ERNDIM

QUALITY ASSURANCE IN LABORATORY TESTING FOR IEM

2016 Participant Survey Report:

[2015 scheme year]

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1. Introduction

- Participants (757 contacts from 382 centres) were sent the link to the ERNDIM Participant Survey on the Survey Monkey website (www.surveymonkey.com) on 23rd June 2016. We asked participants to answer questions relating to the 2015 EQA schemes. The closing date for the survey was 29th July 2016.

2. Summary

- Thank you to everyone who took the time to complete this survey. This report is a summary of all the responses we received. The results from the survey will help us to continue to improve the quality and efficiency of the ERNDIM EQA schemes.
- Over 60% of the laboratories that participated in the 2015 schemes responded to the survey with the response rate for each of the schemes being between 49-67%.
- The survey has again highlighted areas where we need to improve such as the lack of website reporting for all of the qualitative schemes and low sample volume for some of the qualitative schemes. However it is gratifying to see that 39% of respondents rate the quality of products and services we provide as excellent and that 77% of respondents believe that the quality of service we offer is getting better. We will continue to make further improvements to the service that we offer as we work towards applying for accreditation.
- We are still working towards moving all the qualitative schemes to website reporting with the current aim being to test website reporting for the CDG and Qualitative Organic Acids scheme in 2017, with the Acylcarnitines in DBS scheme moving to website reporting in 2018/19.
- The issue of sample volume is more difficult. The schemes that use real clinical samples as the EQA materials are dependent on the Scientific Advisors sourcing suitable clinical samples of sufficient volume either by direct contact with clinicians or via donations from participating laboratories. However we are investigating alternative routes for sample donation, including appeals to the members of the Society for the Study of Inborn Errors of Metabolism (SSIEM, www.ssiem.org) and closer links with patient organisations. Information on the types of samples that would be useful to ERNDIM can be found on the website (www.erndim.org) under EQA schemes\sample donations. If you would be interested in donating a sample please contact the Administration Office.
- We are especially pleased that so many of you took the time to complete the survey and to send comments on the schemes. We hope you find the summary where we answer some of your comments, interesting (see page 11) and we would welcome any other comments or suggestions for improvements.

3. Survey Responses

- 268/757 contacts from 238/382 centres in 51 countries responded to the survey. The response rate by centre was 62% (compared to 59% in the last survey) and the individual response rate was 35% (compared to 34% in the last survey).

Question 1: Please rate the following aspects for each of the ERNDIM quality assurance schemes that you subscribe to

- Number of centre responses = 238 centres (= 100% of all responses)
- The response rate for each EQA scheme is shown in Figure 1 and Table 2. For the individual schemes the highest response rate was for Purines & Pyrimidines (67% of 2015 scheme participants) and the lowest was for Cystine in WBC (49% of 2015 scheme participants). The response rate for 7 of the 12 EQA schemes was higher than in the 2015 survey (= 2014 scheme year, Figure 1).

