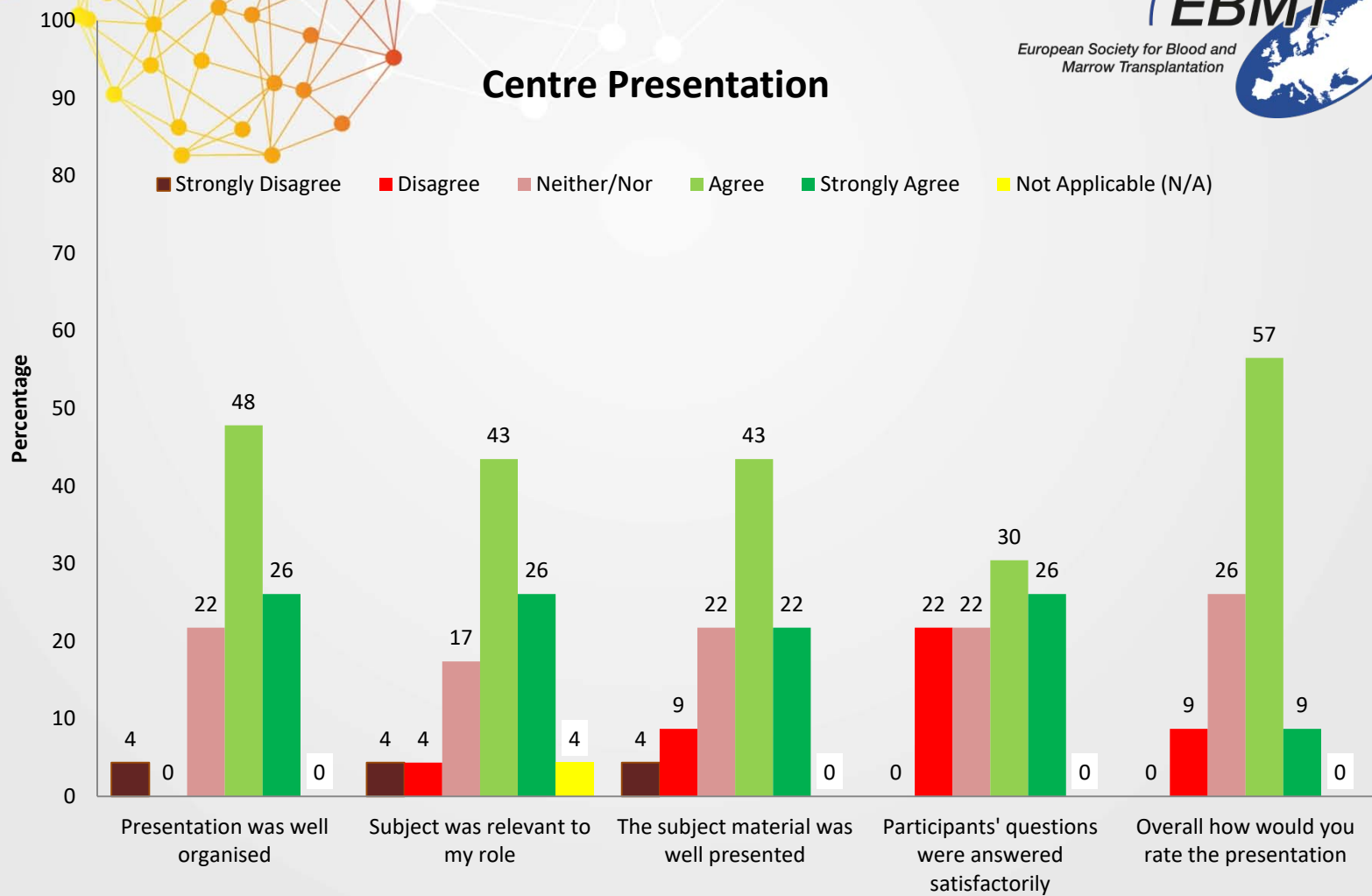How to document complicated patient histories
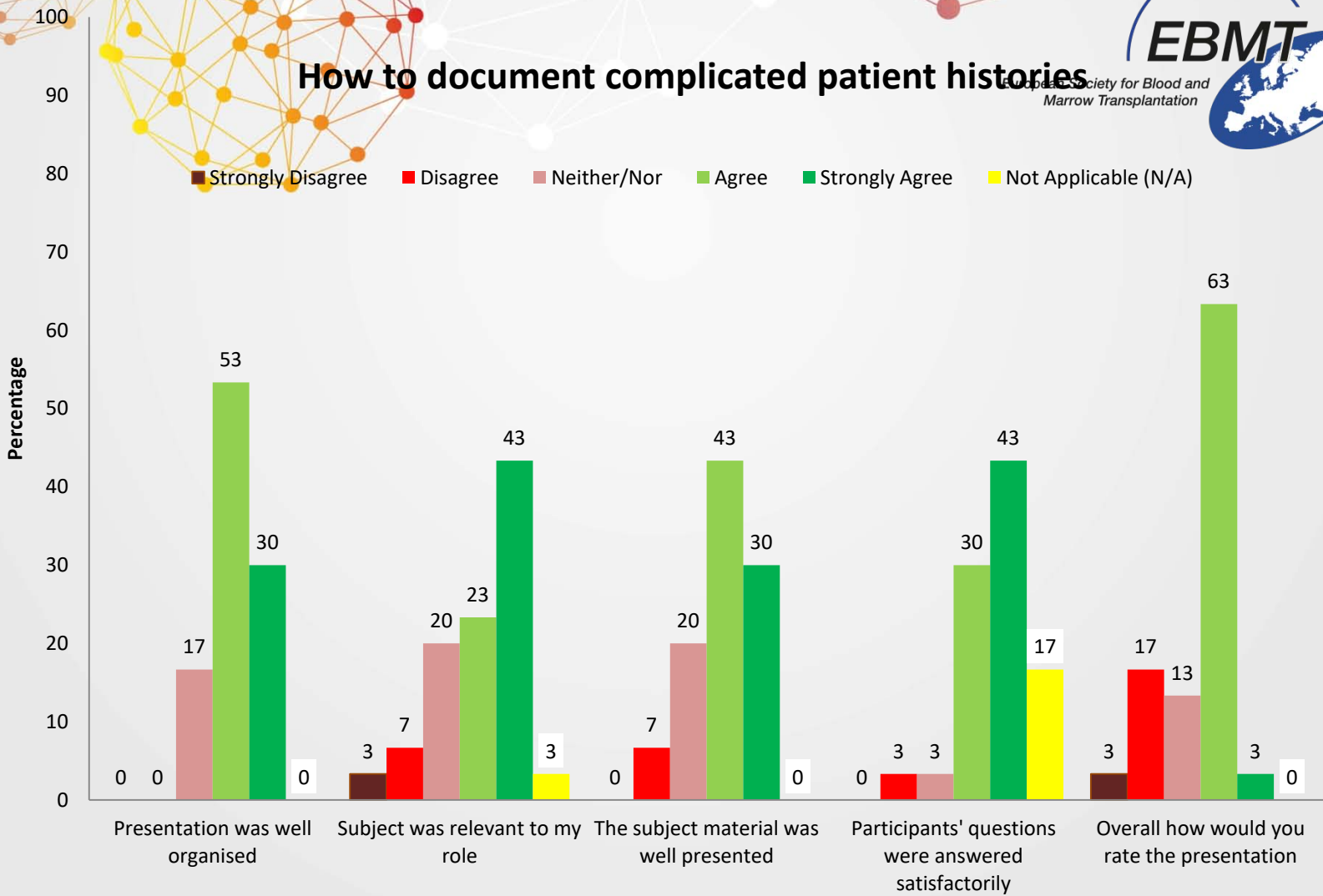
How to document complicated patient histories

