



QUALITY ASSURANCE IN LABORATORY TESTING FOR IEM

# 2013 Participant Survey Report

## **ERNDIM Administration Office**

Manchester Centre for Genomic Medicine  
6th floor, St Mary's Hospital  
Oxford Road, Manchester  
M13 9WL, UK

**Tel:** +44 161 276 6741

**Fax:** +44 161 850 1145

**E-mail:** [admin@erndim.org](mailto:admin@erndim.org)

**Web:** [www.erndim.org](http://www.erndim.org)

## 1. Introduction

- Participants (440 contacts from 342 centres) were sent the link to the ERNDIM Participant Survey on the Survey Monkey website ([www.surveymonkey.com](http://www.surveymonkey.com)) on 17<sup>th</sup> May 2013. The closing date for the survey was 28<sup>th</sup> June 2013.

## 2. Summary

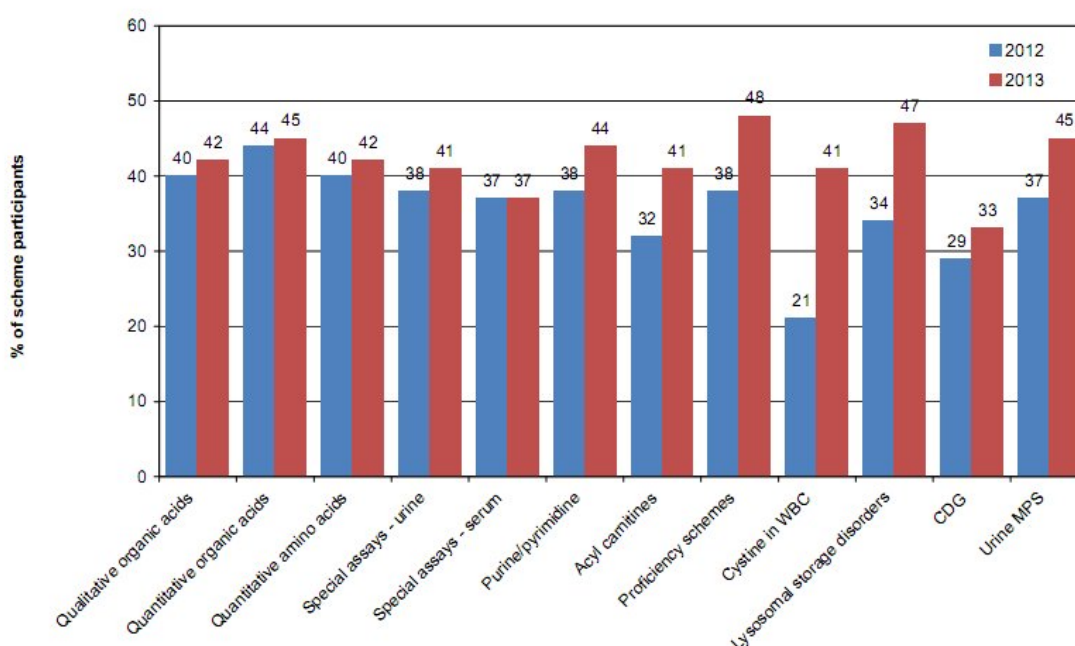
- Thank you to everyone who took the time to complete this survey. This report is a summary of all the responses we received. The results from the survey will help us to continue to improve the quality and efficiency of the ERNDIM EQA schemes. The survey has highlighted areas where we need to improve 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 also gratifying to see that the majority of respondents believe that the quality of service we offer is getting better and we will continue to make further improvements to the service that we offer in the future.

## 3. Survey Responses

- 153/440 contacts from 150/362 centres in 46 countries responded to the survey, (34.8% - response rate in 2012 was 40.1%).

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

- Number of responses = 150 (= 98% 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 Diagnostic Proficiency Schemes (48% of scheme participants) and the lowest was for Congenital Disorders of Glycosylation (33% of scheme participants). The response rate for all the schemes is higher than in 2012 (Figure 1).



