

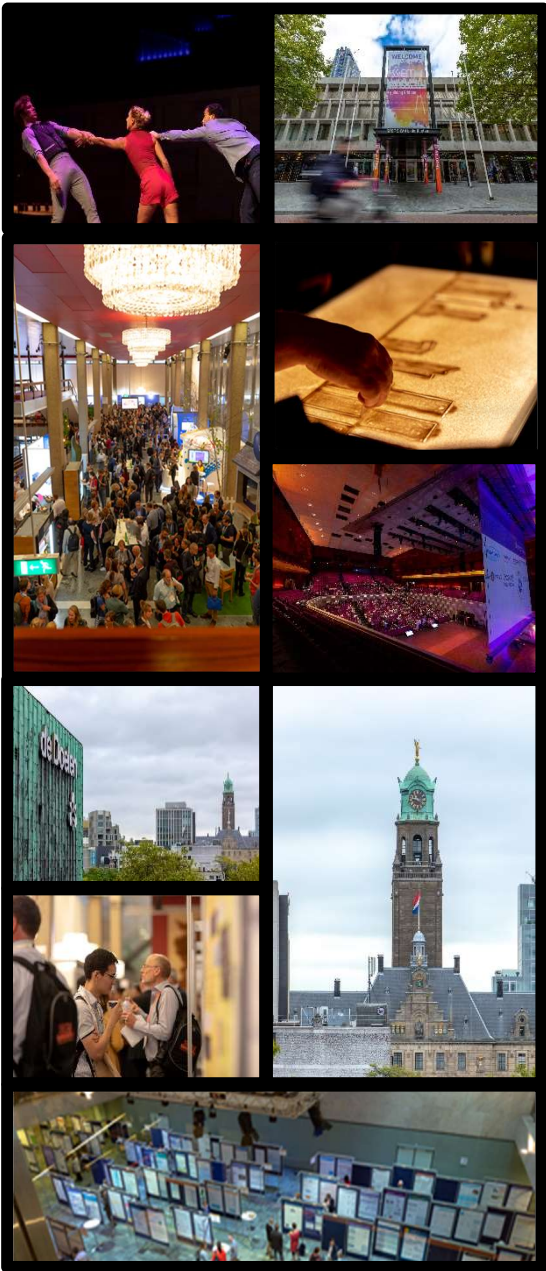


FINAL REPORT

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VISUAL OVERVIEW



THE SYMPOSIUM IN NUMBERS

- **2.878** = delegates have participated to the SSIEM 2019 Annual Symposium
- **2.987** = total registration (excluding accompanying person and including no-show)

Please find below a breakdown of the numbers divided by country

Country	Amount
Albania	2
Algeria	31
Argentina	23
Australia	24
Austria	40
Azerbaijan	2
Bahrain	1
Belarus	5
Belgium	73
Brazil	24
Bulgaria	7
Canada	39
China	18
Colombia	12
Costa Rica	1
Croatia	10
Curaçao	1
Cyprus	4
Czech Republic	27
Denmark	27
Ecuador	1
Egypt	23
Estonia	8
Finland	29
France	101

Country	Amount
Georgia	2
Germany	139
Ghana	4
Greece	24
Hong Kong	3
Hungary	13
India	9
Indonesia	2
Iran	28
Iraq	5
Ireland	18
Islamic Republic of Iran	2
Island	1
Israel	31
Italy	125
Japan	57
Jordan	18
Kazakhstan	7
Kingdom Saudi Arabia	8
Kuwait	2
Latvia	4
Lebanon	2
Libya	9
Lithuania	7
Luxembourg	1

Country	Amount
Malaysia	4
Mexico	20
Moldova (the Republic of)	2
Morocco	15
Nigeria	2
Norway	20
Oman	5
Organisers/Agency	1
Pakistan	6
Peru	6
Poland	52
Portugal	44
Qatar	8
Romania	16
Russia	2
Russian Federation	18
Saudi Arabia	39
Scotland	1
Serbia	5
Slovakia	13
Slovenia	6
South Africa	4
South Korea	23
Spain	102
Sweden	49
Switzerland	44

Country	Amount
Taiwan	18
The Netherlands	222
Tunisia	12
Turkey	128
Uganda	1
Ukraine	12
United Arab Emirate	20
United Kindgom	196
United States	269
Unkown	507
Uruguay	1
Viet Nam	2

European participants	49% - 1445 participants
American participants	North America: 10.48% - 309 participants South America: 3.02% - 89 participants
Canadian participants	1.32% - 39 participants
Other: please specify	Africa: 0.88% - 26 participants Asia: 10.75% - 317 participants Oceania: 0.81% - 24 participants Middle East: 7.87% - 232 participants Unknown: 15.87% - 468 participants

REGISTRATION REPORT

Total Number of Registrations: 2.987

Excluding: Accompanying persons (30 persons) Including: no-show

NO-SHOW: 109

<u>Normal registrations</u>	
Early_Non-member (€650)	341
Late_Non-member (€750)	325
Early_SSIEM Member (€400)	359
Late_SSIEM Member (€550)	132

<u>Group registrations</u>	
Early_Full Group Registration	22
Early_Full Group Registration (€550)	821
Late_Full Group Registration (€650)	76

<u>Exhibitors/sponsor registrations</u>	
Exhibitor	180
Exhibitor only registration (€200)	88
Full Conference Registrations	118

<u>Students/residents registrations</u>	
Early_Students/Residents -in- Training (<35 yrs) (€250)	117
Late_Students/Residents -in- Training (<35 yrs) (€400)	29

<u>Accompanying persons registration</u>	
Early_Accompanying person (€200)	20
Late_Accompanying person (€250)	10

<u>Faculty/Speaker registrations</u>	
Faculty/plenary speaker	46

<u>Complimentary registrations</u>	
Complimentary Registration	14
Local Organizing Committee Member	16
Phd student	37
Press Registration	4
Scholarship Winner Registration	23
Volunteer	44

<u>Day Registrations</u>	
Dietitian Registration Tuesday 3 and Wednesday 4 September 2019	4
<u>Day Registrations 2 September</u>	
Late_Non-Member - day ticket - Monday 2 September (€300)	2
Late_SSIEM Member - day ticket - Monday 2 September (€200)	1
<u>Day Registrations 3 September</u>	
Early_Non-Member - day ticket - Tuesday 3 September (€200)	9
Late_Non-Member - day ticket - Tuesday 3 September (€300)	20
Early_SSIEM Member - day ticket - Tuesday 3 September (€120)	10
Late_SSIEM Member - day ticket - Tuesday 3 September (€200)	5
Free Dayticket - Tuesday 3 September	1
<u>Day Registrations 4 September</u>	
Early_Non-Member - day ticket - Wednesday 4 September (€200)	18
Late_Non-Member - day ticket - Wednesday 4 September (€300)	42
Early_SSIEM Member - day ticket - Wednesday 4 September (€120)	13
Late_SSIEM Member - day ticket - Wednesday 4 September (€200)	12
Free Dayticket - Wednesday 4 September	6
<u>Day Registrations 5 September</u>	
Early_Non-Member - day ticket - Thursday 5 September (€200)	14
Late_Non-Member - day ticket - Thursday 5 September (€300)	15
Early_SSIEM Member - day ticket - Thursday 5 September (€120)	6
Late_SSIEM Member - day ticket - Thursday 5 September (€200)	8
Free Dayticket - Thursday 5 September	2
<u>Day Registrations 6 September</u>	
Late_Non-Member - day ticket - Friday 6 September (€300)	4
Late_SSIEM Member - day ticket - Friday 6 September (€200)	3

<u>Book of Abstracts</u>	
Yes (€25)	23

<u>Council Dinner</u>	
I would like to attend	17

<u>Name /registration change</u>	
Name/registration change (€40)	50

<u>Networking Evening (€25)</u>	
Dinner ticket	1154

<u>Networking Evening Scholarship</u>	
Dinner ticket	21

<u>Presidents Dinner</u>	
I would like to attend	54

<u>Young Investigators</u>	
I would like to attend	93

<u>Networking Activity (€15)</u>	
Central District: rebuilding and reinvention	41
City sightseeing + Blue City's new economy	39
Coolsingel: secrets of an urban boulevard	20
Delfshaven: Pelgrim's bar + Mill	47
Designer Bags & Bad Baristas	13
Highlight Tour: Markthal + De Rotterdam	48
Holland America Line + Katendrecht	87

Immerse multi-cultural : Coolhaveneiland	20
New Erasmus MC + roof park visit	11
Recycled Park & Rotterdamsche Confituur: world changing innovation	36
Rotterdam breaths Architecture: 4 icons + history	48
Rotterdam Food walhallas	46
Tour of Titans: De Rotterdam + Markthal	46
World harbour, Erasmus bridge, 360°-view	192

SCIENTIFIC PROGRAMME IN NUMBERS

Session Breakdown

Sessions	Total
Keynote Lecture Sessions (Garrod / Komrower)	2
Plenary Sessions	6
Parallel Sessions & Late Breaking News	16
Special Sessions open to all delegates	4
Members only and group sessions hosted during the symposium	27

Speakers Breakdown

Speaker	Total
Keynote Speakers	6
Plenary Speakers	14
Parallel Session Speakers (update lectures)	5
Special Session Speakers (late breaking news)	4
Chairs	42

Abstract Submission Breakdown

Presentation	Total
Oral presentation	78
Poster presentation	606
E-poster presentations	203
Rejected submissions	9

SPONSORSHIP REPORT

THE SSIEM 2019 SPONSORS

A total income of € 1.068.800,- was generated from exhibition & sponsoring. Please find the overview of all sponsors and sponsored sessions below.

Platinum sponsors

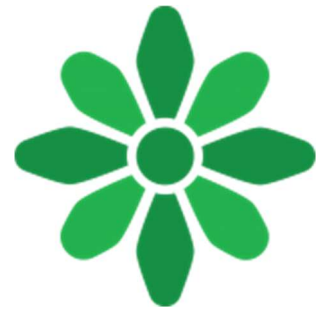


Gold sponsors

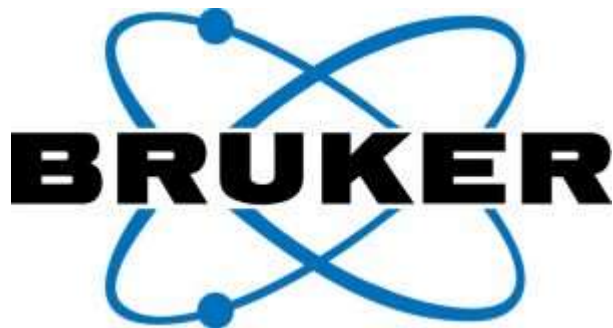


Silver sponsors





Bronze sponsors



ORPHA **Z** YME



LABSYSTEMS
DIAGNOSTICS
speaking your language

Orchard
therapeutics

Industry Sponsored Symposia

Tuesday

12:45-13:45, Jurriaanse Zaal

Navigating and understanding consequences of high Phe in PKU

Sponsored by: BioMarin

12:45-13:45, Willem Burger Zaal

Preliminary results from the Glyde Trail.