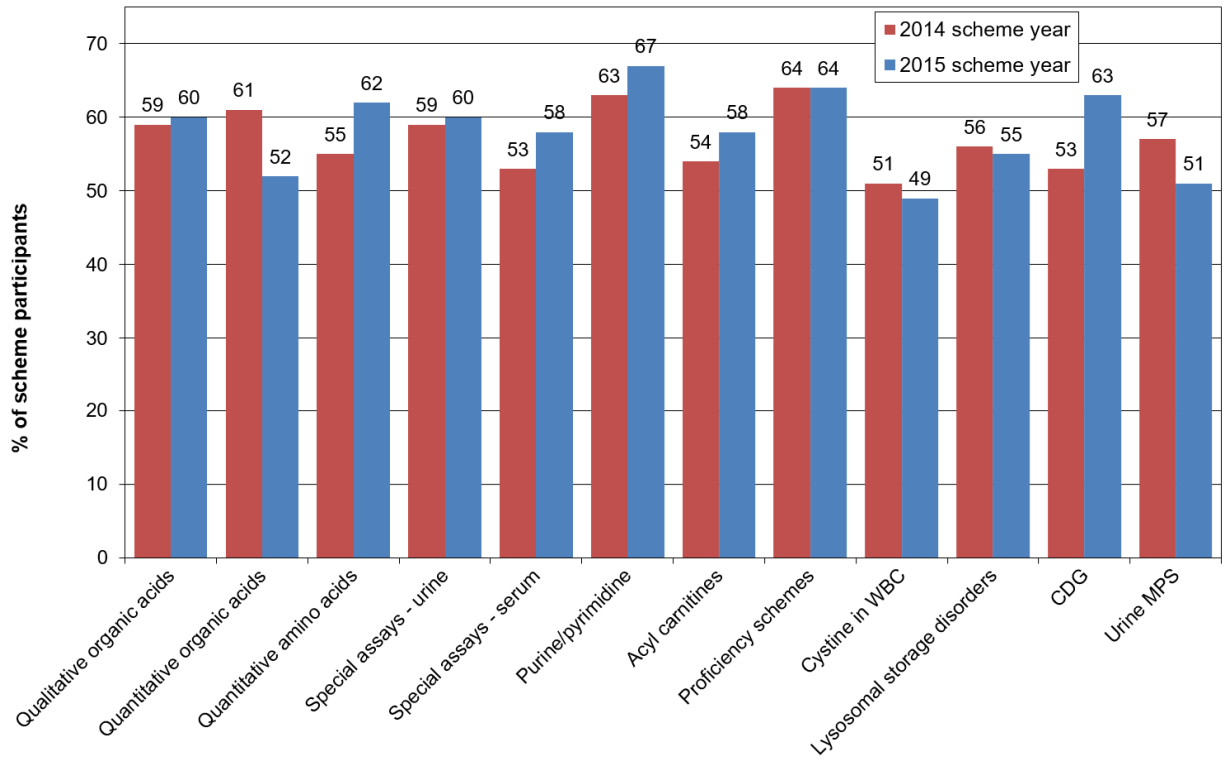


Figure 1. Survey responses per EQA scheme (Question 1) as a percentage of the EQA scheme participants

- Participants were asked to rate the following aspects of each scheme:
  1. Frequency of samples
  2. Sample volume
  3. Appropriateness of analyte concentration
  4. Adequacy of the report
  5. Website display
  6. Usefulness of the annual report
  7. Value for money
  8. Billing arrangements
- Each of the aspects of individual EQA schemes was rated according to the following scoring system:
  1 = Excellent 2 = Good 3 = Poor 4 = Very poor
- Scores ≤ 1.5 are highlighted in blue and scores ≥ 2.0 are highlighted in red.

Table 1. Average scores per scheme (Question 1)

	Average Scores (survey year)								
EQA Scheme	**2016**	**2015**	**2014**	**2013**	**2012**	**2011**	**2007**	**2004**	**2001**
All schemes	**1.7**	**1.8**	**1.7**	**1.7**	**1.7**	**1.8**	**1.7**	**2.0**	**2.0**
Qualitative organic acids	1.7	1.7	1.7	1.7	1.7	1.7	1.6	2.0	1.9
Quantitative organic acids	1.7	1.8	1.7	1.7	1.7	1.9	1.7	1.9	2.1
Quantitative amino acids	1.7	1.7	1.7	1.7	1.7	1.8	1.7	1.9	2.0
Special assays - urine	1.7	1.7	1.7	1.7	1.7	1.7	1.8	1.9	2.1
Special assays - serum	1.8	1.7	1.7	1.7	1.7	1.8	1.7	1.8	2.0
Purines & pyrimidines	1.8	1.8	1.7	1.7	1.7	1.9	1.6	1.8	2.1
Acylcarnitines in DBS	1.9	1.9	2.0	1.9	1.9	2.0	2.0	2.3	-
Diagnostic Proficiency Testing	1.7	1.7	1.7	1.7	1.8	1.8	1.7	2.0	2.0
Cystine in white blood cells	1.7	1.8	1.8	1.6	1.7	1.6	1.4	-	-
Lysosomal storage enzymes (fibroblasts)	1.9	1.9	2.0	1.9	2.0	2.1	-	-	-
Congenital disorders of glycosylation	1.9	2.0	2.0	1.9	1.8	1.9	-	-	-
Urine Mucopolysaccharides	1.7	1.8	1.8	1.8	1.8	-	-	-	-

- The average scores per scheme since 2001 are shown in Table 1 and Figure 2.
- The overall score for all aspects of all schemes was 1.7, which is slightly better than in 2015 (1.8). Seven of the EQA schemes had the same score as last year, 1 scheme had a worse score than last year (Special Assays in serum) and 3 schemes had better scores (Quantitative Organic Acid, Cystine in white blood cells (WBC) and Urine MPS).
- The best scoring schemes were Qualitative. Organic Acids, Quantitative Organic Acids, Quantitative Amino Acids, Special Assays in urine, DPT, Cystine in WBC and Urine MPS which all scored 1.7. The worst scoring schemes were Acylcarnitines in DBS, Lysosomal Enzymes in fibroblasts and the CDG scheme which all scored 1.9.
- The scores for each scheme in each of the individual aspects are given in Table 2. The score for 7 out of the 8 of the individual aspects have improved or stayed the same since last year, while 'while 'Appropriateness of analyte concentration' 'has a slightly worse score than last year.
- The worst scoring aspects were 'Sample Volume', Appropriateness of analyte concentration', 'Website Display' and 'Value for money' which all scored 1.8; with the best scoring aspects being 'Frequency of samples', 'Adequacy of the report', 'Usefulness of the annual report' and 'Billing arrangements' (which all scored 1.7).
- The score for 'Sample volume' has remained the same as in 2015 and 2014 (1.8) and three schemes still scored 2.0 or more (LSDs = 2.1, CDG = 2.5, Urine MPS = 2.0; all equal to their 2015 scores) for this aspect. For the third year the 'Sample volume' score for CDG, was the worst score in the survey, (2.5 in 2016 and 2015, 2.6 in 2014).
- The worst scores for 'Website display' were for Qual Organic Acids (= 2.0) and Acylcarnitines = 2.3) both of which do not yet have online results submission. The CDG score for 'Website display improved from 2.0 in 2015 to 1.7 in 2016.
- The best scores of the whole survey (all 1.5) were for 'Adequacy of the report' (Qual Organic Acids and DPT) and 'Usefulness of the annual report (Qual Organic Acids and DPT).
- The most improved scores of the whole survey were for Cystine in WBC (adequacy of the report, 1.7 compared to 2.0 in 2015; website display, 1.7 compared to 2.0 in 2015; billing arrangements, 1.7 compared to 2.0 in 2015) and CDG (website display, 1.9 compared to 2.2 in 2015; value for money, 1.8 compared to 2.1 in 2015).