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

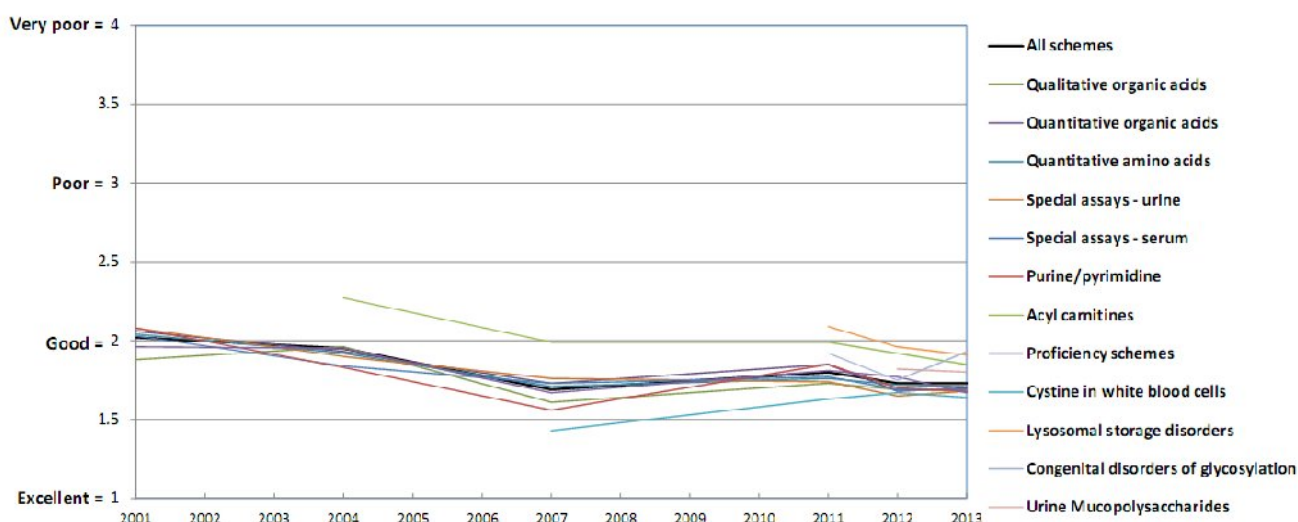
- Participants were asked to rate the following aspects of each scheme:
  1. Frequency of samples
  2. Sample volume
  3. Appropriateness of analyte concentration
  4. Adequacy of the report
  5. Website display
  6. Usefulness of the annual report
  7. Value for money
  8. Billing arrangements

- 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  $\leq 1.5$  are highlighted in blue and scores  $\geq 2.0$  are highlighted in red.

**Table 1.** Average scores per scheme (Question 1)

EQA Scheme	Average Scores					
	2013	2012	2011	2007	2004	2001
<b>All schemes</b>	<b>1.7</b>	<b>1.7</b>	<b>1.8</b>	<b>1.7</b>	<b>2.0</b>	<b>2.0</b>
Qualitative organic acids	1.7	1.7	1.7	1.6	2.0	1.9
Quantitative organic acids	1.7	1.7	1.9	1.7	1.9	2.1
Quantitative amino acids	1.7	1.7	1.8	1.7	1.9	2.0
Special assays - urine	1.7	1.7	1.7	1.8	1.9	2.1
Special assays - serum	1.7	1.7	1.8	1.7	1.8	2.0
Purines/pyrimidines	1.7	1.7	1.9	1.6	1.8	2.1
Acyl carnitines	1.9	1.9	2.0	2.0	2.3	-
Proficiency schemes	1.7	1.8	1.8	1.7	2.0	2.0
Cystine in white blood cells	1.6	1.7	1.6	1.4	-	-
Lysosomal storage disorders	1.9	2.0	2.1	-	-	-
Congenital disorders of glycosylation	1.9	1.8	1.9	-	-	-
Urine Mucopolysaccharides	1.8	1.8	-	-	-	-

- The overall score for all aspects of all schemes was 1.7, the same as in 2012. Eleven of the EQA schemes showed an improvement or had the same score as in 2012.
- The best scoring scheme was Cystine in WBC (1.6) and the worst scoring schemes were CDG and LSDs although the score for LSDs has improved since 2012 (1.9 compared to 2.0).
- The average scores per scheme since 2001 are shown in Table 1 and Figure 2, and show a general trend of improvement.



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

- In 2013 the best scoring aspect was ‘Usefulness of the annual report’ (1.6) with the worst scoring aspects being ‘Sample volume’, ‘Appropriateness of analyte concentration’, ‘Website display’, ‘Value for money’ and ‘Billing arrangements’ which all scored 1.8.

