ERDNIM Participant Survey 2011:
Summary Report

1. Introduction

- Participants were sent the hyperlink to the ERNDIM Participant Survey on the Survey Monkey website (www.surveymonkey.com) on 12th July 2011. The closing date for the survey was 8th August 2011.
- 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 the tables in this report scores above 2.0 are highlighted in red and scores below 1.5 are highlighted in blue.

2. Survey Responses

Summary

- 160/336 participants responded to the survey, (47.4% - response rate in 2007 was 29.6%).
- For the individual schemes the highest response rate was for Quantitative Amino Acids (47.4%) and the lowest was for Cystine in WBC (27.0%).
- The overall score for all aspects of all schemes has increased slightly from 1.69 in 2007 to 1.80 in 2011. This isn't due to any particular scheme as the overall scores for all schemes (except Acyl carnitine which has stayed the same) have increased from those in 2007.
- The lowest scoring scheme was Cystine in WBC (1.63) and the highest was LSDs (2.09).
- This report includes a table which just shows the scores for 2011 (table 2.3). All the information in this table is shown in table 2.4 but it is easier to see how each scheme is doing just looking at the data for 2011.
- The worst scoring aspect for all schemes was 'Billing' (1.90) and the best was 'Usefulness of the annual report' (1.71).
- Qualitative Organic Acids scored the lowest scores of the whole survey for 'Usefulness of the annual report' (1.47) and 'Adequacy of the report' (1.47).
- The proficiency schemes scored badly (2.05) for Website display, as did Qualitative Organic Acids (2.10), Acyl carnitines (2.56) and CDG (2.11), presumably because they don't have website reporting yet.
- The worst score of the survey was for LSDs for 'Appropriateness of analyte concentration' (2.67).

Table 1: Average scores per scheme

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

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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 = 158 (= 98.8% 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	1.67	1.89	1.70	1.47	2.10	1.47	1.77	1.89	**1.73**	70 (37.8%)
Quantitative organic acids	1.75	1.68	1.88	1.88	1.90	1.90	1.95	1.92	**1.85**	44 (45.4%)
Quantitative amino acids	1.69	1.62	1.79	1.76	1.77	1.70	1.86	1.93	**1.76**	108 (47.4%)
Special assays - urine	1.68	1.65	1.72	1.75	1.72	1.71	1.78	1.90	**1.74**	68 (43.3%)
Special assays - serum	1.77	1.57	1.87	1.80	1.73	1.72	1.82	1.91	**1.77**	87 (42.9%)
Purines & pyrimidines	1.84	1.68	1.94	1.79	1.89	1.89	1.94	1.87	**1.85**	19 (36.5%)
Acylcarnitines	2.26	1.92	1.68	1.84	2.56	1.91	2.06	1.85	**1.99**	39 (35.8%)
Proficiency schemes	1.71	2.02	1.66	1.65	2.05	1.61	1.87	1.90	**1.81**	45 (44.1%)
Cystine in white blood cells	1.70	1.70	1.80	1.60	1.50	1.40	1.70	1.60	**1.63**	10 (27.0%)
Lysosomal storage disorders	1.88	2.08	2.67	2.08	1.75	2.05	2.26	1.96	**2.09**	25 (39.1%)
Congenital disorders of glycosylation	1.89	2.50	1.82	1.76	2.11	1.53	1.81	1.93	**1.92**	44 (43.1%)
Average for all schemes	**1.77**	**1.77**	**1.82**	**1.75**	**1.87**	**1.71**	**1.87**	**1.90**		

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Question 2 Do you have any other remarks, comments or suggestions for improvements?

- Number of responses = 73 (= 45.6% of all respondees).

Questions 3 to 8: Analytes in Quantitative Schemes

Q.3 Quantitative organic acids

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)	
methylcitrate	n = 3	Hexanoylglycine	n = 1
3-hydroxy-glutaric	n = 2	Tiglylglycine	n = 1
orotic acid	n = 2		
oxalic acid	n = 2		

Q.4 Quantitative amino acids

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)	
Arginosuccinic acid	n = 5	5-Aminolevulinic acid (delta aminolevuline acid)	n = 10
Sulphocysteine	n = 4	aspartylglucosamine	n = 3
Homocitrulline	n = 4	tryptophan	n = 2
		Arginisuccinate	n = 1
		1-methylhistidine	n = 1
		3-methylhistidine	n = 1
		Aspartic acid	n = 1
		Asparagine	n = 1
		Hydroxyproline	n = 1
		allo-isoleucine	n = 1
		phosphoethanolamine	n = 1
		saccharopine	n = 1

Q.5 Special assays - urine

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)	
Oxalic Acid	n = 4	succinylacetone	n = 1
methylmalonic acid	n = 3	5-OH-Indolic acid	n = 1
cystine	n = 2		
galactitol	n = 2		
Mevalonic Acid	n = 2		
S-sulphocysteine	n = 2		

Q.6 Special assays – serum

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)
biotinidase	n = 6	NONE
total carnitine	n = 4	
Acylcarnitine	n = 3	
DESMOSTEROL	n = 2	
DHA	n = 2	
SITOSTEROL	n = 2	
lathosterol	n = 2	

Q.7 Purines & pyrimidines

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)	
SAICAR	n = 3	Adenine	n = 1
Succinyladenosine	n = 2		
uridine	n = 2		

Q.8 Lysosomal Enzymes

Suggested Analytes to be added (>1 response)		Suggested analytes to be removed (all responses)	
alpha galactosidase	n = 4	alpha-Mannosidase	n = 1
ß-glucosidase	n = 3	beta-Mannosidase	n = 1
		ß-Glucosaminidase	n = 1
		ß-Glucuronidase	n = 1
		Iduronate-Sulphatase	n = 1
		galactosylceramidase	n = 1
		sphingomyelinase	n = 1
		all enzymes with known very low activities on lymphoblasts (viz, galactocerebrosidase, alfa iduronidase....)	n = 1

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

- Number of responses = 23 (= 14.4% of all respondees)

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

- Number of responses = 141 (= 88.1% of all respondees)