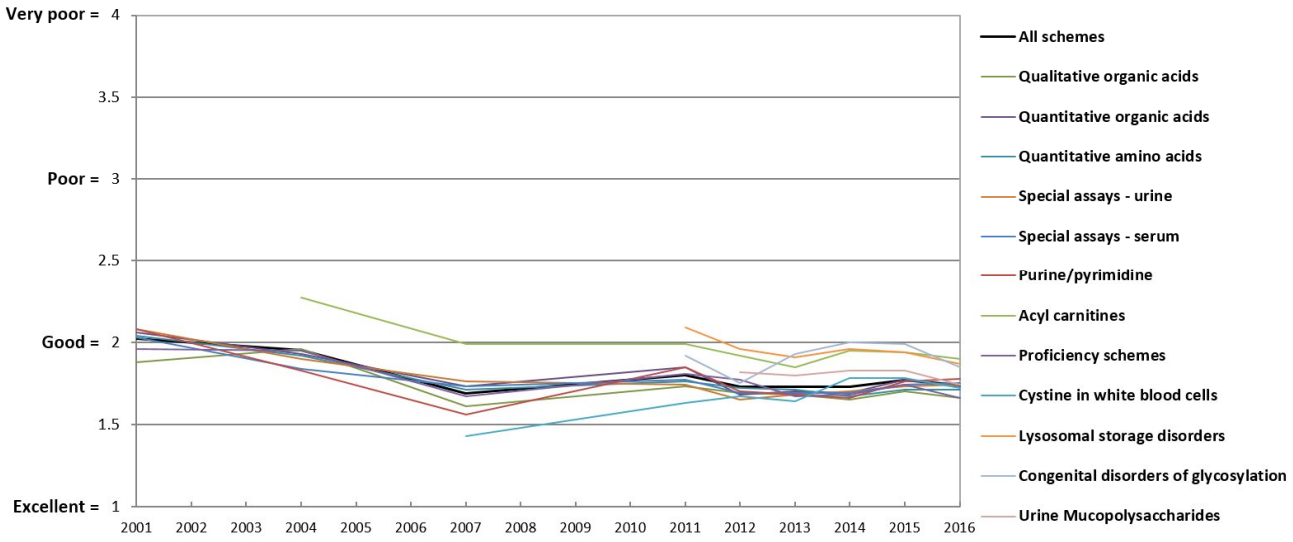


Figure 2. Average score per EQA scheme (Question 1)

Table 2: Average scores per aspect of each scheme (Question 1)

Scheme Aspects	Frequency of samples	Sample volume	Appropriateness of analyte concentration	Adequacy of the report	Website display	Usefulness of the annual report	Value for money	Billing arrangements	Average per scheme	No. of responses (% of scheme participants)
Qual. organic acids	1.6	1.8	1.6	1.5	2.0	1.5	1.7	1.7	**1.7**	125 (60.1%)
Quant. organic acids	1.6	1.6	1.8	1.8	1.7	1.8	1.8	1.8	**1.7**	57 (52.3%)
Quant. amino acids	1.6	1.6	1.8	1.7	1.7	1.7	1.8	1.8	**1.7**	158 (61.7%)
Special assays - urine	1.6	1.8	1.8	1.7	1.7	1.8	1.8	1.8	**1.7**	101 (59.4%)
Special assays - serum	1.7	1.7	1.8	1.8	1.7	1.8	1.8	1.8	**1.8**	130 (57.5%)
Purines/pyrimidines	1.6	1.6	1.8	1.9	1.8	1.9	1.8	1.7	**1.8**	34 (66.7%)
Acyl carnitines	2.2	1.9	1.7	1.8	2.3	1.7	1.9	1.7	**1.9**	70 (58.3%)
Proficiency schemes	1.6	1.9	1.6	1.5	1.8	1.5	1.7	1.7	**1.7**	68 (63.6%)
Cystine in WBC	1.7	1.8	1.7	1.7	1.7	1.8	1.8	1.7	**1.7**	17 (48.6%)
LSD	1.7	2.1	1.9	2.0	1.8	1.9	1.8	1.7	**1.9**	41 (54.7%)
CDG	1.7	2.5	1.7	1.7	1.9	1.6	1.8	1.8	**1.9**	40 (62.5%)
Urine MPS	1.7	2.0	1.8	1.7	1.8	1.7	1.8	1.6	**1.7**	54 (51.4%)
Average for all schemes	**1.7**	**1.8**	**1.8**	**1.7**	**1.8**	**1.7**	**1.8**	**1.7**		