- The worst scores in the survey were for 'Sample volume' for CDG (2.5), LSDs (2.3) and Urine MPS (2.3).
- The most improved aspect score compared to 2012 is for 'Usefulness of the annual report' (1.6 in 2013 and 1.7 in 2012).
- The best score of the whole survey was for 'Usefulness of the annual report' (DPT = 1.4).
- The most improved scheme score of the whole survey was for Acyl carnitines for 'Adequacy of the report' (1.7 in 2013 compared to 2.0 in 2012).

**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	1.7	1.5	2.0	1.5	1.7	1.8	1.7	78 (42%)
Quant. organic acids	1.6	1.5	1.8	1.8	1.7	1.7	1.8	1.8	1.7	46 (45%)
Quant. amino acids	1.6	1.6	1.7	1.8	1.7	1.7	1.8	1.8	1.7	101 (42%)
Special assays - urine	1.6	1.7	1.8	1.7	1.6	1.7	1.7	1.7	1.7	66 (41%)
Special assays - serum	1.6	1.5	1.8	1.7	1.7	1.7	1.7	1.8	1.7	76 (37%)
Purines/pyrimidines	1.6	1.6	1.8	1.7	1.7	1.7	1.9	1.7	1.7	24 (44%)
Acyl carnitines	2.3	1.9	1.7	1.7	2.0	1.6	1.9	1.9	1.9	48 (41%)
Proficiency schemes	1.7	1.8	1.7	1.6	1.9	1.4	1.7	1.7	1.7	48 (48%)
Cystine in WBC	1.6	1.8	1.6	1.6	1.6	1.7	1.6	1.7	1.6	14 (41%)
LSD	1.7	2.3	2.0	1.9	1.6	1.9	2.1	1.9	1.9	33 (47%)
CDG	1.7	2.5	1.9	1.8	2.2	1.5	1.9	1.9	1.9	20 (33%)
Urine MPS	1.7	2.3	1.8	1.8	1.8	1.6	1.7	1.7	1.8	47 (45%)
<b>Average for all schemes</b>	<b>1.7</b>	<b>1.8</b>	<b>1.8</b>	<b>1.7</b>	<b>1.8</b>	<b>1.6</b>	<b>1.8</b>	<b>1.8</b>		

## Question 2: Do you have any other remarks, comments or suggestions for improvements in Quantitative Schemes?

- Number of responses = 64 (= 42% of all responses)
- These comments are summarised with the comments made in response to Q13 and Q14 on page 7.

## Questions 3 to 8: Analytes in Quantitative Schemes

- A total of 64/153 respondents (42%) 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 to or removed, with some responses from ERNDIM, is on page 5.

**Q.3: Quantitative amino acids** (34 responses, 22.2% of all respondents)**Suggested Analytes to be added**

Total suggested = 15

**Analytes with >1 response**

Alloisoleucine	n = 15
Arginosuccinic acid	n = 7
sulphocysteine.	n = 6
homocitrulline	n = 4
Homocysteine	n = 2

**Suggested Analytes to be removed**

Total suggested = 8

**Analytes with >1 response**

Pipecolic acid	n = 5
aspartyl glucosamine	n = 4
Sarcosine	n = 3
1-methylhistidine	n = 2
3-methylhistidine	n = 2

**Q.4: Quantitative organic acids** (12 responses, 7.8% of all respondents)**Suggested Analytes to be added**

Total suggested = 20

**Analytes with >1 response**

3-Methylglutaconic acid	n = 4
suberylglycine	n = 3
3OH glutarate	n = 3
3-hydroxybutyric acid	n = 2
isovalerylglycine	n = 2
propionylglycine	n = 2

**Suggested Analytes to be removed**

Total suggested = 7

**All Analytes suggested**

pyroglutamic acid	n = 2
arylsulphatase-B	n = 1
Glycerate	n = 1
Mevalonate	n = 1
N acetylaspartae	n = 1
Take out one or two of 4- 5 carbons DCAs.	n = 1
leave only one DCA	n = 1

**Q.5: Purines & pyrimidines** (10 responses, 6.5% of all respondents)**Suggested Analytes to be added**

Total suggested = 7

**Analytes with >1 response**

SAICAR	n = 6
2,8-Dihydroxyadenine	n = 3
SADO	n = 3

**Suggested Analytes to be removed**

Total suggested = 0

**All Analytes suggested**

NONE

**Q.6: Lysosomal Enzymes** (11 responses, 7.2% of all respondents)**Suggested Analytes to be added**

Total suggested = 16

**Analytes with >1 response**

Arylsulfatase A	n = 5
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**Suggested Analytes to be removed**

Total suggested = 3

**All Analytes suggested**

a-glucosidase	n = 1
Arylsulfatase B	n = 1
heparin sulfamidase	n = 1

**ERNDIM Response:**

- Arylsulfatase A will be included in the 2014 scheme.