■ Too Basic ■ Just Right ■ Too Advanced

0%

7%
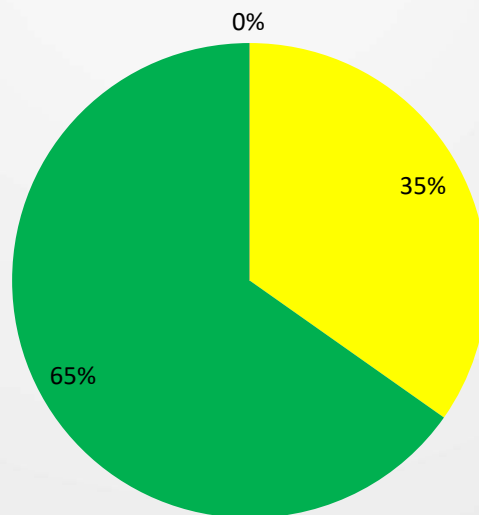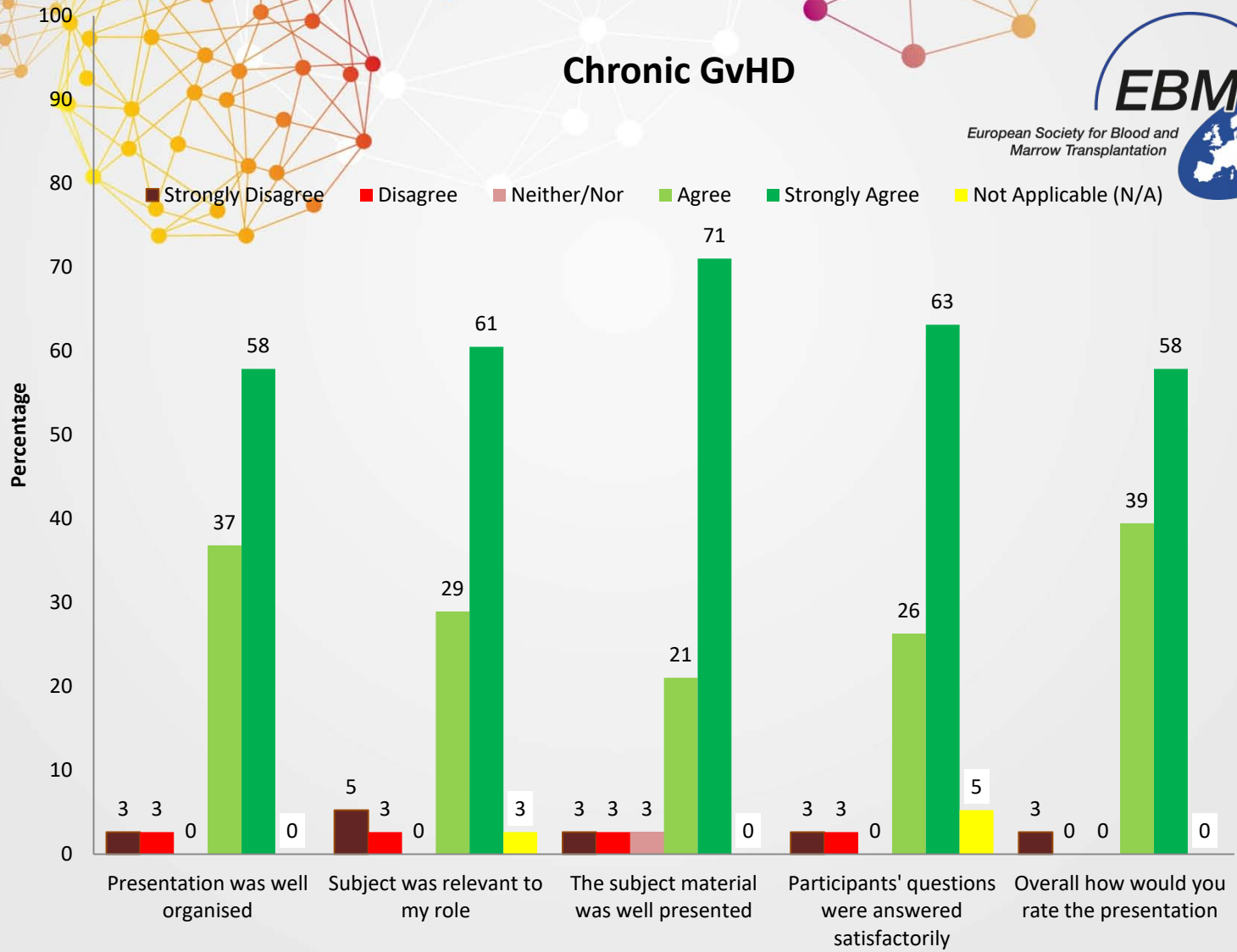
93%

Centre Presentation

Centre Presentation

■ Too Basic　■ Just Right　■ Too Advanced

0%

35%

65%

Chronic GvHD

Percentage

Legend: Strongly Disagree, Disagree, Neither/Nor, Agree, Strongly Agree, Not Applicable (N/A)