The first randomised double blind crossover trial on the dietary management of Glycogen Storage Disease

Sponsored by: Vitaflo

12:45-13:45, Van Weelde & Mees Zaal

Setting solid foundations in early life. The importance of nutrition for the fetus, infant and growing child with IEM

Sponsored by: Nutricia Metabolics

Wednesday

7:30-8:30, Jurriaanse Zaal

Drug-target and disease networks: rethinking the role of glucosylceramide synthase

Sponsored by: Sanofi Genzyme

7:30-8:30, Van Weelde & Mees Zaal

Physiological absorption of amino acids: nitrogen balance and patient outcomes

Sponsored by: Applied Pharma Research

18:00-19:30, Grote Zaal

Re-evaluating short- and long-term management goals for lysosomal storage diseases

This independent medical education activity is funded via an unrestricted educational grant from Shire, now a part of Takeda.

18:00-19:10, Jurriaanse Zaal

Improving patient care in MPS VI and IVA: From evidence to consensus

Sponsored by: BioMarin

18:00-20:00, Willem Burger Zaal

Exploring long-term strategies for patients with propionic and methylmalonic acidurias

Sponsored by: Recordati Rare Diseases

18:00-19:30, Van Weelde & Mees Zaal

The Story of Arginase 1 Deficiency: Time for a New Chapter

Sponsored by: Aeglea

Thursday

7:30-8:30, Jurriaanse Zaal

When to treat late-onset Pompe disease? The latest view from pathology to clinical evidence and guidelines

Sponsored by: Sanofi Genzyme

12:45-13:45, Grote Zaal

The role of glycerol phenylbutyrate in the management of UCD: Bridging the gap between clinical data and real world experience

Sponsored by: Sobi

12:45-13:45, Jurriaanse Zaal

Turning the tide in PKU, the role of PALYNZIQ[®],(pegvaliase)

Chairs: Cary Harding (Portland, United States) – Ania Muntau (Hamburg, Germany)

Sponsored by: BioMarin

12:45-13:45, Willem Burger Zaal

Fabry Disease: The Pharmacogenomic Approach

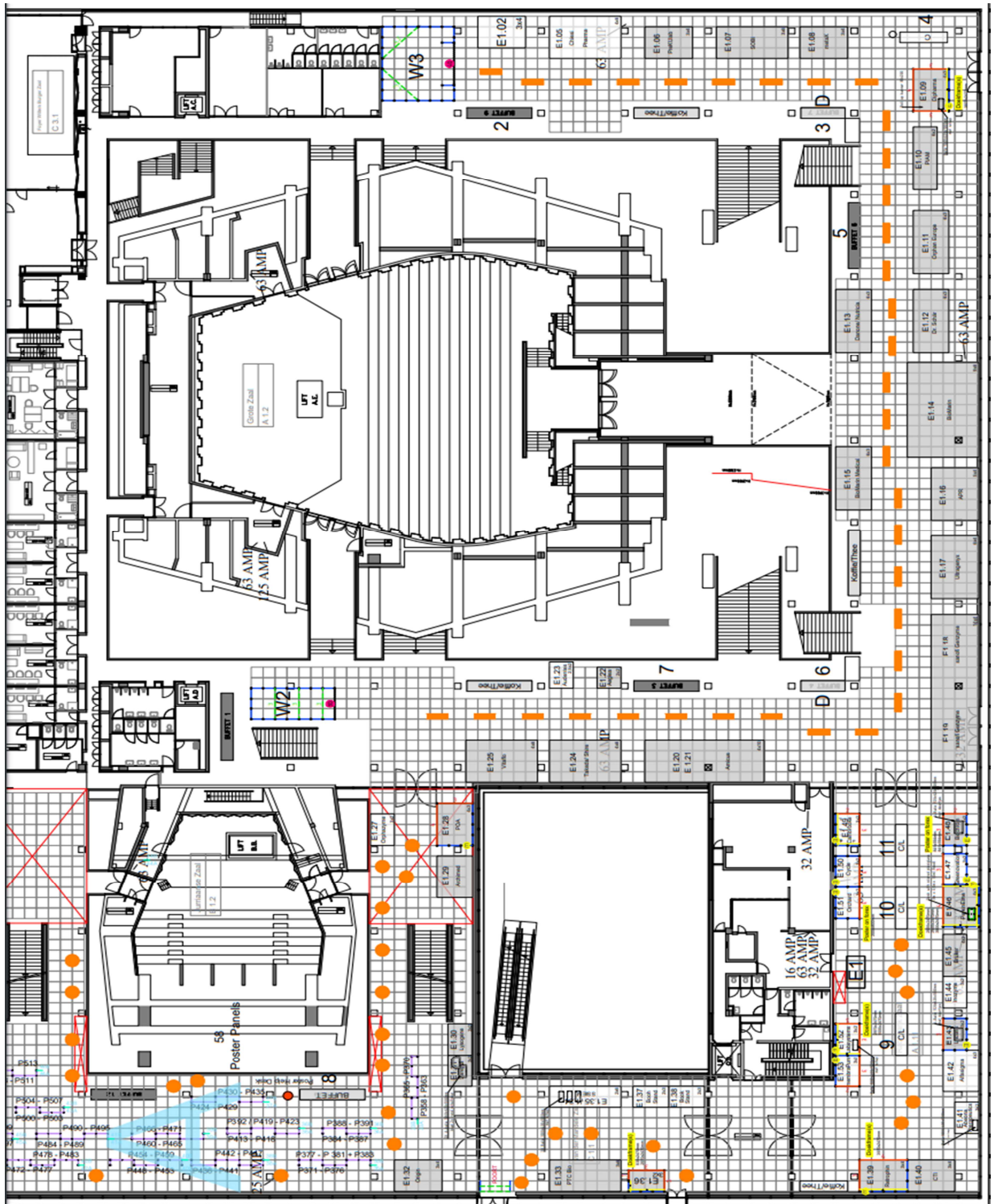
Sponsored by: Amicus Therapeutics

12:45-13:45, Van Weelde & Mees Zaal

The Advancing Science of Brain Directed Gene Therapy

Sponsored by: Lysogene / Sarepta Therapeutics

Exhibition Floorplan



Exhibition list

Company Booth.	No.	Sponsor
Abeona Therapeutics	E 1.41	Bronze
Aeglea BioTherapeutics	E 1.22	Bronze
Ajinomoto Cambrooke	E 1.49	Bronze
Alfasigma Spa	E 1.42	Silver
Amicus Therapeutics	E 1.20/E1.21	Platinum
APR Applied Pharma Research s.a.	E 1.16	Silver
ARCHIMEDlife	E 1.29	Silver
Audentes Therapeutics	E 1.23	Bronze
Biochrom, a division of Harvard Bioscience, Inc.	E 1.48	Bronze
BioMarin	E 1.14/E1.15	Platinum
Bruker	E 1.45	Silver
Chiesi Farmaceutici SpA	E 1.05	Platinum
CTI Clinical Trial and Consulting	E 1.40	Silver
Cycle Pharmaceuticals	E 1.50	Bronze
Dipharma SA	E 1.09	Silver
Dr. Schär SpA	E 1.12	Gold
Greenovation Biotech GmbH	E 1.47	Bronze
Inozyme Pharma	E 1.44	Bronze
Labsystems Diagnostics	E 1.52	Bronze
Lactalis Nutrition Sante	E 1.43	Bronze
Lysogene	E 1.30	Bronze
membraPure	E 1.53	Bronze
metaX Institut für Diätetik GmbH	E 1.08	Silver
Nutricia Metabolics	E 1.13	Gold
Orchard Therapeutics	E 1.51	Bronze
Origin Biosciences	E 1.32	Silver
Orphan Europe	E 1.11	Gold
Orphazyme	E 1.27	Bronze
Perkin Elmer	E 1.46	Silver
PIAM Farmaceutici	E 1.10	Silver

POA Pharma	E 1.28	Silver
PREKULAB	E 1.06	Silver
PTC	E 1.33	Silver
Retrophin	E 1.39	Silver
Sanofi Genzyme	E 1.18/E1.19	Platinum
Sarepta Therapeutics	E 1.31	Bronze
SOBI	E 1.07	Gold
Takeda	E 1.24	Platinum
Ultragenyx	E 1.17	Platinum
Vitaflo International Ltd.	E 1.25	Platinum

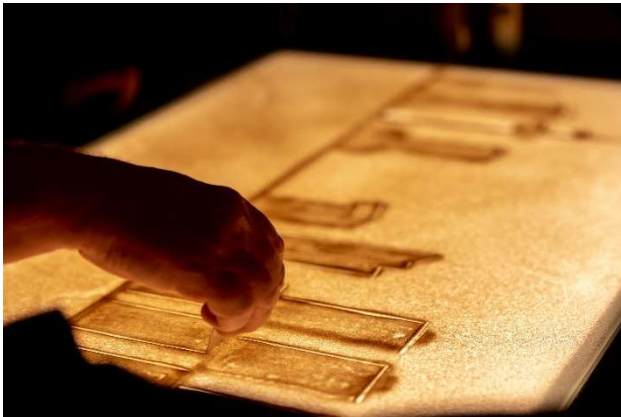
NETWORKING PROGRAMME

Young Investigators Event

Monday, September 2, 2019 – 20.00

Opening Ceremony

De Zandtovenaar and Tête-bêche



Welcome Reception

Tuesday, September 3, 2019 – 18.30-20.30



Poster Walk

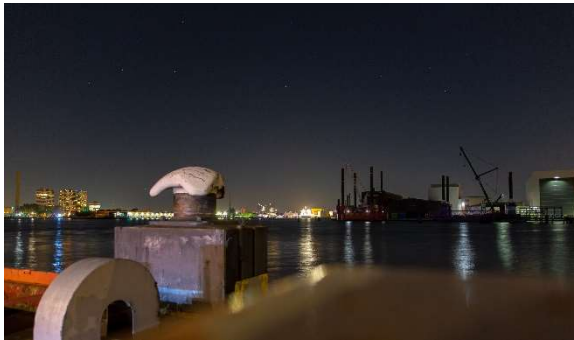
Wednesday, September 4, 2019 – 18.00-20.00