**Q.7: Special assays – serum** (18 responses, 11.8% of all respondents)**Suggested Analytes to be added**

Total suggested = 28

**Analytes with >1 response**

biotinidase	n = 7
chitotriosidase	n = 2
total carnitine	n = 2

**Suggested Analytes to be removed**

Total suggested = 0

**All Analytes suggested**

NONE

**ERNDIM Response:**

- Biotinidase and chitotriosidase are not commercially available so can not be added.

**Q.8: Special assays – urine** (13 responses, 8.5% of all respondents)

**Suggested Analytes to be added**

Total suggested = 19

**Analytes with >1 response**

methylmalonic acid *	n = 3
Delta Aminolevulinic acid	n = 2

\* = including one request for 1-10 µmolar range

**Suggested Analytes to be removed**

Total suggested = 7

**All Analytes suggested**

Arabinitol	n = 1
Erythritol	n = 1
Galactose	n = 1
oxalic acid	n = 1
Ribitol	n = 1
Sedoheptitol	n = 1
Sedoheptulose	n = 1

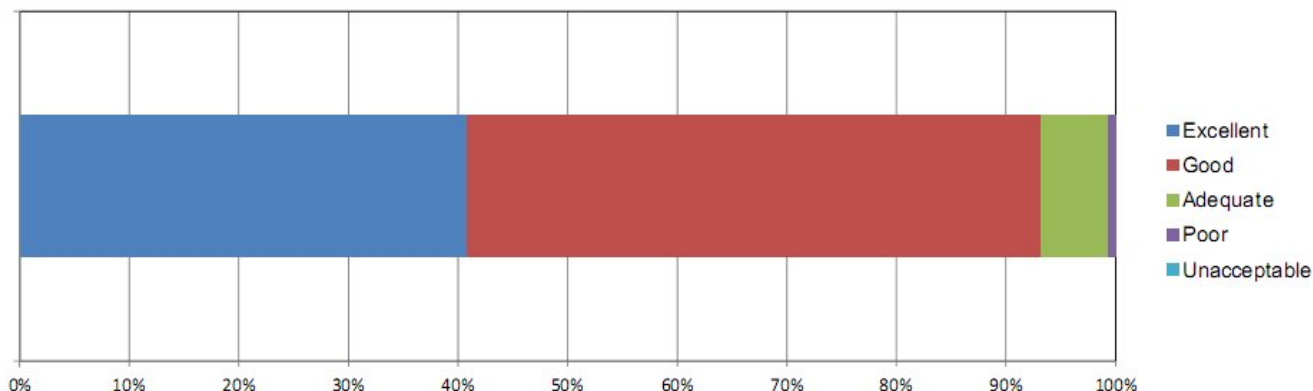
**ERNDIM Response:**

- Methylmalonic acid is already in the Quantitative Organic Acids scheme. The Scientific Advisory Board will discuss whether it should be moved to the Special Assays in Urine scheme.

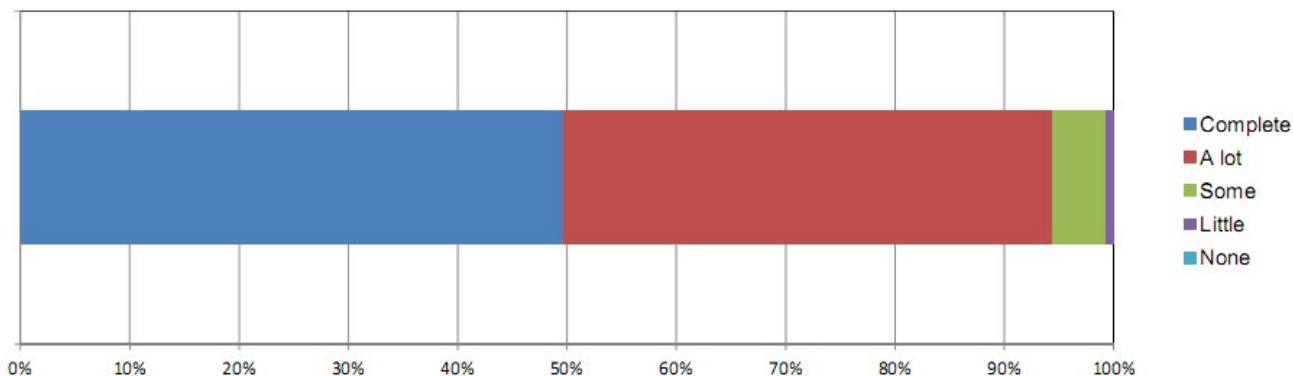
**Questions 9 to 12: Comments on the overall performance of ERNDIM**