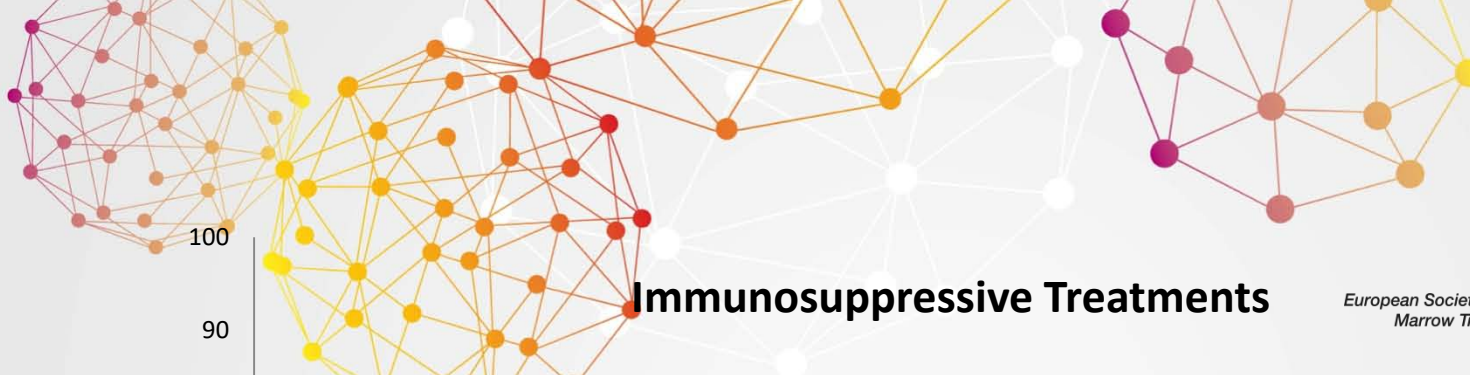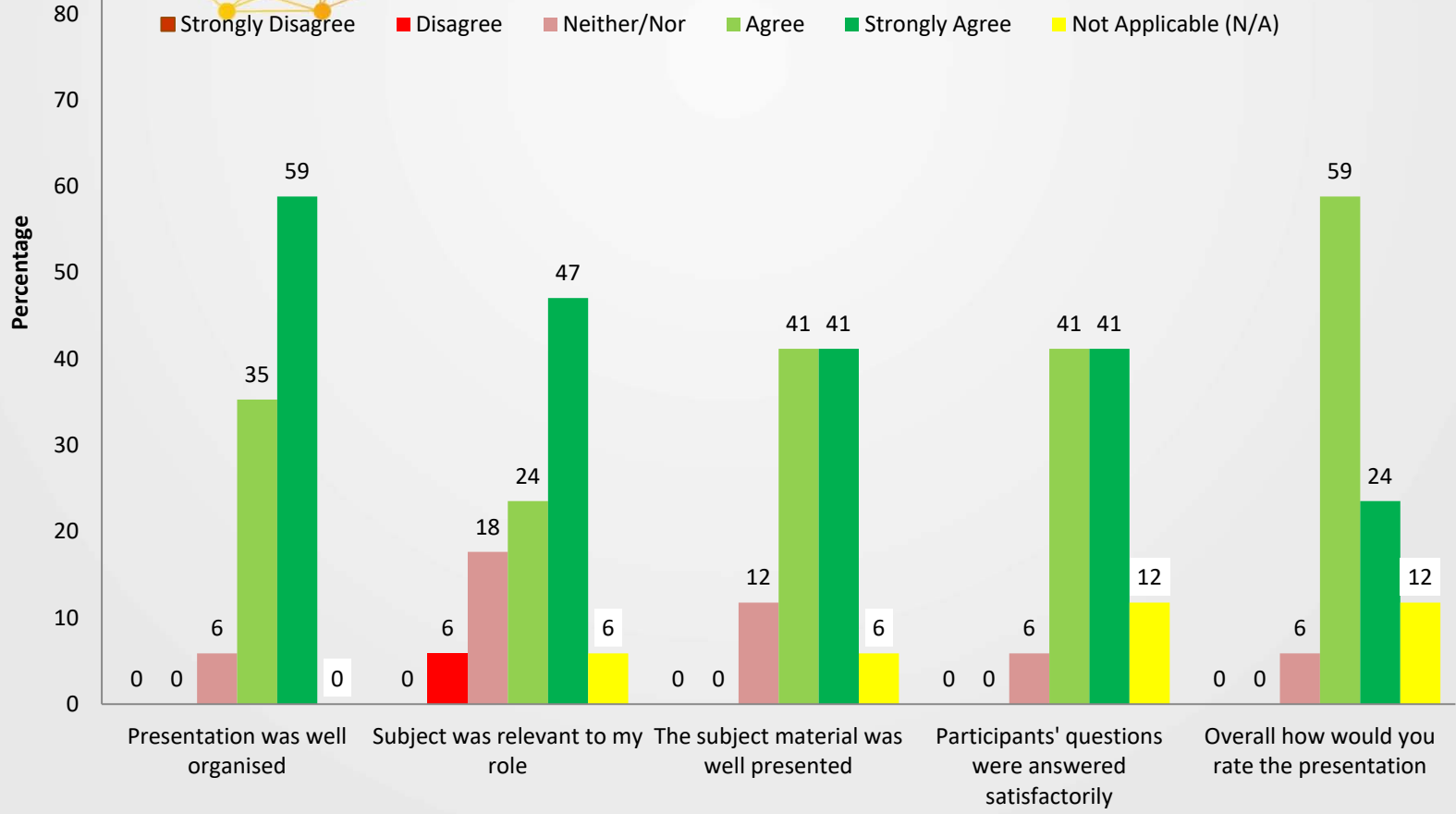| Category	Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree	Not Applicable (N/A)
Presentation was well organised	3	3	0	37	58	0
Subject was relevant to my role	5	3	0	29	61	3
The subject material was well presented	3	3	3	21	71	0
Participants' questions were answered satisfactorily	3	3	0	26	63	5
Overall how would you rate the presentation	3	0	0	39	58	0

Chronic GvHD

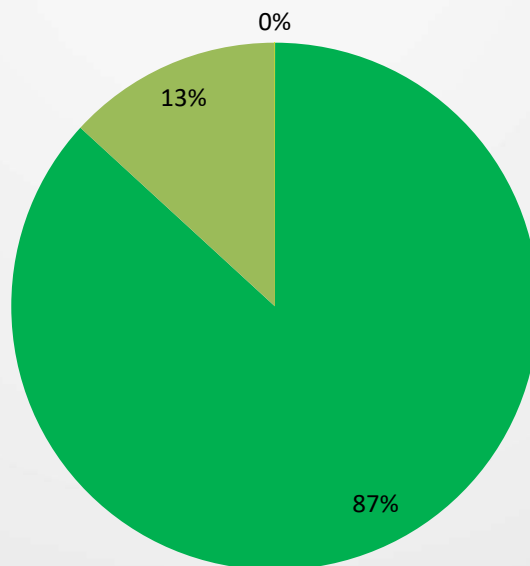Too Basic   Just Right   Too Advanced

0%   3%

97%
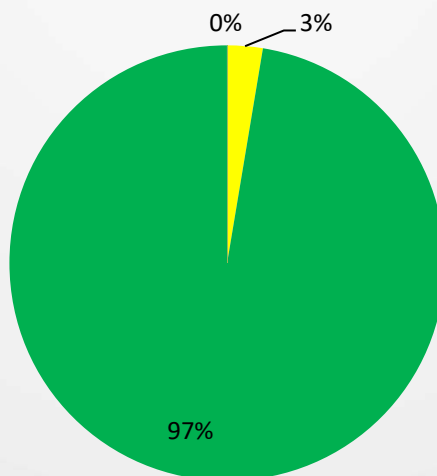
Immunosuppressive Treatments

Immunosuppressive Treatments

■ Too Basic ■ Just Right ■ Too Advanced

0%

13%

87%

Med-A Discussion Forum

Legend: Strongly Disagree, Disagree, Neither/Nor, Agree, Strongly Agree, Not Applicable (N/A)