Questions 2 to 7: Analytes in Quantitative Schemes

- A total of 89/268 individuals (33%) made suggestions for analytes to be added to or removed from the Quantitative schemes.
- Where possible we do try to incorporate suggestions for additional analytes and but unfortunately this is not always possible. A summary of the suggestions for analytes to added or removed, with some responses from ERNDIM, is below.

Q.2: Quantitative amino acids (47 responses, 17.5% of all respondents)

Suggested Analytes to be added

Total suggested = 24

Analytes with >1 response

Tryptophan	n = 13
S-Sulfo-L-Cysteine	n = 11
Argininsuccinic acid	n = 10
alloisoleucine	n = 3
homocystine	n = 3
pipecolic acid	n = 3
anserine	n = 2
carnosine	n = 2
Cystathionine	n = 2
Homocysteine (total)	n = 2

Suggested Analytes to be removed

Total suggested = 9

Analytes with >1 response

Homocitrulline	n = 12
saccharopine	n = 10
Phosphoethanolamine	n = 4

ERNDIM Response:

- Tryptophan, alloisoleucine, pipecolic acid, cystathionine, phosphoethanolamine, homocitrulline and saccharopine are all only included in the scheme as 'special amino acids' which vary from year to year.

Q.3: Quantitative organic acids (15 responses, 5.6% of all respondents)

Suggested Analytes to be added		Suggested Analytes to be removed	
Total suggested = 36		Total suggested = 3	
Analytes with >1 response		**All Analytes suggested**	
3-hydroxybutyric acid	n = 4	3-hydroxyisobutyric acid	n = 1
3-hydroxypropionic acid	n = 3	glycolic acid	n = 1
orotic acid	n = 3	sebacate	n = 1
lactic acid	n = 2		
malonic	n = 2		
methyl citric acid	n = 2		
methylmalonic acid	n = 2		
methylsuccinic	n = 2		
suberylglycine	n = 2		
succinylacetone	n = 2		

ERNDIM Response:

- 3-hydroxyisobutyric acid was removed from the 2016 scheme onwards.
- 2-methylcitric acid and methylmalonic acid are included in the 2017 scheme.

Q.4: Purines & pyrimidines (6 responses, 2.2% of all respondents)

Suggested Analytes to be added		Suggested Analytes to be removed
Total suggested = 8		Total suggested = 0
Analytes with >1 response		**All Analytes suggested**
Succinyladenosine	n = 4	
N-carbamoyl-beta-alanine	n = 3	
Uridine	n = 3	
SAICAR	n = 2	
Adenylosuccinic acid	n = 2	
Guanine	n = 2	

ERNDIM Response:

- The additions of SAICAR (SAICAriboside) and SAdo to this scheme have been requested in the past. The availability of both these analytes is very limited and unfortunately the addition of these compounds is financially not feasible.

Q.5: Lysosomal Enzymes (17 responses, 6.3% of all respondents)

Suggested Analytes to be added		Suggested Analytes to be removed	
Total suggested = 6		Total suggested = 2	
Analytes with >1 response		**All Analytes suggested**	
Aryl sulfatase A	n = 4	sphingomyelinase	n = 2
iduronate sulfatase	n = 3	Galactose-6-sulphate sulphatase	n = 1
Aryl sulfatase B	n = 2		
Chitotriosidase	n = 2		
Enzymes for MPS III A	n = 2		
lysosomal acid lipase	n = 2		

Q.6: Special assays – serum (36 responses, 13.4% of all respondents)

Suggested Analytes to be added		Suggested Analytes to be removed	
Total suggested = 55		Total suggested = 5	
Analytes with >1 response		**All Analytes suggested**	
biotinidase	n = 6	acylcarnitines	n = 2
acetylcarnitine	n = 3	pipecolic acid	n = 2
NEFA (non-esterified fatty acids)	n = 3	Creatine	n = 1
ACYLCARNITINE C10	n = 2	Guanodinoacetate	n = 1
ACYLCARNITINE C4	n = 2		
ACYLCARNITINE C6	n = 2		
chitotriosidase activity	n = 2		
demosterol	n = 2		
glucosylsphingosine	n = 2		
oxysterol	n = 2		
Total Carnitine	n = 2		

ERNDIM Response:

Suggested additions

- Biotinidase is not commercially available so it cannot be added. CDC (www.cdc.gov/nsqap) provides an EQA scheme for biotidinase in dried blood spots.
- Chitotriosidase is not commercially available so it cannot be added.
- NEFA are not added to the samples for this scheme but are present in the sample matrix however results can be submitted for comparison between labs.
- Both 7-Ketocholesterol and Cholestane 3b, 5a, 6b-triol (markers for diagnosis and follow-up of Niemann-Pick type C disease) are added since 2014.
- Acetylcarnitine, C10 carnitine, C6 carnitine and C4 carnitine are all included on the 2017 Acylcarnitines in serum scheme.
- For Demosterol and Glucosylsphingosine a survey was carried out in Jan 2017 to assess need.