Networking Evening

Thursday, September 5, 2019 – 20.30 – 02.00

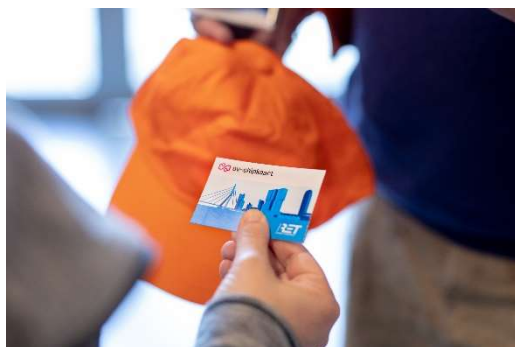
Onderzeebootloods, Rotterdam



Networking Tours

Thursday, September 5, 2019 – afternoon (694 tickets sold)

1. World harbour & Erasmus bridge
2. Delfshaven: Pilgrim's bar & windmill
3. Holland America Line & Katendrecht
4. Tour of titans: De Rotterdam & Markthal
5. Rotterdam breathes architecture: 4 icons & history
6. Coolsingel: secrets of an urban boulevard
7. New Erasmus MC & roof park
8. Recycled Park & Rotterdamsche Confituur: world-changing innovation
9. Designer bags & bad baristas
10. City sightseeing & BlueCity's new economy
11. The Rotterdam way: air street, roof garden & water plaza / Central District rebuilding and reinvention
12. Highlight Tour: Markthal & De Rotterdam
13. Rotterdam Food Walhalla
14. Immersed in multi-cultural Coolhaven island

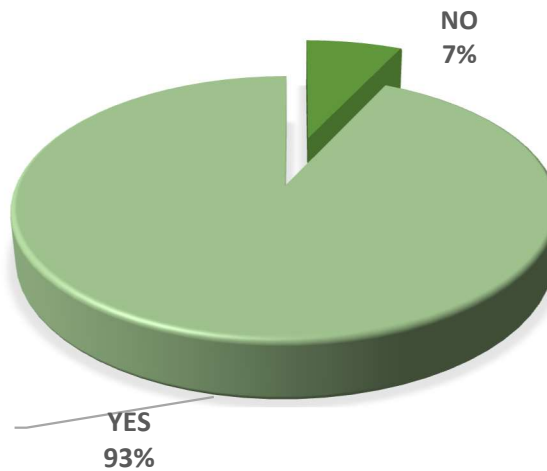


EVALUATION REPORT

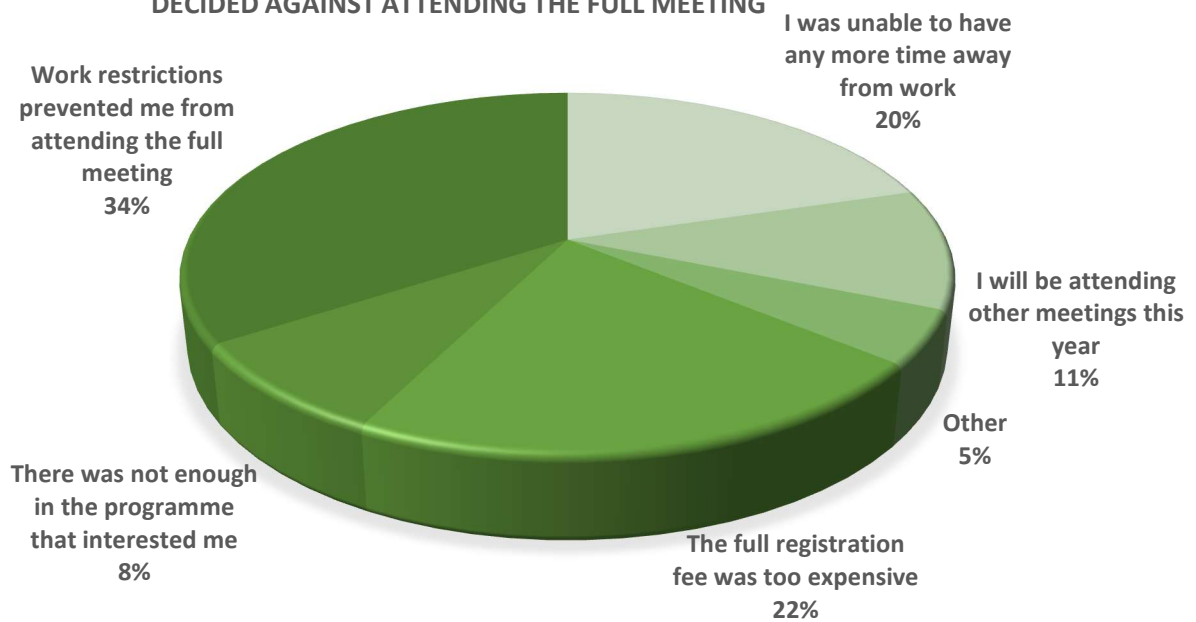
THE SURVEY

The survey was send out to all participants (excluding exhibitors) and had 1402 respondents at the closing date.

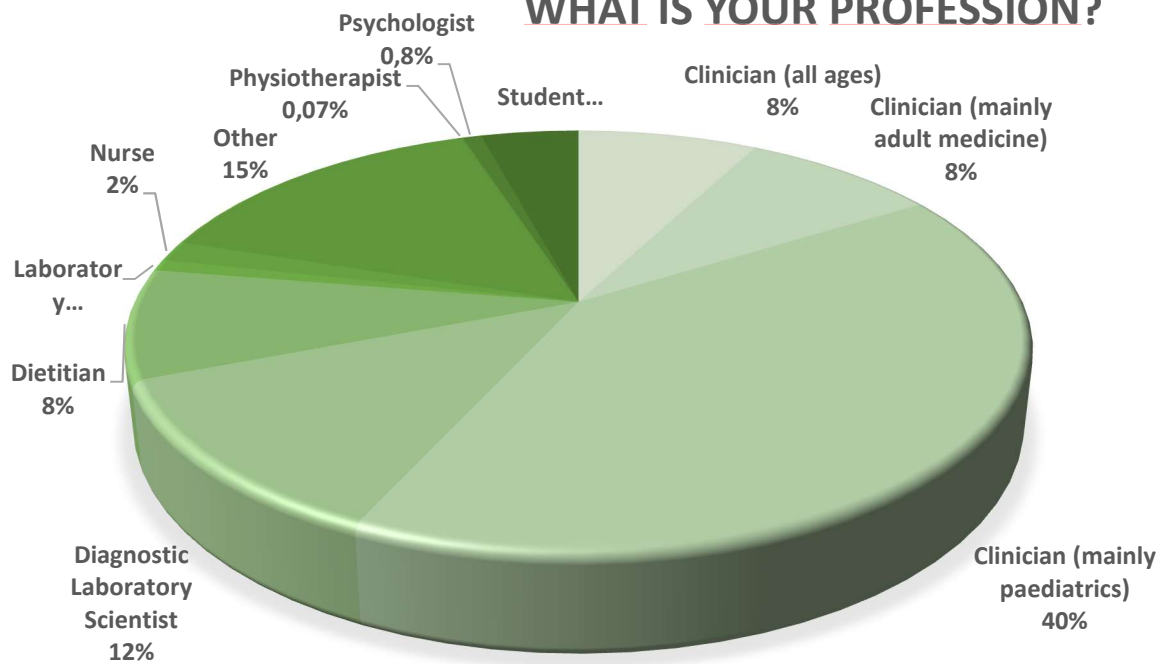
DID YOU REGISTER FOR THE FULL MEETING?



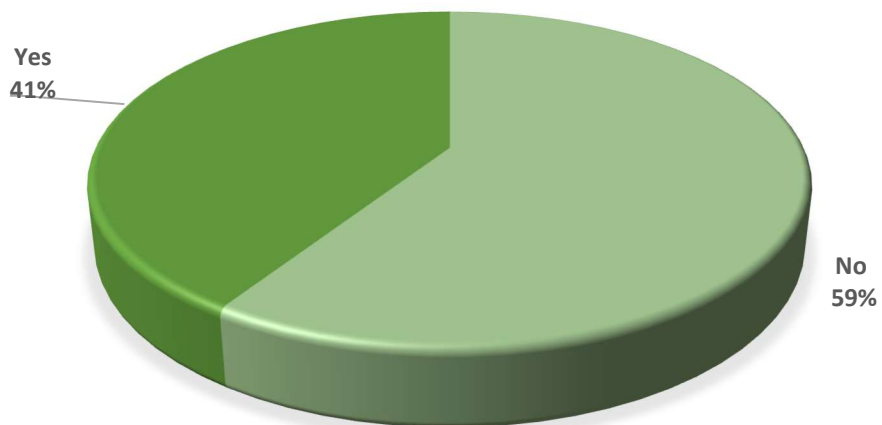
IF YOU REGISTERED FOR ONE OR TWO DAYS ONLY, PLEASE TELL US WHY YOU DECIDED AGAINST ATTENDING THE FULL MEETING



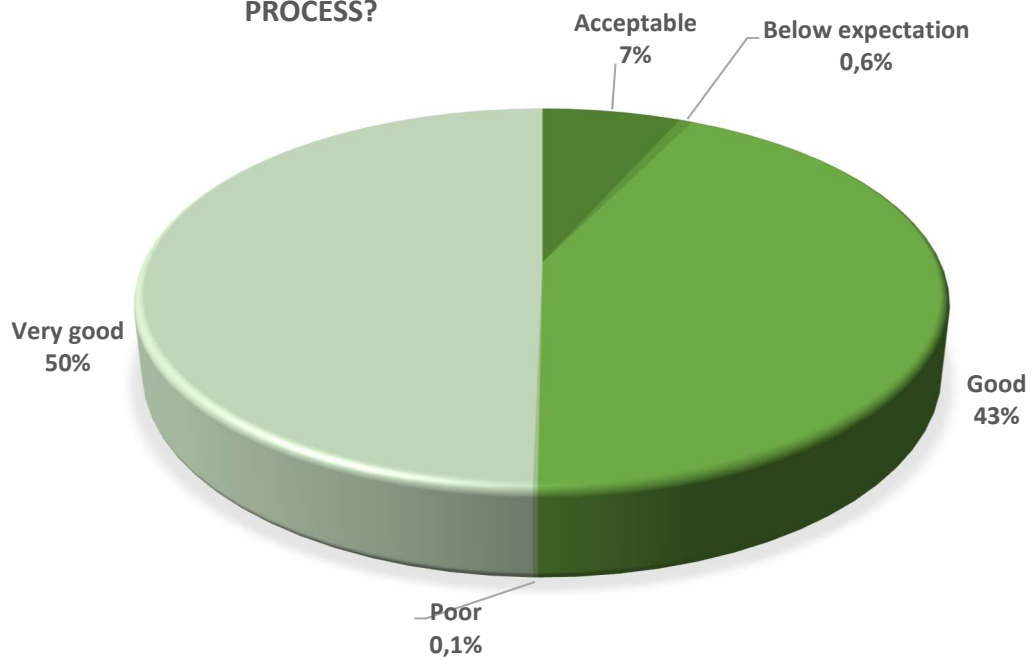
WHAT IS YOUR PROFESSION?