Question	Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree	Not Applicable (N/A)
Presentation was well organised	0	0	16	37	47	0
Subject was relevant to my role	0	0	11	32	58	0
The subject material was well presented	0	0	16	47	37	0
Participants' questions were answered satisfactorily	0	5	16	32	47	0
Overall how would you rate the presentation	0	0	11	68	21	0
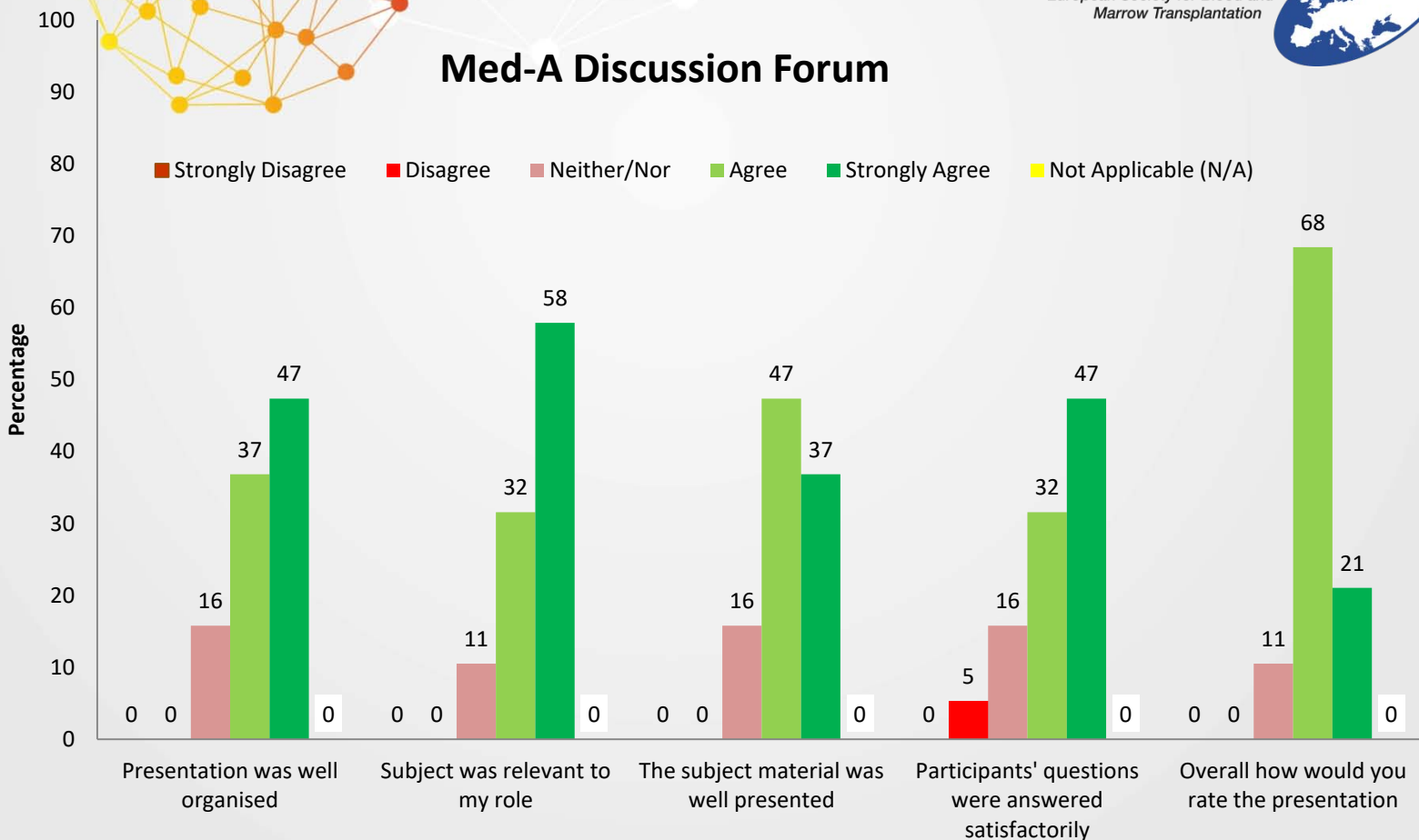
Med-A Discussion Forum
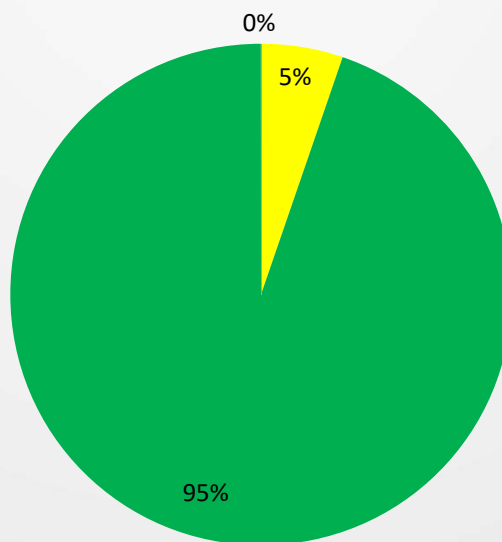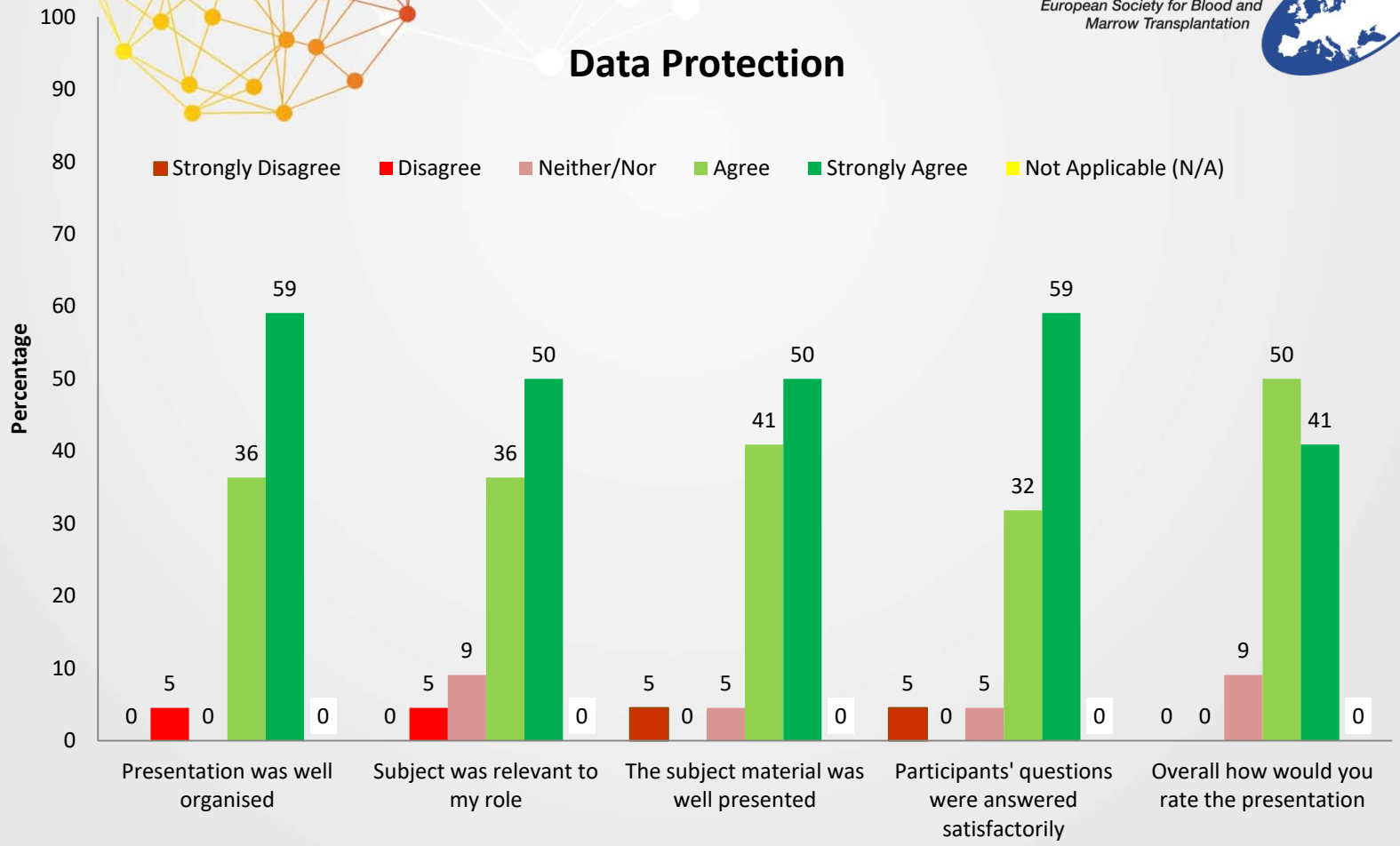
Data Protection