Suggested removals

- Acylcarnitines - These analytes have been removed in the 2017 samples.
- Pipecolic acid, Creatine and Guanidinoacetic acid - There are more than 50 labs reporting results for each of these analytes so their removal will not be considered.

Q.7: Special assays – urine (22 responses, 8.2% of all respondents)

Suggested Analytes to be added		Suggested Analytes to be removed	
Total suggested = 34		Total suggested = 6	
Analytes with >1 response		**All Analytes suggested**	
cystine	n = 3	glycolic acid	n = 1
2-aminoadipic-semialdehyde (2-AASA)	n = 2	lactic acid	n = 1
arabitol	n = 2	oxalic acid	n = 1
delta aminolevulinic acid	n = 2	pipecolic acid	n = 1
Galactose	n = 2	Succinylacetone	n = 1
methylmalonic acid	n = 2	sulfocysteine	n = 1
ribitol	n = 2		
vanylmandelic acid	n = 2		

ERNDIM Response:

Suggested additions

- Arabitol, Ribitol, Vanylmandelic acid, galatose were all rejected by the SAB in 2014.
- MMA has been added in the Quantitative Organic Acids (urine) scheme.
- Cystine is included in the 2017 scheme.
- The possible addition of 2-AASA will be studied by the SAB in 2017 but this may be difficult as it is an unstable metabolite and not commercial available.
- For delta-aminolevulinic acid a survey was carried out in Jan 2017 to assess need.
- Glyceric acid will be added to the scheme in the future.

Suggested removals

- The addition of Glycolic acid, oxalic acid and sulphocyteine has been accepted since 2013.
- Lactic acid, Succinylacetone (marker for Tyrosinemia type I) and Pipecolic acid - There are more than 50 labs reporting results for each of these analytes so removal will not be considered

Question 8: Do you have any other remarks, comments or suggestions for any of the schemes you subscribed to?

- Number of individual responses = 61 (= 23% of all responses).
- These comments are summarised on page 11 with the comments made in response to Q16.

Q.9 to Q.11: Dried blood spots (DBS) are increasingly used in both monitoring and diagnosis; ERNDIM is therefore investigating the possibility of a Special Assays in DBS pilot EQA scheme.

Question 9: Would your laboratory be interested in participating in a Special Assays in DBS pilot EQA scheme?

- Number of centres responses = 217 (= 81% of all centre responses).
- 95 centres answered 'Yes, they would be interested in participating in a Special Assays in DBS pilot scheme' (= 44% of centres that answered this question).

ERNDIM Response (for Q.9. – Q.11.)

- We are pleased there was such a positive response to these questions. The options for this pilot scheme being investigated and we will circulate more details when they are available.

Question 10: If you answered yes to Q.9 please indicate which analytes/metabolite your laboratory would be submitting results for, we would begin by including THcys, Val, Ile, Leu, Allile, Phe Tyr in the scheme

- Number of centres responses = 86 (= 91% of centre responses to Q.9).

Table 3: Number of 'yes' responses per analyte (Question 10)

Individual Metabolites (n > 1)	Number of Centres[1]
Phenylalanine	78
Valine	62
Isoleucine	54
Alloisoleucine	50
Leucine	45
Total homocysteine	40
Tyrosine	15

Question 11: If there are any additional metabolites you would like to see included in a Special Assays in DBS pilot in the future please list them below

- Number of centres responses = 52 (= 55% of centre responses to Q.9).

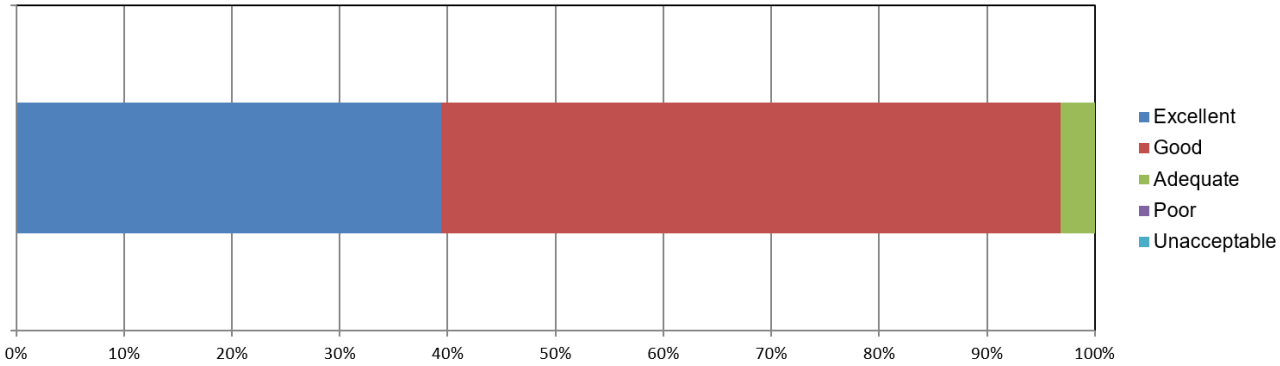
Table 4: Suggested additional analytes & number of 'responses (Question 11)