- This was a new section of questions introduced with the aim of assessing participants’ perception of the overall performance of ERNDIM.
- In summary, 93% of respondents rated the quality of services provided by ERNDIM as ‘excellent’ or ‘good’; with 95% of respondents having ‘complete’ or ‘a lot’ of confidence that ERNDIM can deliver the service required by participants.
- 71% of respondents agreed that overall ERNDIM’s performance is ‘getting better’ or ‘getting much better’; with 99% of respondents stating that it was ‘certain’ or ‘very likely’ that they would use ERNDIM services in the future.

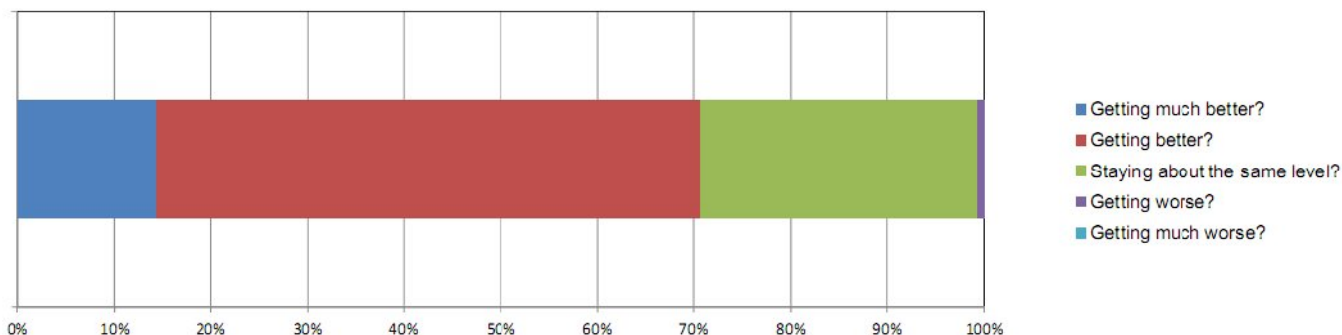
**Q.9: Overall, how do you rate the quality of products and services we provide?**  
(147 responses, 96% of all responses)



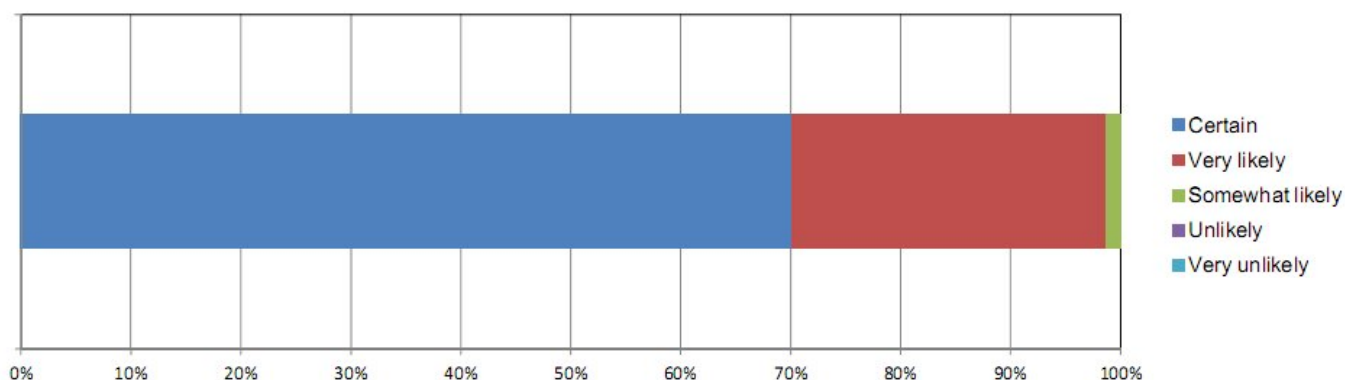
**Q.10: What level of confidence do you have in us to deliver the products and services that you require?** (145 responses, 96% of all responses)



**Q.11: Overall, is our performance...**  
(147 responses, 96% of all responses)



**Q.12: Based on our performance, how likely is it that you will use us in the future?**  
(147 responses, 96% of all responses)



**Questions 2, 13 & 14: Remarks, comments or suggestions for improvements**

- Number of responses = 63 (= 41.2% 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. General Comments**

**1.1.** Timetable of submission deadlines on the website.

- For the quantitative schemes a timetable of submission deadlines is already on the SKML results website but we will add submission deadlines for all the EQA schemes to the ERNDIM website (erndim.org) later this year.