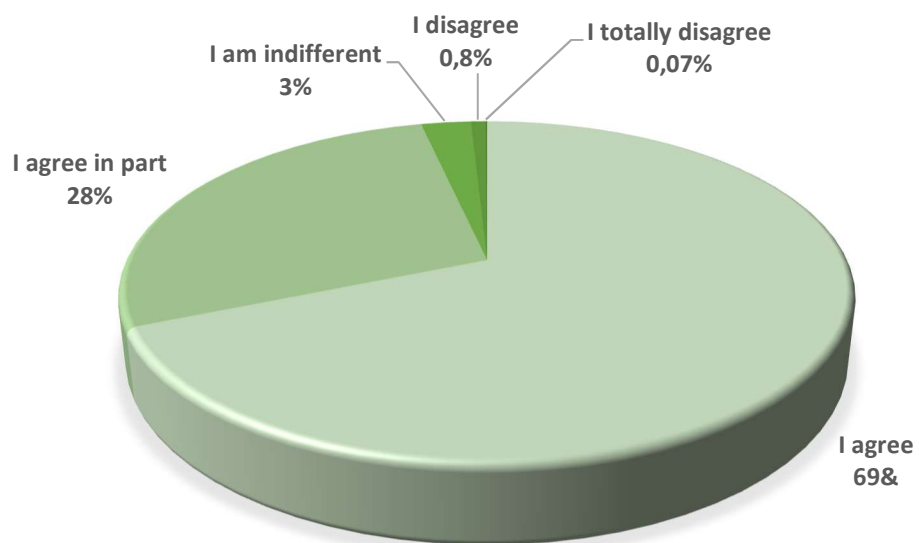
DID YOU SUBMIT AN ABSTRACT FOR THE MEETING?



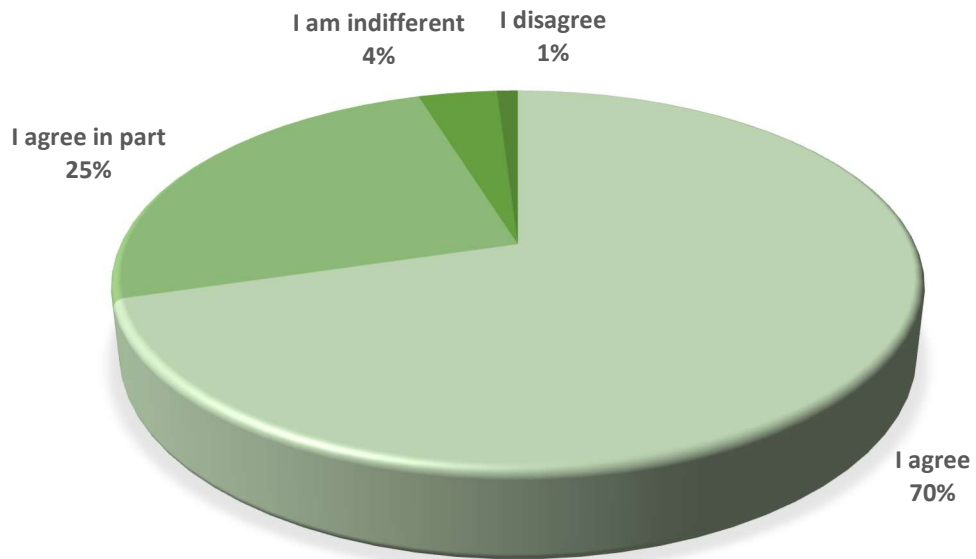
IF YES, HOW WOULD YOU JUDGE THE ABSTRACT SUBMISSION PROCESS?



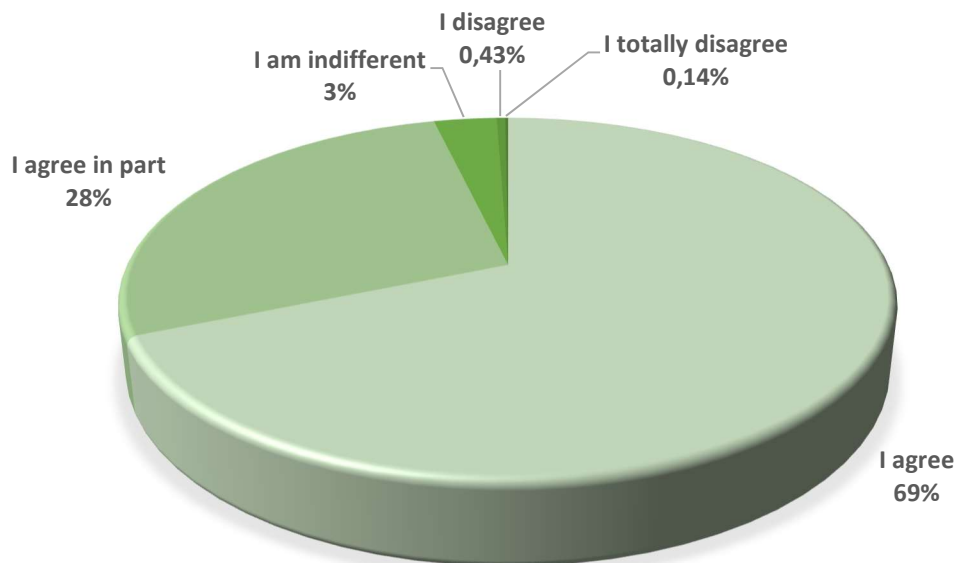
THIS EVENT HAS FULFILLED MY EDUCATIONAL GOALS AND MY EXPECTED LEARNING OUTCOMES



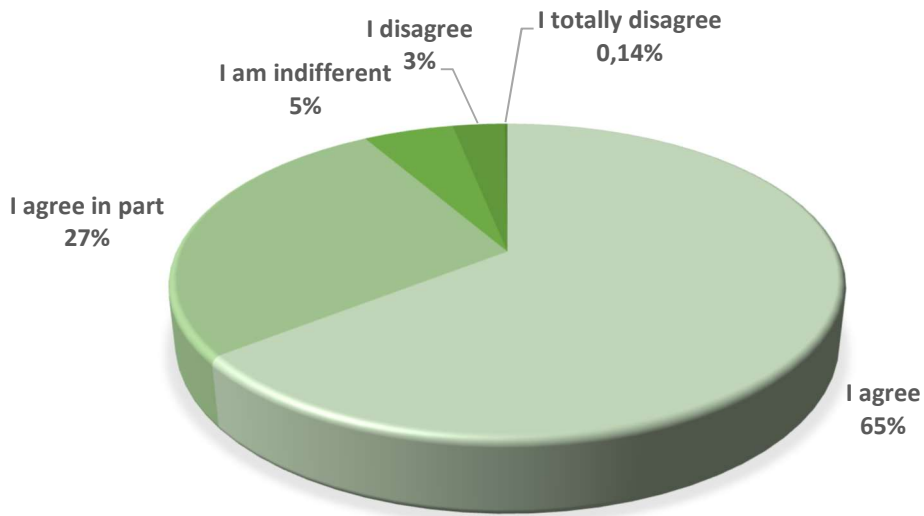
I HAVE LEARNED INFORMATION FROM THIS EVENT THAT WILL HELP ME TO IMPROVE MY PRACTICE