Other suggested metabolites (n >1)	Number of Centres[1]
Methyl Malonic acid	11
Methyl Citric acid	9
Methionine	7
Succinylacetone	7
Lysosomal enzymes	6
Acylcarnitines	4
Citrulline	3
Galactose-1-phosphate	3
17-hydroxyprogesterone	2
All amino acids	2
Alpha-galactosidase	2
Androstenedione	2
Arginine	2
Cortisol	2
Creatine	2
Free carnitine	2
Galactose	2
Galactose 1 phosphate uridyl transferase	2
Glycine	2
Guanidinoacetate	2
Leucine	2
Orotic acid	2

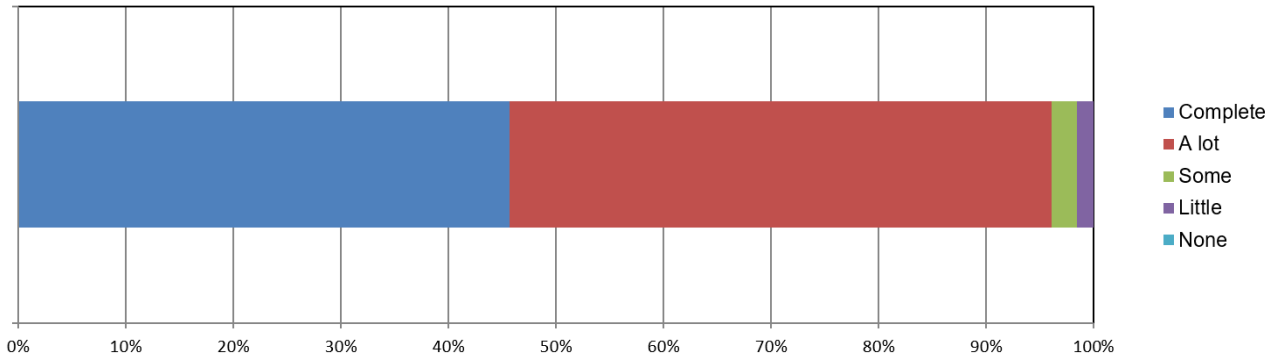
Questions 12 to 15: Comments on the overall performance of ERNDIM

- This aim of this section is to assess participants' perception of the overall performance of ERNDIM.
- In summary, 97% of respondents rated the quality of services provided by ERNDIM as 'excellent' or 'good'; with 96% of respondents having 'complete' or 'a lot' of confidence that ERNDIM can deliver the service required by participants.
- 77% of respondents agreed that overall ERNDIM's performance is 'getting better' or 'getting much better'; with 98% of respondents stating that it was 'certain' or 'very likely' that they would use ERNDIM services in the future.

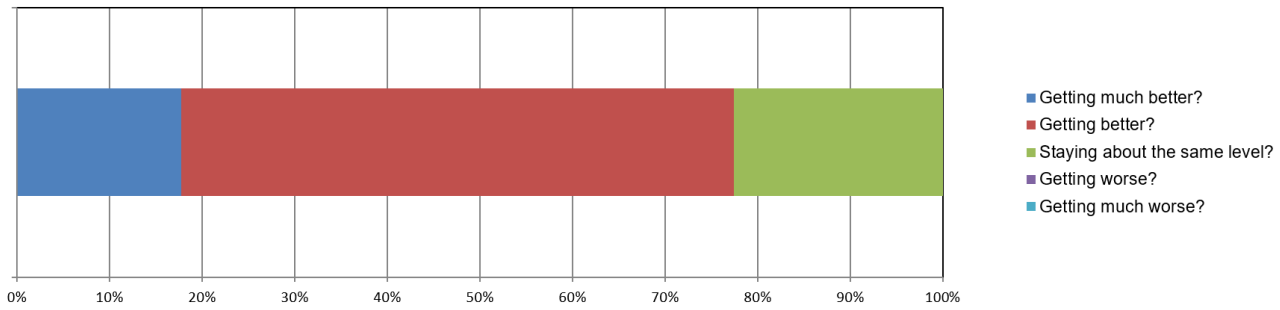
Q.12: Overall, how do you rate the quality of products and services we provide?
(127 individual responses, 99% of all responses)