Data Protection

Too Basic   Just Right   Too Advanced

Pie chart: 0%, 10% (Too Basic), 90% (Just Right)
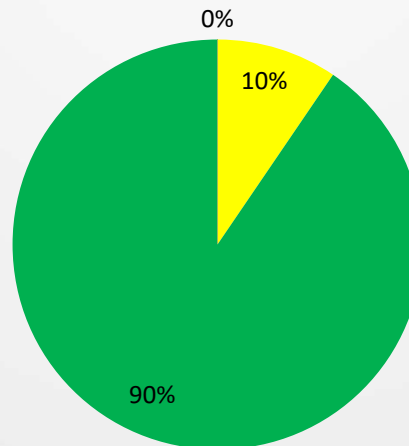
Long term survivors
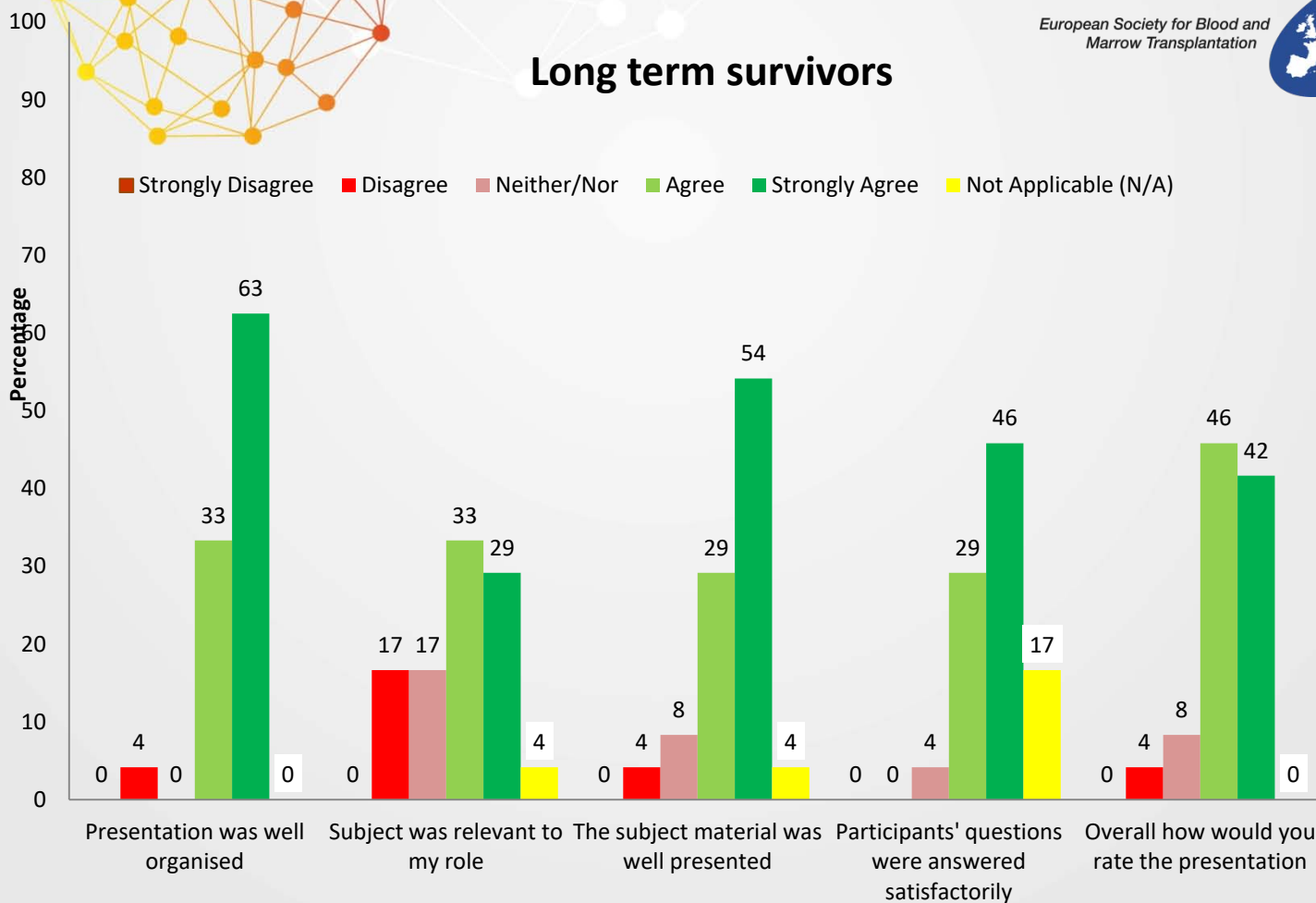
Long term survivors

Too Basic ■ Just Right ■ Too Advanced
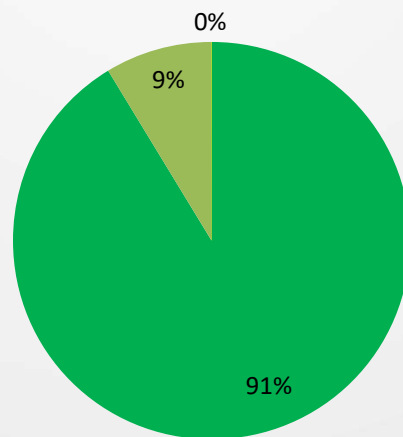
0%

9%

91%

How is HLA data in the Registry database being used by EBMT?!