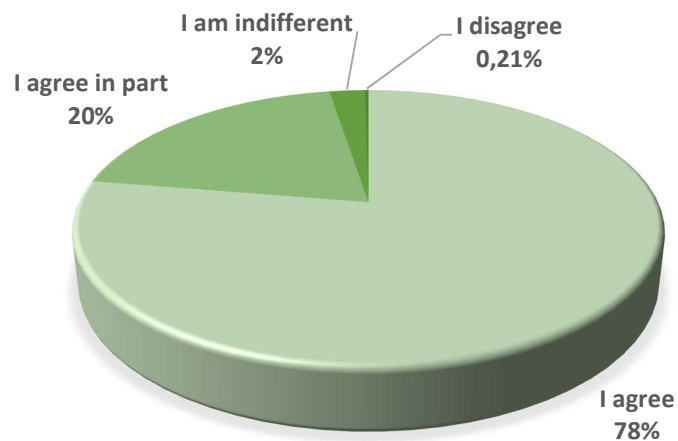
THE EDUCATION PROVIDED AT THIS EVENT WAS VERY GOOD OR EXCELLENT



**THERE WAS SUFFICIENT TIME FOR DISCUSSIONS,
QUESTIONS, ANSWERS AND LEARNER ENGAGEMENT**

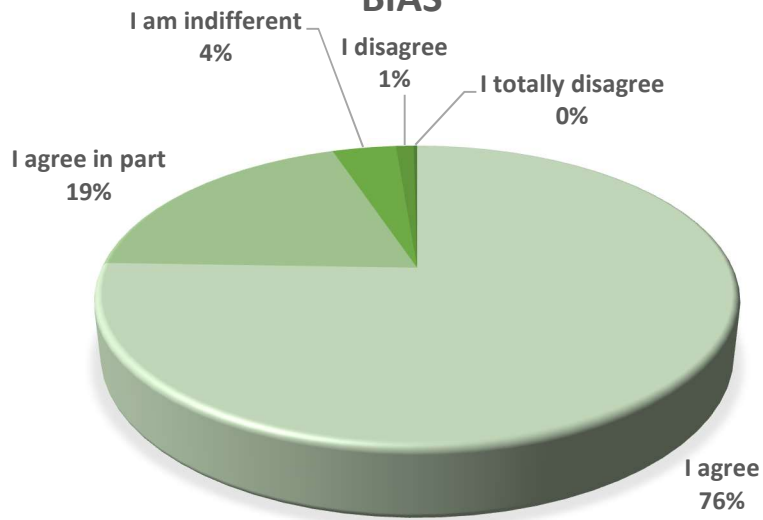


**THE INFORMATION PRESENTED CONSISTENTLY WERE
SUPPORTED BY A VALID SCIENTIFIC EVIDENCE BASE**

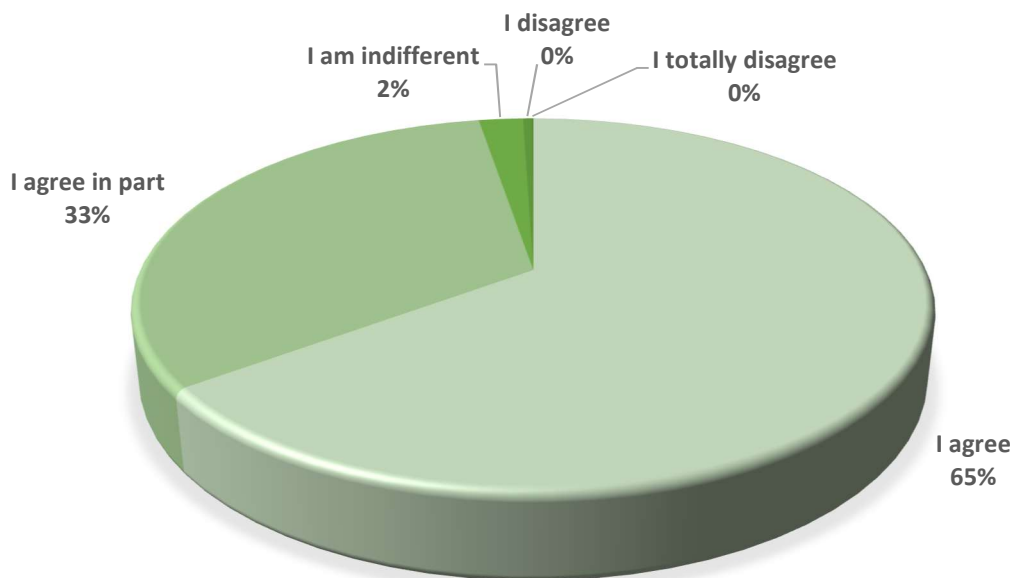


THE SCIENTIFIC PROGRAMME (EXCLUDING INDUSTRY SUPPORTED SESSIONS) WAS FREE OF COMMERCIAL