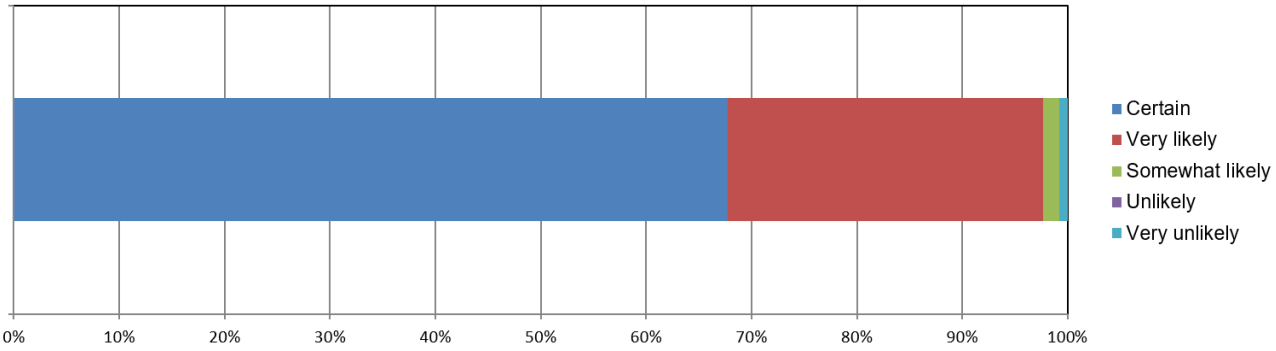
Q.13: What level of confidence do you have in us to deliver the products and services that you require? (127 individual responses, 99% of all responses)



Q.14: Overall, is our performance...
(124 individual responses, 97% of all responses)



Q.15: Based on our performance, how likely is it that you will use us in the future?
(127 individual responses, 99% of all responses)



Question 16: Do you have any other remarks, comments or suggestions for how we could improve the services we provide?

- Number of individual responses = 55 (= 21% of all responses).
- These comments are summarised below with the comments made in response to Q9.

Questions 8 & 16: Remarks, comments or suggestions for improvements

- Total number of responses was 116 from 93 individuals (= 35% of all responses).
- There were a large number of comments and suggestions for improvement. Below is a summary of some of the most frequent comments with responses from ERNDIM.

Participant Comment	ERNDIM Response
1. Administration	
• Would it be possible to introduce credit card payments?	• We will investigate if this is possible without increasing costs to participants.
2. EQA Schemes	
2.1. General	
• Countries outside Europe may have different guidelines for import of QC material. Maybe setting up a document with these guidelines may assist effective and timely distribution of ERNDIM samples.	• Currently laboratories from 60 different countries participate in the ERNDIM EQA schemes and it is unfortunately just not practical for ERNDIM to produce and maintain a document on all the different guidelines for importing to each of these countries.
• There were, again, a number of comments on the frequency of submission deadlines – some wanting more frequent (up to 12 per year) and some wanting less frequent deadlines (4-6 over year).	• Increasing the number of submission deadlines so that there were 12 submissions per year would make running the schemes extremely difficult. • Decreasing the number of submissions per year would mean very long periods without EQA coverage which would not be acceptable.
• Decrease the gap between the end of one scheme year and the beginning of the next scheme year.	• It isn't currently possible for us to do this but we are investigating options for the future.
• Lack of website reporting for all the qualitative schemes.	• ERNDIM's long term aim is to move all of the qualitative schemes to the CSCQ Results website. It is planned that the CDG and the Qualitative Organic Acids schemes will begin to move to website reporting in 2017 with the Acylcarnitines in DBS scheme moving to website reporting in 2018.
• Sample donations: It might be helpful to add some information about required pathological samples on the website.	• Information on the types of samples that would be useful to ERNDIM can now be found on the website (www.erndim.org) under EQA schemes\sample donations. If you would be interested in donating a sample please contact the Administration Office.