European Society for Blood and Marrow Transplantation
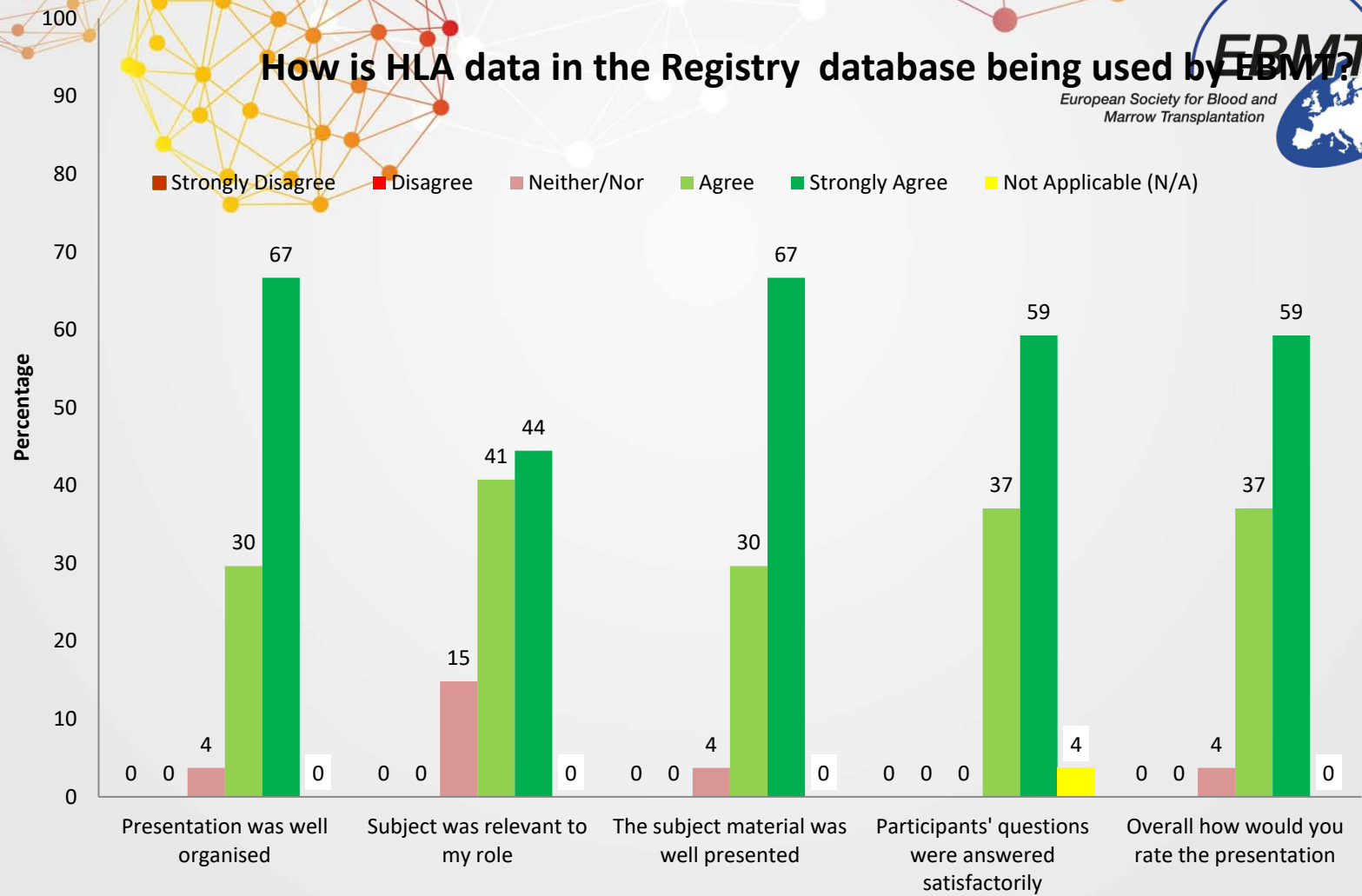
How is HLA data in the Registry database being used by EBMT?

Too Basic   Just Right   Too Advanced

0%

12%

88%
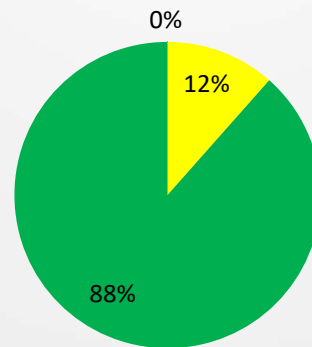
MDS

MDS

Too Basic ■ Just Right ■ Too Advanced

0%

21%

79%

Cytogenetics

Cytogenetics

Legend: Too Basic, Just Right, Too Advanced

- 0%
- 28%
- 72%
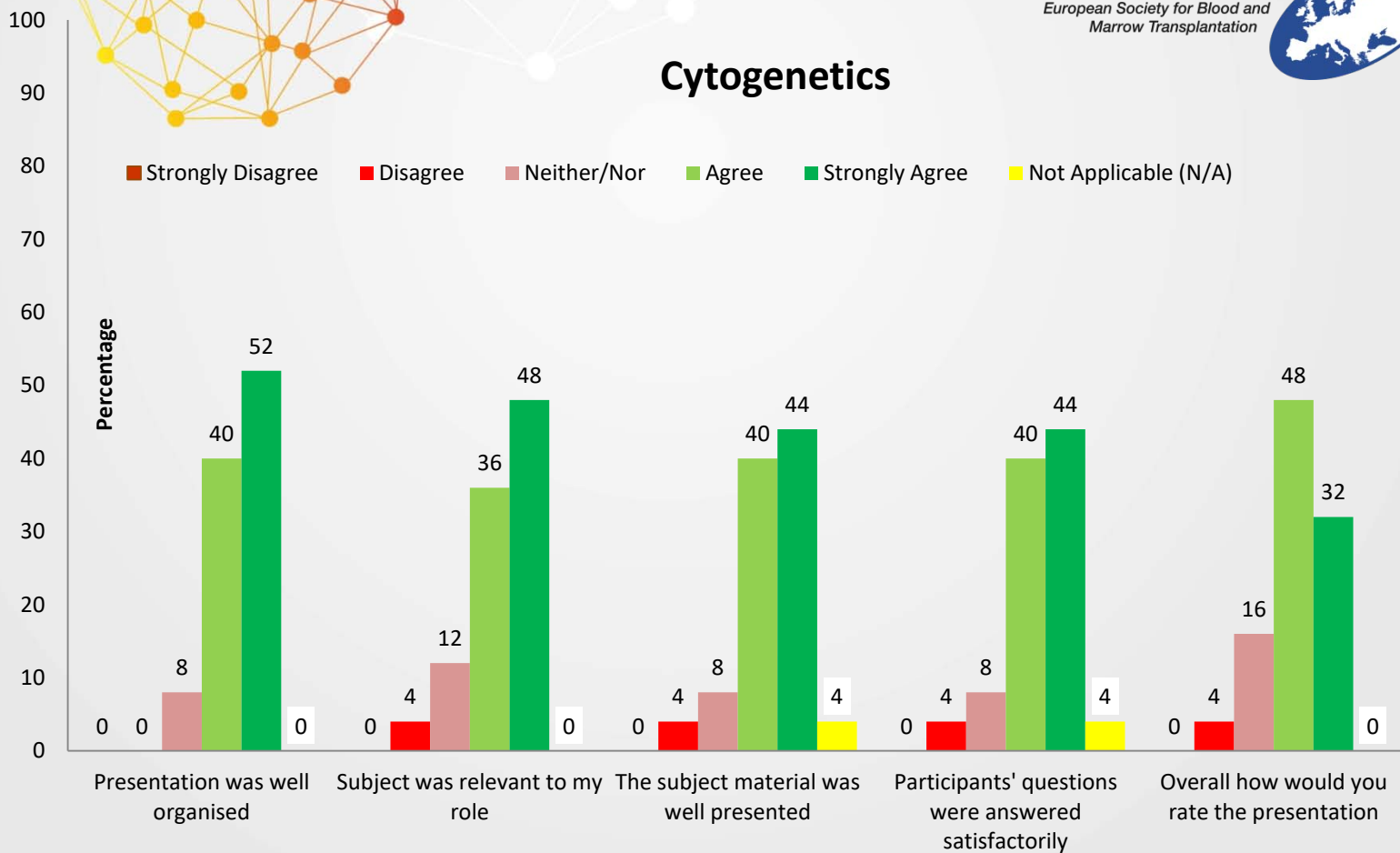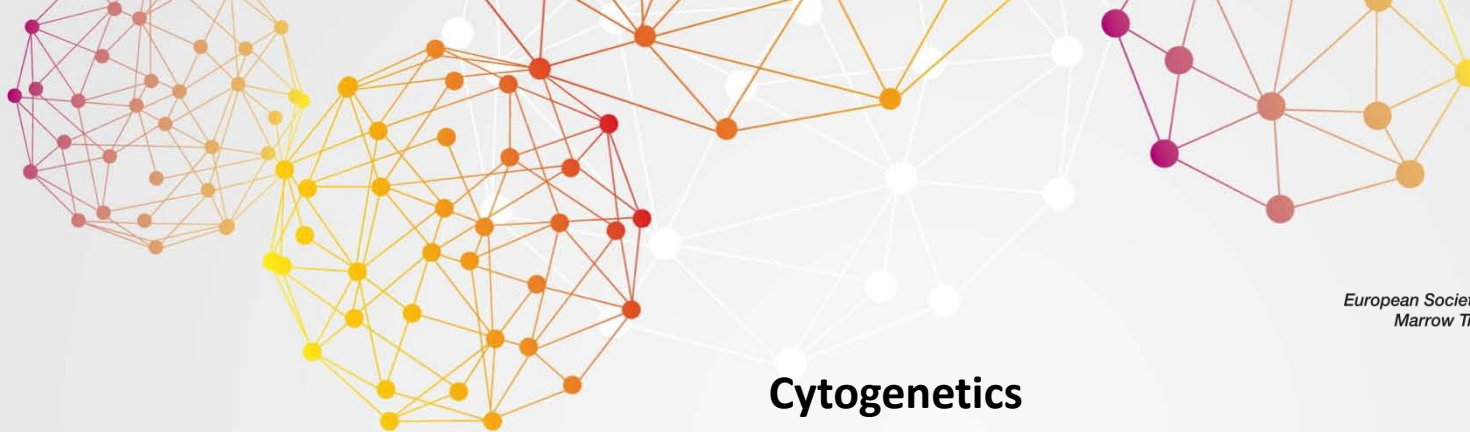
EBMT ANNUAL MEETING 2017
REVIEW OF DATA MANAGENT SESSIONS
Khrystyna Valkiv
EBMT Data Manager