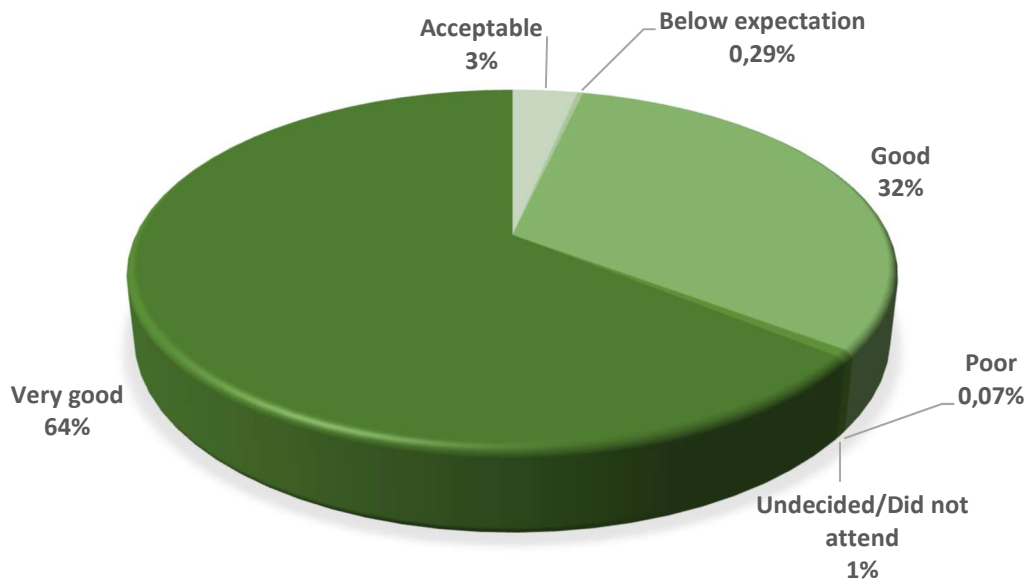
BIAS



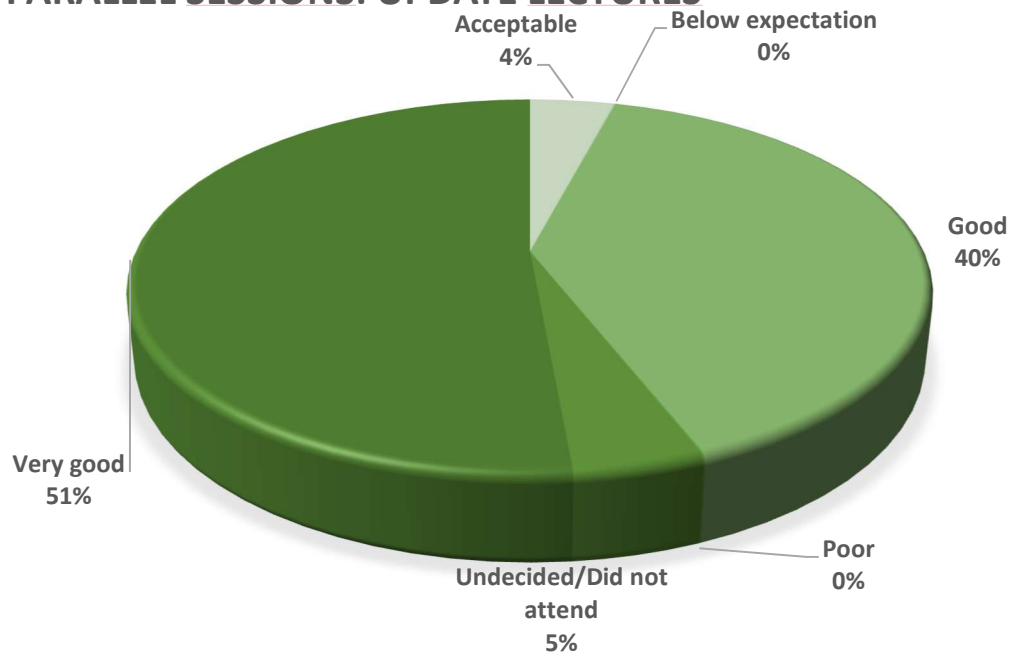
THE SPEAKERS WERE CONSISTENTLY VERY GOOD OR EXCELLENT



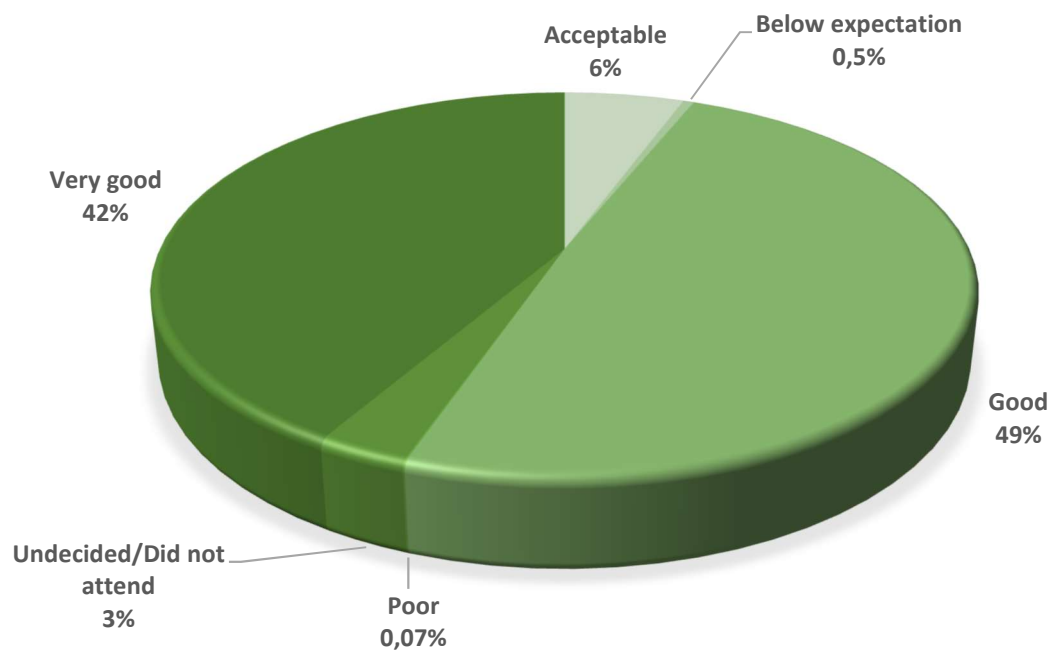
PLENARY SESSIONS



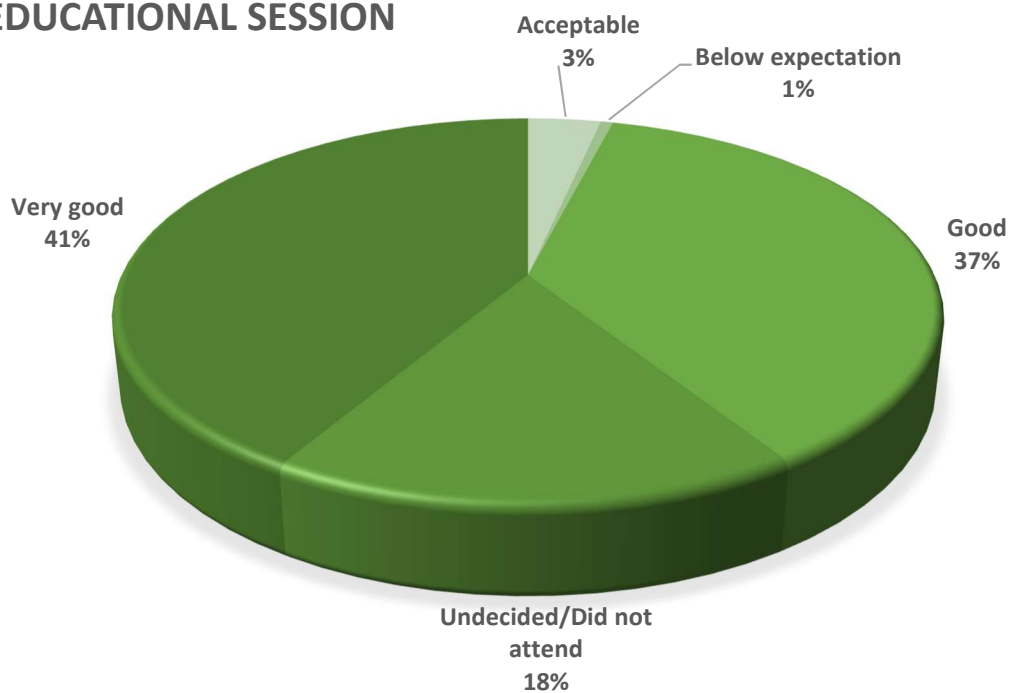
PARALLEL SESSIONS: UPDATE LECTURES



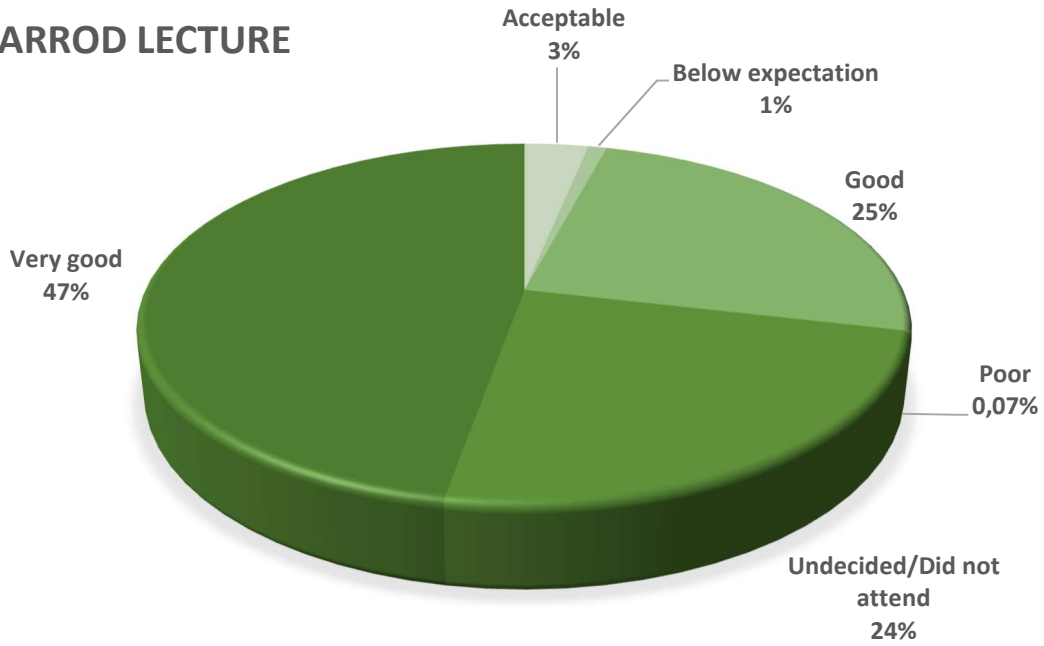
PARALLEL SESSIONS: ORAL PRESENTATIONS



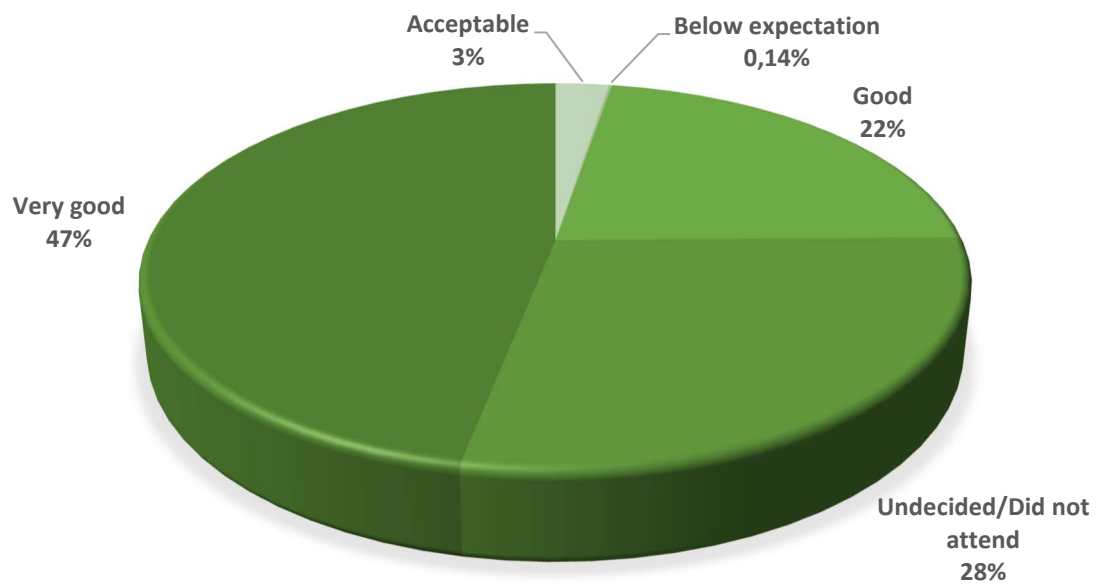
EDUCATIONAL SESSION



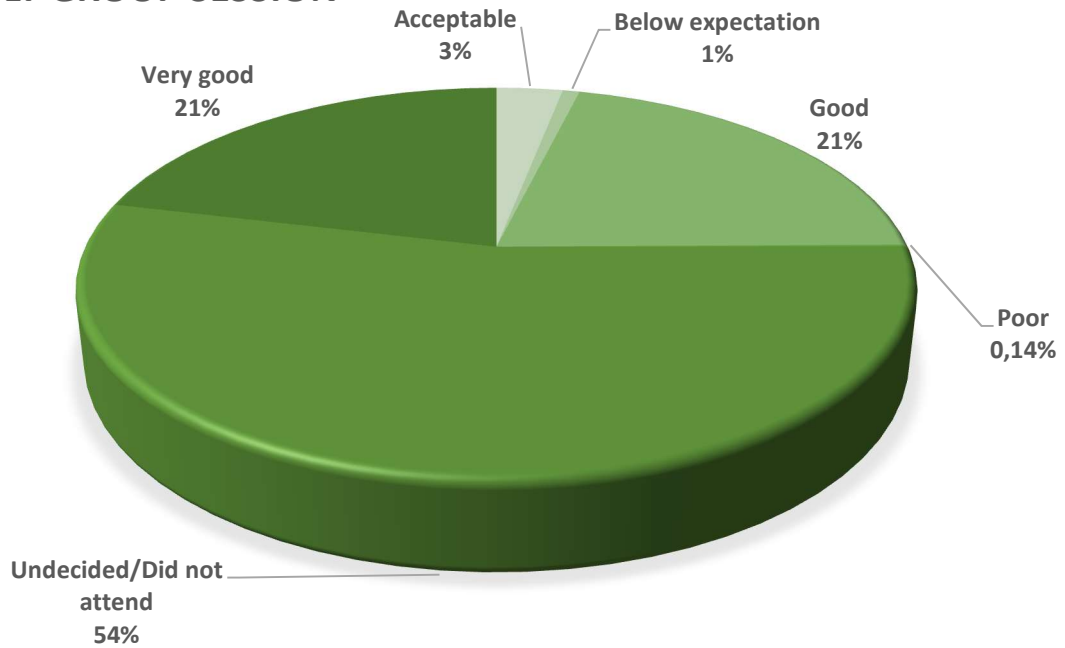