Participant Comment	ERNDIM Response
• Faster access to the annual reports.	• We agree that the annual reports need to be published earlier. For the 2016 schemes, all the scheme results will have been ratified by mid-February (instead of March) and the annual reports will be published as soon as possible after that.
• Certificates of Participation to be sent earlier.	• The delay in publishing the certificates is because all the scheme results need to be finalised before any of the certificates can be produced. For the 2016 schemes, all the scheme results will have been ratified by mid-February and we're hoping to publish the certificates in May. We're working towards publishing them earlier next year.
2.2. Acylcarnitines in DBS	
• Delivery of samples is delayed.	• The EQA materials for the scheme are real clinical samples and delays in sample dispatch are due to difficulties obtaining suitable samples. • For 2017 there will be an additional organising centre for this scheme, which we are hoping will help with sample supply.
• Interim reports should be published earlier.	• We are working towards online submission of results for this scheme which will make it easier for the Scientific Advisor to evaluate the results and send out reports earlier.
2.3. CDG scheme	
• On-line results submission.	• We are working towards online submission of results for this scheme.
• Low sample volume.	• This scheme uses real clinical samples and at least 3ml plasma is needed for each sample. The difficulty obtaining suitable samples of a large enough volume means that the volume per EQA sample is restricted. It is possible to order additional sample volume at a reduced fee but the availability of this is limited. The Scientific Advisor regularly appeals for sample donations but with few responses. Please contact the Administration office if you would be interested in donating a sample.
2.4. DPT scheme	
• Too many samples for very uncommon diseases which in the lab would not be diagnosed only using urine – this could give a wrong impression about the performance of the individual labs.	• We agree a balance between uncommon and more common disorders would be ideal however the scheme can only use the samples that are available and have been donated by participants. Please contact the Administration office if you would be interested in donating a sample.
• Problems with the submission deadlines for the second DPT round and middle Qualitative Organic Acids round coinciding.	• The submission deadlines from the 2016 schemes onwards have been changed so this should no longer be a problem.
2.5. Lysosomal Enzymes in fibroblasts	
• The amount of sample sent should be increased.	• It is very difficult to increase the amount of material sent due to the very long time which is already needed to culture enough fibroblasts for the amount of material which is currently sent to participants. The Scientific Advisor tests all samples before they are sent and performs the assays with a protein concentration of 1 mg/ml and has found that the amount of material in the samples is enough.
• Negative scores should not be given if we do not measure the relevant enzyme.	• The scoring system was changed for the 2015 scheme onwards so that for each enzyme a maximum of 2 points each could be scored for CV and diagnosis, giving a maximum total of 4 points. If results were not submitted for an enzyme no score is recorded. Full details of the scoring scheme can be found in the 2015 LSE in fibroblasts annual report (www.erndim.org under Meetings & Reports\EQA scheme annual reports).
2.6. Qualitative Organic Acids.	
• Interim and final reports should be published earlier.	• We are working towards online submission of results for this scheme which will make it easier for the Scientific Advisor to evaluate the results and send out reports earlier.

Participant Comment	ERNDIM Response
• Slow responses to email communication.	• We are sorry for any delays in replying to emails. These schemes do not yet have online results submission and the Scientific Advisors for each of these schemes have over 100 participants each. While they try to respond to all emails in a timely manner unfortunately this is not always possible. If you have any problems contacting one of the Scientific Advisors please contact the Administration Office and we will direct your query to the correct person.
• Online submission of results.	• We are working on website submission of results and hope to begin implementing this in 2017.
• Problems with the submission deadlines for the second DPT round and middle Qualitative Organic Acids round coinciding.	• The submission deadlines from the 2016 schemes onwards have been changed so this should no longer be a problem.
• More new and abnormal cases of organic aciduria, some of the cases have been circulated in the past.	• We agree a balance between uncommon and more common disorders would be ideal however the scheme can only use the samples that are available and have been donated by participants. Please contact the Administration office if you would be interested in donating a sample.
2.7. Special Assays in serum	
• Would it be possible to have a range of concentrations for NEFA?	• NEFA are not added to the samples for this scheme but are present in the sample matrix so the concentrations do not vary, however results can be submitted for comparison between labs.
2.8. Special Assays in urine	
• It is more convenient to combine oxalate, glycerate and glycolate in one urine sample.	• Glyceric acid will be moved from the Quantitative Organic Acids scheme to the Special Assays in urine scheme for 2018 onwards.
2.9. Urine MPS	
• Would be useful to access reports via the website (fully electronic result submission and reports).	• The reports module for the UMPS results website is in development.
• It is very important to have increased sample volume.	• The reason for sending 5 mL samples is the limited sample availability (both volume and number of samples). Hence, sample volumes can't be larger than 5 mL. The scheme organisers prepare 120 aliquots of 5 mL, which requires 600 mL of urine. Larger aliquots would require proportionally larger stock samples. Since the Urine MPS scheme uses authentic human urine samples, we depend on participants to contribute these and for this scheme only a very few participants donate samples. If you would be interested in donating a sample please contact the Administration office. • One possibility is to offer labs the option to purchase as second set of samples at a reduced fee however this will be possible only for 5-10 participants.
3. Suggestions for future schemes	We do welcome suggestions for future schemes but unfortunately it is not possible to cater for every request.
• Acyl carnitines in serum.	• A full EQA scheme for Acylcarnitines in serum was introduced for 2017.
• Cognitive scheme for amino acids.	• Plans for a cognitive amino acids pilot scheme are being developed and we hope to launch this later this year. Initially participation will be limited but the aim will be to increase the number of participants once the pilot phase is completed.
• Reintroduce the Lysosomal Enzymes in DBS pilot scheme.	• Unfortunately, it will not be possible to reintroduce this pilot scheme unless sufficient samples to run the scheme are donated by participating labs as there is a lack of suitable clinical materials to use as the EQA materials. Please contact the Administration office if you would be interested in donating a sample.

Question 17 Please complete your name and institute address details.

- Number of individual responses = 231 (= 86% of all responses).