The 16th Meeting of the Data Management Group was held at the EBMT Annual Meeting in Marseille in 2017.

There was a good attendance with **122** Data Managers preregistered from all over the world.

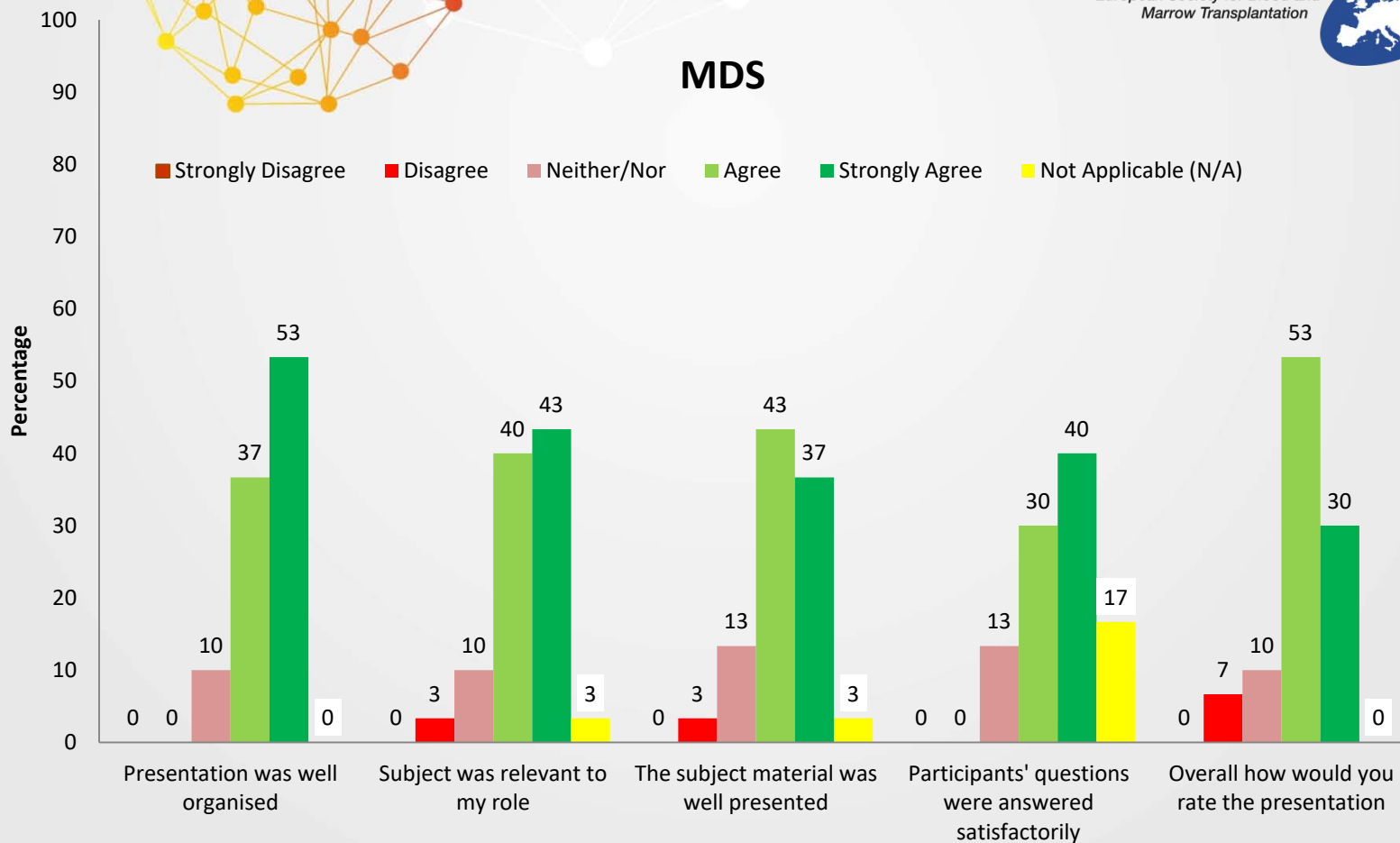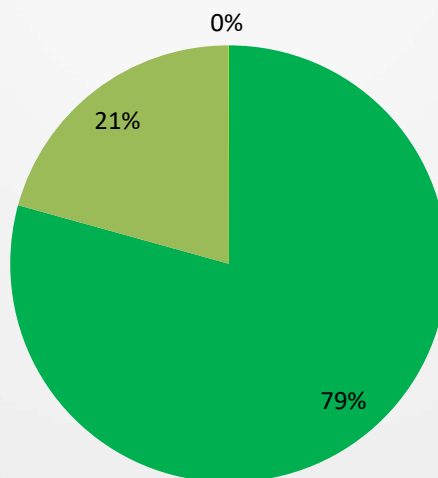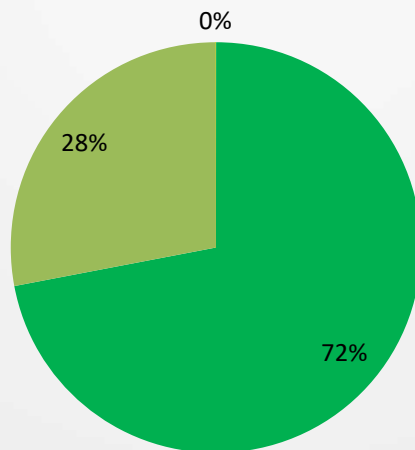Once again, we are extremely grateful to all of our speakers at the Data Management Education sessions who generously shared their expertise and gave us the benefit of their knowledge.
Thank you therefore to:
Attilio Bondanza, Helen Baldomero, Christina Peters, Asuncion Brager, Massimo Berger, Fiona Dignan, Alain Barrois, Marleen van Os and Sofie Terwel, Sebastian Giebel, Johannes Schetelig, Peter Dreger, Hildegard Greinix, Jeroen Knijpenga, Monika Sztankay, Marie Robin, Jordi Esteve.
Big thank you goes to the trainers of the ProMISE training sessions: Asterios, Carmen, Emmanuelle, Lucas, Shelley and Tunde.