GARROD LECTURE



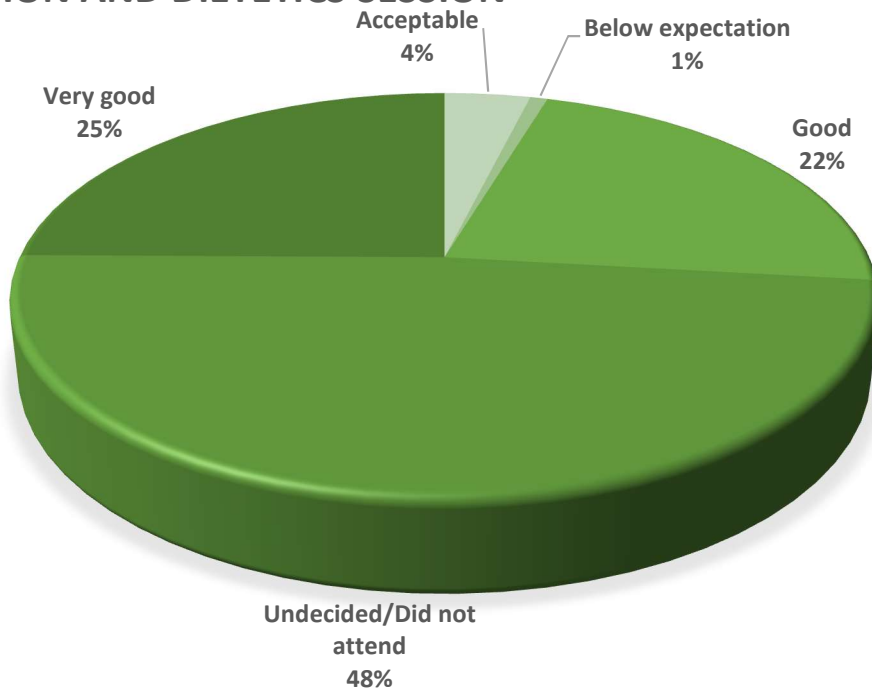
KOMROWER LECTURE



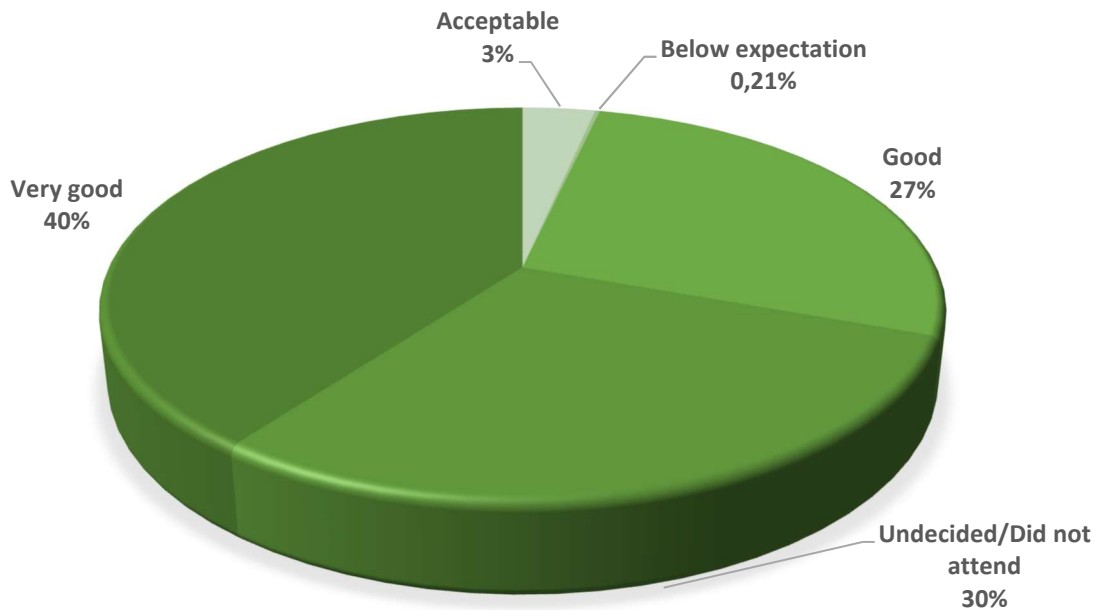
ADULT GROUP SESSION



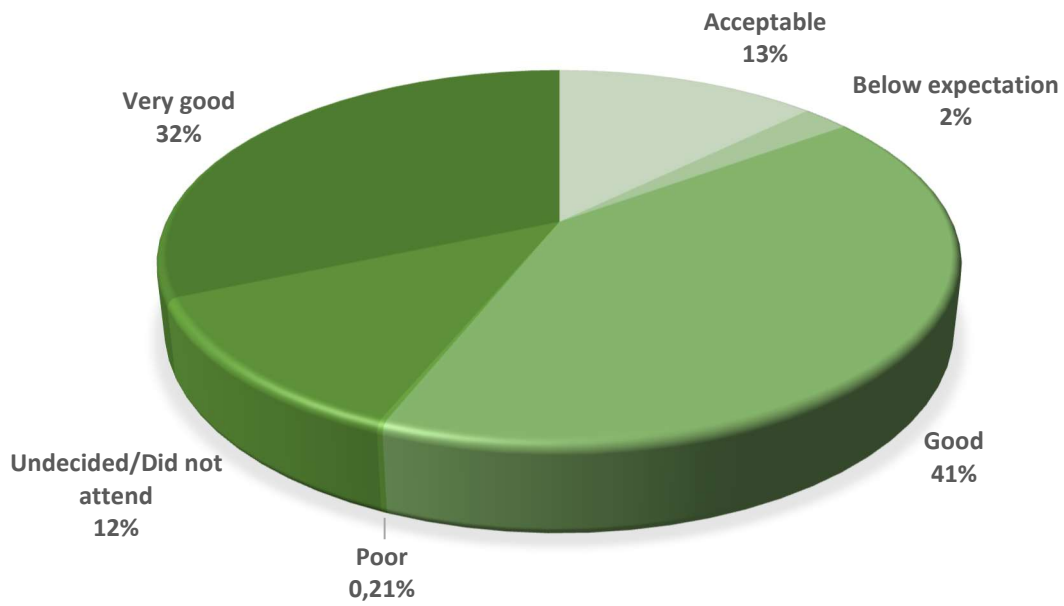
NUTRITION AND DIETETICS SESSION



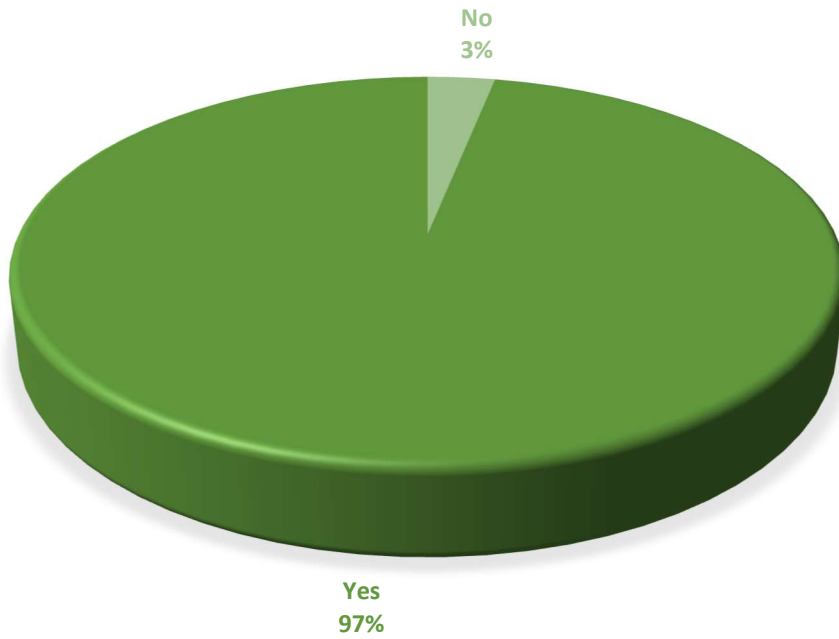
LATE BREAKING NEWS SESSION



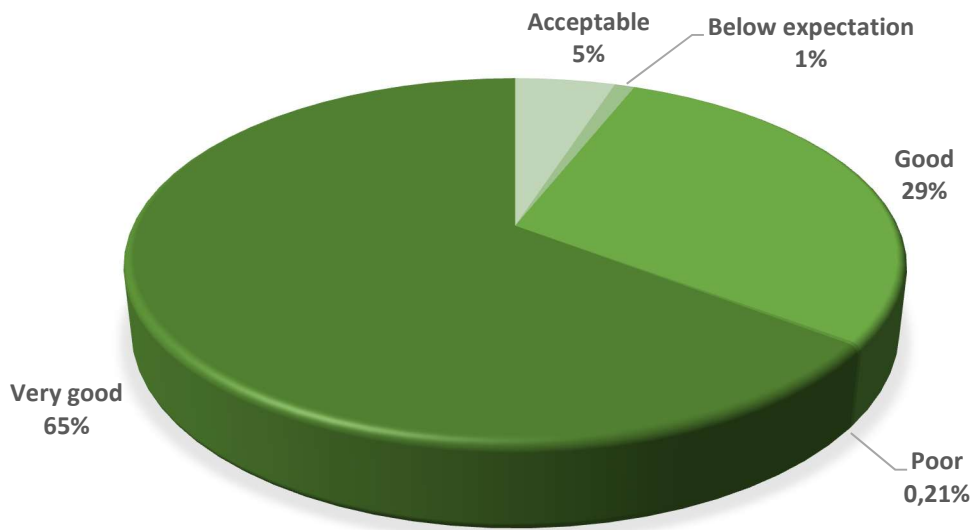
POSTERWALK



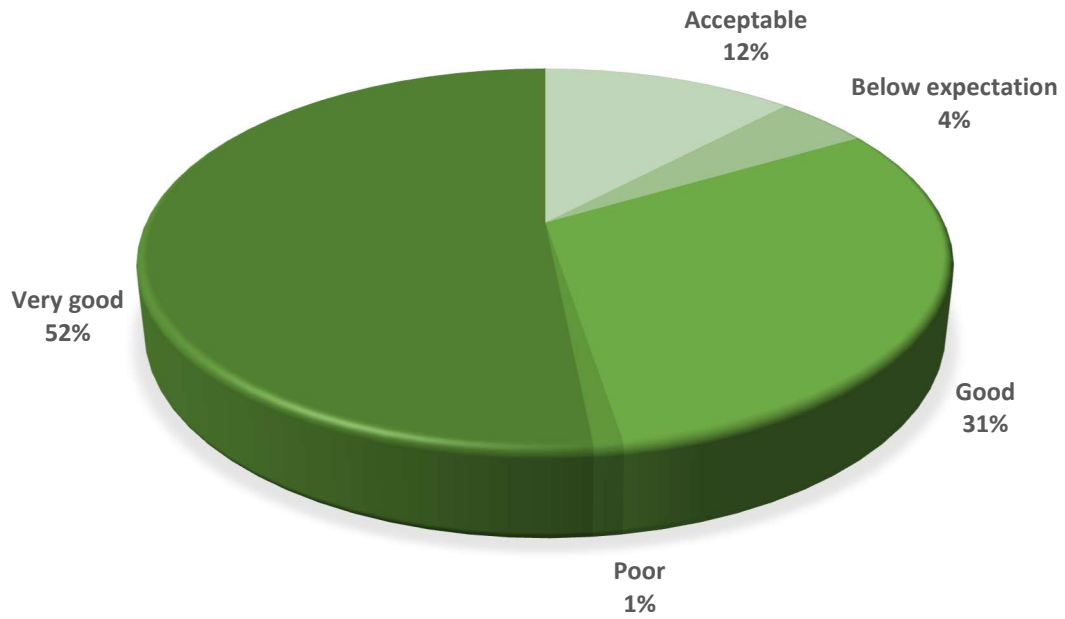
SHOULD UPDATE LECTURES BE A REGULAR FEATURE OF FUTURE SSIEM ANNUAL MEETINGS?



