

# ERNDIM Participant Survey 2012: Summary Report



## 1. Introduction

- Participants were sent the link to the ERNDIM Participant Survey on the Survey Monkey website ([www.surveymonkey.com](http://www.surveymonkey.com)) on 18<sup>th</sup> May 2012. The closing date for the survey was 22<sup>nd</sup> July 2012.
- Participants were asked to rate the different aspects for each of the ERNDIM quality assurance schemes according to the following scoring system:
 

1 = Excellent	3 = Poor
2 = Good	4 = Very poor
- In this report scores  $\geq 2.0$  are highlighted in red and scores  $\leq 1.5$  are highlighted in blue.

## 2. Survey responses

### Summary

- 137/342 participants responded to the survey, (40.1% - response rate in 2011 was 47.4%).
- For the individual schemes the highest response rate was for Quantitative Amino Acids (43.7% of scheme participants) and the lowest was for Cystine in WBC (20.6% of scheme participants).
- The overall score for all aspects of all schemes improved slightly from 1.80 in 2011 to 1.73 in 2012. This was due to an improvement in the scores for all schemes (except Cystine in WBC), with the most improved scores being for CDG (1.75 in 2012 compared to 1.92 in 2011) and Quantitative Organic Acids (1.68 in 2012 compared to 1.85 in 2011).
- The score for all but one of the individual aspects have improved since 2011.
- The best scoring schemes were Special Assays Urine (1.65) and Cystine in WBC (1.67) and the worst scoring schemes were LSDs (1.96) and Acyl carnitines (1.92).
- The worst scoring aspect for all schemes was 'Value for money' (1.79) although this has improved since 2011, and the best was 'Frequency of samples' (1.64).
- The most improved scores compared to 2011 are for 'Billing Arrangements' (1.76 in 2012 and 1.90 in 2011) and 'Frequency of samples' (1.64 in 2012 and 1.77 in 2011).
- CDG scored the lowest score of the whole survey for 'Usefulness of the annual report' (1.25), with the next lowest being for Cystine in WBC for 'Frequency of samples' (1.43).

**Table 1:** Average scores per scheme

<b>EQA Scheme</b>	<b>2012</b>	<b>2011</b>	<b>2007</b>	<b>2004</b>	<b>2001</b>
<b>Average for all aspects in all schemes</b>	<b>1.73</b>	<b>1.80</b>	<b>1.69</b>	<b>1.95</b>	<b>2.02</b>
<b><u>Average per scheme</u></b>					
Qualitative organic acids	1.69	1.73	1.61	1.96	1.88
Quantitative organic acids	1.68	1.85	1.73	1.93	2.06
Quantitative amino acids	1.72	1.76	1.71	1.92	2.04
Special assays - urine	1.65	1.74	1.76	1.90	2.08
Special assays - serum	1.69	1.77	1.73	1.84	2.03
Purine/pyrimidine	1.70	1.85	1.56	1.83	2.08
Acyl carnitines	1.92	1.99	1.99	2.27	-
Proficiency schemes	1.77	1.81	1.67	1.95	1.96
Cystine in white blood cells	1.67	1.63	1.43	-	-
Lysosomal storage disorders	1.96	2.09	-	-	-
Congenital disorders of glycosylation	1.75	1.92	-	-	-
Urine Mucopolysaccharides	1.82	-	-	-	-

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

- Number of responses = 137 (= 100% of all respondees).

**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)
Qualitative organic acids	1.64	1.91	1.63	1.57	1.87	1.50	1.72	1.73	1.69	76 (40.4%)
Quantitative organic acids	1.53	1.59	1.84	1.71	1.63	1.61	1.74	1.80	1.68	45 (43.7%)
Quantitative amino acids	1.56	1.56	1.72	1.78	1.76	1.78	1.82	1.76	1.72	96 (39.8%)
Special assays - urine	1.48	1.66	1.69	1.70	1.62	1.65	1.69	1.69	1.65	61 (37.9%)
Special assays - serum	1.54	1.53	1.83	1.74	1.67	1.65	1.77	1.80	1.69	74 (36.5%)
Purine/pyrimidine	1.57	1.52	1.75	1.76	1.81	1.75	1.79	1.69	1.70	21 (38.2%)
Acyl carnitines	2.14	1.76	1.81	1.97	2.00	1.88	1.97	1.81	1.92	37 (31.9%)
Proficiency schemes	1.76	2.00	1.77	1.50	1.94	1.47	1.88	1.87	1.77	38 (37.6%)
Cystine in white blood cells	1.43	2.00	1.71	1.57	1.57	1.57	1.86	1.67	1.67	7 (20.6%)
Lysosomal storage disorders	1.88	2.38	1.86	2.09	1.87	1.90	1.96	1.71	1.96	24 (33.8%)
Congenital disorders of glycosylation	1.53	2.41	1.71	1.63	1.80	1.25	1.69	1.87	1.75	17 (28.3%)
Urine Mucopolysaccharides	1.84	2.21	1.81	1.74	1.77	1.67	1.75	1.70	1.82	38 (36.5%)
<b>Average for all schemes</b>	<b>1.64</b>	<b>1.78</b>	<b>1.75</b>	<b>1.73</b>	<b>1.76</b>	<b>1.66</b>	<b>1.79</b>	<b>1.76</b>		