Finally **thanks to all the staff** from the registries, centres and EBMT offices who helped with chairing or supporting all of these sessions: Anja, Carmen, Arnaud, Helen, Marie, Henric-Jan, Helen, Paul, Beate, Linda, Emmanuelle, Alain, Henk Jan, Jude, Reda and many others.

We are very lucky to have so many volunteers who do not get tired of helping with the Meeting year after year.

We would like to apologise if you experienced any difficulties or inconveniences related to the organisational part of the Meeting. We know that drinking water supply was low, we will be doing our best for it not to be repeated at the future meetings.

Most of the Education Sessions presentations can now be downloaded from:
http://www.ebmt.org/Contents/Data-Management/Helpdesk/Pages/Helpdesk.aspx

We understand the importance of having sufficient training materials especially at the time when centres transition to a paper free data submission and the need to start using Promise themselves.

However, due to technical issues, Promise training sessions were not recorded this year. We are very sorry for this. If you feel you need additional training or training resources, please use our youtube training videos at
https://www.youtube.com/watch?v=e8Qjs4P4cP0&list=PLd5j0y9uSMDk5W1xzHXKs8adU0yr0djMz

We are always very happy to receive any ideas or suggestions for topics for future Data Management sessions. Please let us know what you think, contact me at khrystyna.valkiv@ebmt.org

COMMENTS FROM FEEDBACK FORMS

Education Sessions:

CAR-T cells: basics, applications and data reporting:
- If the slides would be available in the app that would be great; a very interesting presentation, thanks;
- Speaker was too fast;
- Too advanced. I would have been interested to know how many of the centres present the CAR-T cells;
- Very interesting talk;
- More basic explanation for all cell therapies in general;

EBMT Transplant Activity Survey: very good, but too fast.

"Haplo identical" transplants: Slides should be provided in EBMT app.

How to document complicated patient histories:
- This is too complicated to make it in a short education session;
- Thank you very much, there is a request for extra training sessions for data management.

Centre Presentation on how new Med-A form has affected working practices in centres:
- Was not what I expected from the session title;
- Possibly speaker misunderstood instructions?
- A more general discussion on Med A implementation may be a better idea, perhaps if centres were surveyed in advance detailing their ability to comply with Med-A, deadlines, resources – it could have been a better discussion;
- I would like to know more on how we can improve collaboration between physicians and data managers;

Chronic GvHD:
- As a non perfect English speaker it was understandable;
- Too little discussion on Med-A;
- I am from an auto centre but found it really interesting, great speaker!
- More explanations of biological mechanisms (on a level of non biologists) would have been appreciated. Very clear speaker;
- Always need sessions on GVHD, always difficult to repeat;
- One of the best sessions attended that explains the topic which is complex in "lay" terms.

Immunosuppressive Treatments in Aplastic Anaemia: n/a

Med-A form: Discussion forum:

- A detailed survey on MED-A should be sent out to all centres asking for problems, glitches etc. The compilation of these data may promote a better discussion.
- A very good way of learning to report quality data, repetition of similar sessions every year!
- Hope to have separate sessions for Med-A and Med-B for Lymphoma because it is so different from Myeloma and Leukaemia.
- Panel seemed unable to clarify fully/confidently many questions; look forward to written clarifications following this.
- Presentation was too small.

Data protection:

- Sound engineering could be better;
- Thanks for a good presentation;

Long-term survivors:

- Very much enjoyed, thank you;
- May have been more useful and specific to the topic if long term survivors rated the quality of life;
- Thanks for your excellent speech;
- I had expected more special results after transplantation;

How is HLA data in the registry database being used by EBMT?

- Well explained and presented;
- Very interesting and excellently explained, thank you;
- Thanks for good information and presentation, please provide the slides;
- I could not hear it well because of the air con and bad sound engineering;
- There are microphones but presentations were not loud enough

Myelodysplastic syndromes (MDS): very good

Cytogenetics (with a focus on Med-A):

- Very good level, excellent presentation, very important topic, but it is too difficult to explain in such a short time, more practice can help Data Managers.
- Thank you, we need information like this but perhaps it should be presented a bit simpler.
- Sorry but it was very complex and I had problems following it.

Comments from participants on training sessions:

HLA:
- Need more time for training
- Bravo
- Perfect session, exactly what I needed to correctly enter the HLA data
- The slides were too small, it's Promise which is a bit too narrow and then the speaker went a bit too fast
- Screen on the wall is too small

Data Entry:
- The Registry staff were extremely helpful.
- Each disease has different questions and you cannot show it all. But when entering on site, you have difficulty answering a few questions.
- Good session, need more training, 1:1 would be good.
- Difficult to hear the presenter.
- It would be good to have documentations for use of Promise, issues with principal problems.

Data Retrieval:
- Next time it would be good to focus on reports that are required by JACIE.
- More manuals.
- Next training to be for advanced users.
- Rushed and not easy to follow what was happening on the big screen, would like to have known the types of reports that can be run
- The session was very interesting but not easy to follow. The explanations were not clear enough.

Cell Therapy:

- It is better to show things and not let people do their own data entry meanwhile.
- It is very complex! It seems that there are still a lot of "unknowns". Good luck Carmen!

Donor Outcome:

- It was hard to find a patient that our Donor outcome matched. It is hard to change every date.

Advanced Data Entry:

- This is a very important session because we can all ask about the problems we all encounter in reporting.

SUMMARY AND COMMENTS

STRENGTHS

Computer equipment was flawless.

Topics are explained in an understandable way.

Excellent and invaluable.

The program this year was particularly well thought out and informative.

WEAKNESSES

There were microphones but presentations were not loud enough

Essential coloured print outs were missing from HLA training.

No coffee at all (you had to go to a different building and queue - time consuming process).

No quick access to drinking water.

Unable to get lunch on Monday.

Must be careful to have good language skills and good speakers for the 'non educational sessions'. i.e. the centre experience talks, 'how do I do this in my centre' talks

SUGGESTIONS

Slides should be provided in EBMT app.

A repeat of the Med A questions Forum, but early on the first day to ensure a better attendance as everyone has questions to ask!

Any questions?

Thank you for listening!