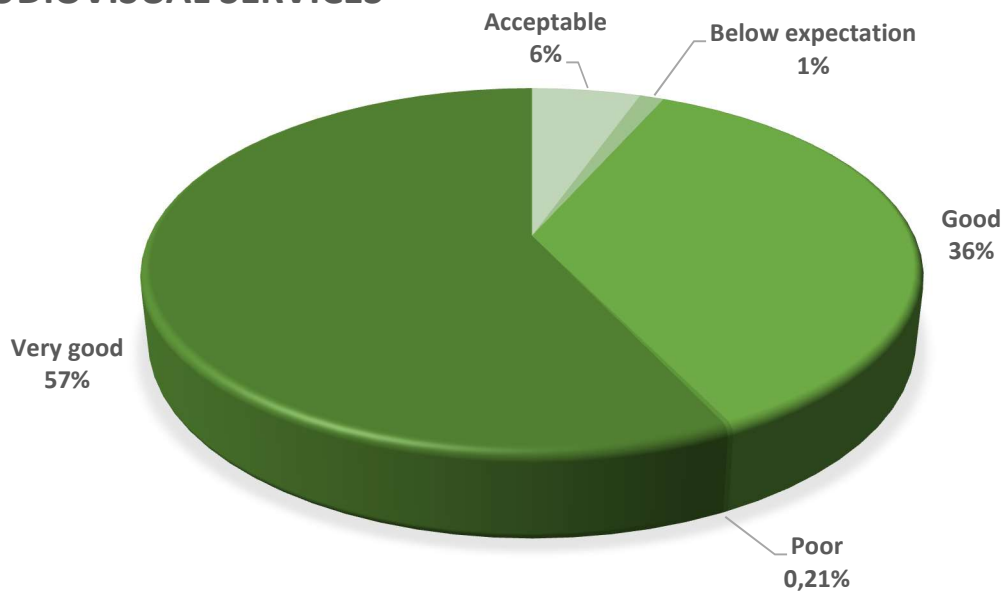
VENUE FACILITIES



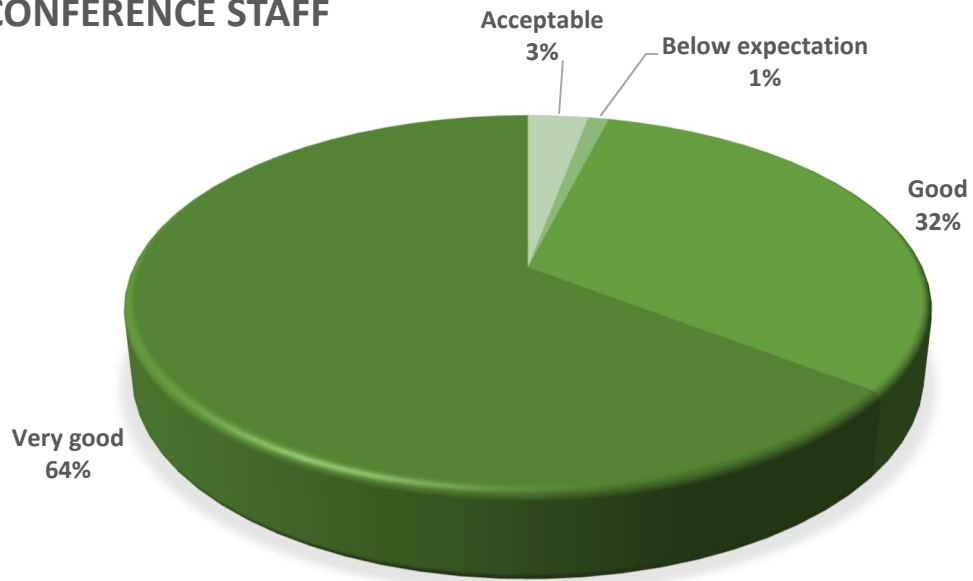
WIFI ACCESS



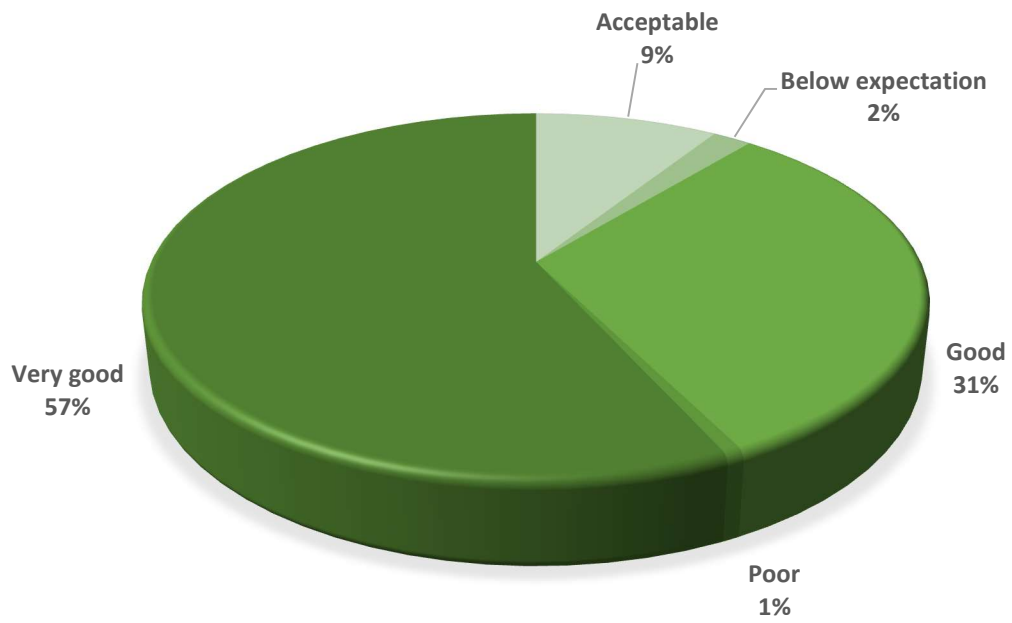
AUDIOVISUAL SERVICES



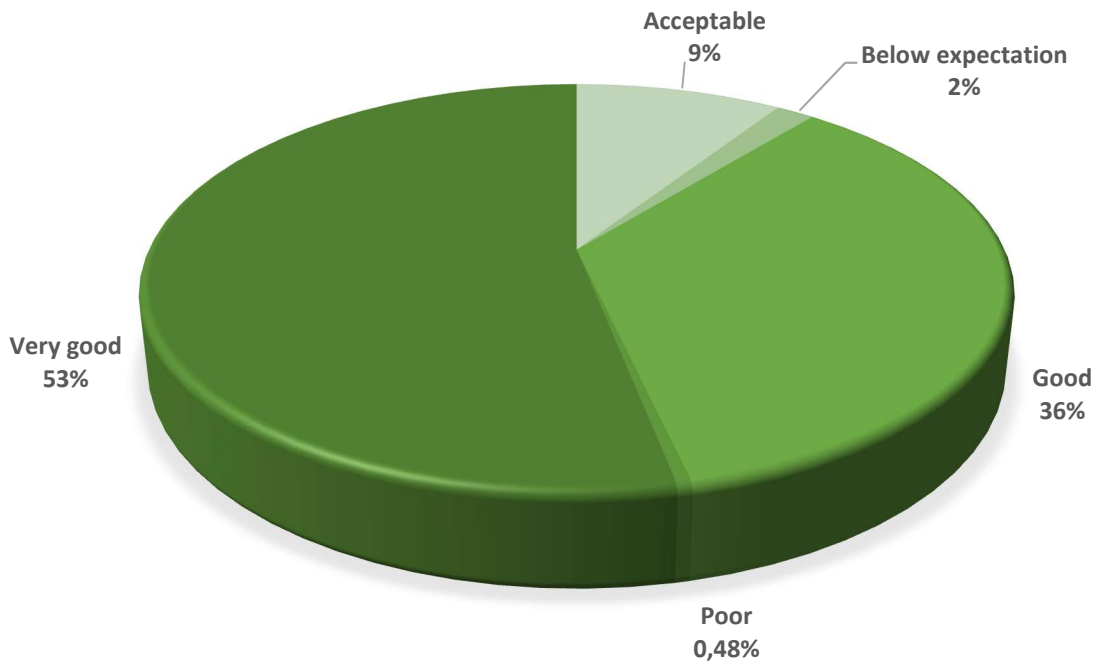
CONFERENCE STAFF



CATERING



ACCOMMODATION (IF BOOKED THROUGH THE SSIEM BOOKING SITE)

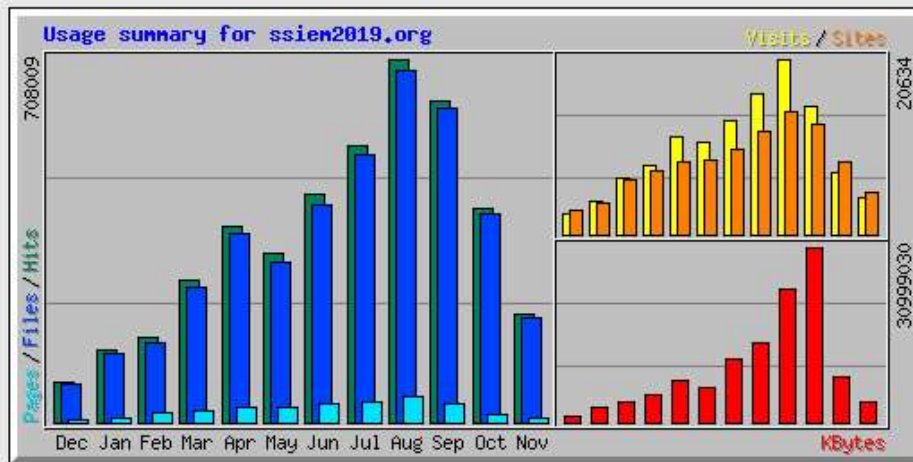


ARE YOU SATISFIED WITH THE CURRENT FORMAT OF THE SYMPOSIUM?



Answers on the open questions can be found in the attached excel sheet.

WEBSITE REPORT



Summary by Month										
Month	Daily Avg				Monthly Totals					
	Hits	Files	Pages	Visits	Sites	KBytes	Visits	Pages	Files	Hits
Nov 2019	11064	10798	487	225	4941	3646253	4289	9259	205172	210221
Oct 2019	13414	13151	479	235	8478	7970636	7289	14851	407682	415849
Sep 2019	20843	20394	1186	505	12949	30999030	15159	35593	611843	625302
Aug 2019	22839	22089	1650	665	14371	23539295	20634	51174	684768	708009
Jul 2019	17437	16773	1285	532	12149	14139590	16508	39846	519972	540568
Jun 2019	14774	14178	1205	443	9900	11095197	13317	36164	425357	443228
May 2019	10637	10046	1002	349	8763	6029112	10835	31079	311431	329775
Apr 2019	12761	12238	997	381	8465	7583470	11443	29915	367159	382830
Mar 2019	8966	8534	749	261	7422	4959061	8116	23227	264570	277958
Feb 2019	5937	5527	654	238	6400	3514372	6673	18318	154758	166239
Jan 2019	4549	4367	303	123	3672	2708260	3819	9416	135386	141022
Dec 2018	2521	2418	148	76	2788	1161172	2371	4597	74984	78181
Totals						117345448	120453	303439	4163082	4319182