**1.2.** There were a number of comments on the frequency of submission deadlines – some wanting more frequent (12 per year) and some wanting less frequent deadlines (2 per year).

- There are no plans at the moment to alter the number or frequency of submission deadlines for the EQA schemes.

**1.3.** Increased number of sample distributions for some of the qualitative schemes.

- For the qualitative schemes there are often problems sourcing suitable clinical material of a sufficient volume to use as the EQA materials. For most of these schemes the Scientific Advisor sources all the EQA materials themselves and we would welcome offers to donate suitable samples from participating centres. Please contact the Administration office if you would be interested in donating a sample.

- 1.4. Sample volume for some of the qualitative schemes is too low.
  - Please see point 1.3.
  - For the Lysosomal Enzymes sample volume is limited due to time constraints when culturing the samples but the scheme organisers will try to culture a larger volume of fibroblasts.
- 1.5. 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. The Urine MPS scheme should move to website reporting in 2014 and the other qualitative schemes will move over gradually in the next few years.
- 1.6. Faster access to the annual reports.
  - The final results for each scheme are ratified by the Scientific Advisory Board at its Spring meeting so all annual reports are published as soon as possible after that meeting.
- 1.7. Copies of annual reports on the website.
  - Current and previous annual reports are available to download from the SKML results website (cms.erndimqa.nl). We're hoping to move these all across to the ERNDIM website later this year.
- 1.8. Certificates of Participation to be sent earlier.
  - In the past the Certificates have sometimes been published in August which, we agree, is too late. In 2013 the certificates were published in July. This year we're hoping to publish them in June and we're working towards publishing them earlier next year.

## 2. EQA Schemes

### 2.1. DPT UK scheme

- Time scale of 2 weeks is too short and there should be 3 weeks to analyse and report.
- In fact the timescale allowed 13 working days to analyse and report the samples for each EQA round which we believe reflects normal laboratory practice.

### 2.2. CDG scheme

- 6 samples per survey is too much. It would be better to have 4 surveys of 3 samples.
- There were actually 2 surveys of 3 samples but this perhaps could be made clearer.
- The reports are not sent by mail but only on the website.
- The aim is for the CDG scheme to move to the CSCQ results website but in the interim reports will be sent by email. The Scientific Advisor is also looking at the feasibility of sending interim reports after each survey.

### 2.3. Lysosomal Enzymes

- Improve the annual report.
- The Scientific Advisor and the Scheme Organiser are looking at ways to improve the annual report.
- Make it clearer that this scheme is a mix of quantitative and qualitative testing.
- In the future participants will be asked to report if the enzyme activity is in the normal range, or likely to be affected.

### 2.4. Qualitative Organic Acids

- Respond to comments sent to the organic acids email address.
- This will be addressed and the scheme email address will be checked more often.

### 2.5. Quantitative Amino Acids

- More discussion of the unusual compounds.
- Comments for more unusual compounds will be added to the reports in future.

### 2.6. Urine MPS

- It would be nice to have some clinical information accompany the samples.
- This scheme is a mixed quantitative-qualitative scheme. It was developed to test analytical performance plus interpretation of results and not to test knowledge on phenotypes. We have decided not to provide clinical information as this would make it easier to establish diagnosis.

## 3. Suggestions for future schemes

- Lysosomal DBS
  - We do welcome suggestions for future schemes but unfortunately it is not possible to cater for every request.
  - It was unfortunately not possible to continue in 2013 the short Lysosomal Enzymes in DBS pilot which ran in 2012. This was due to limited sample supply. However a full pilot scheme for Lysosomal DBS will run again in 2014.
- Plasma acyl carnitines
  - A very small pilot study is currently running for plasma Acyl carnitines and the feasibility of extending this will be looked at.

## Question 15 Please complete your name and institute address details.

- Number of responses = 118 (= 86.1% of all responses).