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

- Number of responses = 55 (= 40.1% of all respondees)

## Questions 3 to 8: Analytes in Quantitative Schemes

### Q.3. Quantitative amino acids (28 responses, 20.4% of all respondees)

#### Suggested Analytes to be added

Total suggested = 18

#### Analytes with >1 response

Alloisoleucine	n = 11
Argininosuccinic acid	n = 9
Sulphocysteine	n = 7
Tryptophan	n = 2
homocitrulline	n = 2

#### Suggested Analytes to be removed

Total suggested = 12

#### Analytes with >1 response

pipecolic acid	n = 6
aspartylglucosamine	n = 4
tryptophan	n = 3
Alloisoleucine	n = 2
PEA	n = 2
delta-ALA	n = 2

### Q.4. Quantitative organic acids (13 responses, 9.5% of all respondees)

#### Suggested Analytes to be added

Total suggested = 69 \*

#### Analytes with >1 response

suberylglycine	n = 4
Butyrylglycine	n = 3
isovalerylglycine	n = 3
methylcitrate	n = 3
Succinic	n = 3
Succinylacetone	n = 3
3-hydroxypropionate	n = 2
3-methylcrotonylglycine	n = 2
3-methylglutaconic	n = 2
4 OH phenyllacetic	n = 2
Citric	n = 2
Glycerol	n = 2
Malonate	n = 2
Methylsuccinate	n = 2
Propionylglycine	n = 2
Pyruvate	n = 2

#### Suggested Analytes to be removed

Total suggested = 0

#### All Analytes suggested

NONE

### Q.5. Purines & pyrimidines (4 responses, 2.9% of all respondees)

#### Suggested Analytes to be added

Total suggested = 6

#### All Analytes suggested

2,8 dihydroxyadenine	n = 1
Cytosine,	n = 1
Dihydrothymine	n = 1
SAICAR	n = 1
Succinyladenosine	n = 1
Uridine	n = 1

#### Suggested Analytes to be removed

Total suggested = 0

#### All Analytes suggested

NONE

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## Q.6. Lysosomal Enzymes (10 responses, 7.30% of all respondees)

### Suggested Analytes to be added

Total suggested = 20

#### Analytes with >1 response

alpha fucosidase	n = 4
a-mannosidase	n = 4
arylsulfatase A,	n = 3
beta mannosidase	n = 3
beta-glucuronidase	n = 3
iduronate sulfatase	n = 2

### Suggested Analytes to be removed

Total suggested = 0

#### All Analytes suggested

NONE

## Q.7. Special assays – serum (20 responses, 14.6% of all respondees)

### Suggested Analytes to be added

Total suggested = 47 \*\*

#### Analytes with >1 response

Biotinidase	n = 3
Desmosterol	n = 3
Lathosterol	n = 3
total carnitine	n = 3
Acylcarnitines	n = 2
Palmitoylcarnitine	n = 2
chitotriosidase	n = 2
Glutaric Acid	n = 2
Octanoylcarnitine	n = 2
Propionylcarnitine	n = 2
Sitosterol	n = 2

### Suggested Analytes to be removed

Total suggested = 0

#### All Analytes suggested

NONE

## Q.8. Special assays – urine (16 responses, 11.7% of all respondees)

### Suggested Analytes to be added

Total suggested = 30

#### Analytes with >1 response

S-Sulfocysteine	n = 3
Acylglycines	n = 2
cystine	n = 2
Methylmalonic acid	n = 2

### Suggested Analytes to be removed

Total suggested = 1

#### All Analytes suggested

succinic acid n = 1

\* = A total of 31 & 39 analytes each were suggested by two respondents

\*\* = A total of 25 analytes were suggested by one respondent

## Question 9 Do you have any other remarks comments or suggestions for improvement?

- Number of responses = 20 (= 14.6% of all respondees)

## Question 10 Please complete your name and institute address details below.

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