Separate meetings of DPT participants and none-DPT participants

Needs and deficits in Biochemical Genetic Testing in Europe

AIM

Develop outcome of first EU25 Best Practice Meeting towards Improvement and Expansion of Biochemical Genetic Testing

- Feedback and Comments to Interim report by National Representatives
- Determine how to ensure correctness of the data in order to write the definitive report

Needs and deficits in Biochemical Genetic Testing in Europe

- Critically evaluate Recommendations to overcome deficits, especially focused on the EUGT project

- Confirm / Modify the Recommendations
- Prioritise the Recommendations

"During the meeting in Prague, we have to define:
The role of national societies
How to train individuals, financed by Eurogentest
The guidelines for minimal laboratory services."
cited from Exec. Comm. April 2006

Recommendations to overcome deficits, especially focused on the EUGT project

1. Define basic standards / minimum core requirements / test repertoires in relation to size of country. This could be based on a minimum number of samples, requests / tests per annum, taking into account the need for quality markers, e.g. turnaround time and the importance of gate keeping for specimens sent away.

2. Identification of clusters of countries/sharing where workloads are very low. Exchange visits and / or workshops for the particular groups of countries should be promoted by the Eurogentest project.

3. Training initiatives for implementing new tests identified and potential role of Eurogentest to support and fund such initiatives. Eurogentest could promote initiatives for trainees to train in the more developed countries with some funding to support the training institution.

4. Reference laboratories should be identified at both the national and international level with proposals for how should they be financed.

Recommendations to overcome deficits, especially focused on the EUGT project

5. Stimulation of accreditation of laboratories by a scoping exercise to evaluate present situation throughout Europe and then working to pull together the best / minimum recommendations.

6. The EQA schemes themselves need to achieve accreditation.
A survey of the scope of Metabolic Physician and Biochemist Training across Europe should be initiated.

7. An Initiative similar to that taking place in the UK to scope the size of the problem, perhaps initially to collect data on number of patients with certain IMD disorders across Europe.

8. Expansion of EQA so that quality assessment materials is made easily available including the provision of cell banks for biological material from patients.

Recommendations to overcome deficits, especially focused on the EUGT project

9. Establishment of National registers of diagnosed cases. EUGT/ERNDIM should work together with existing national organisations such as those in the UK, Germany, Spain and Italy. In the absence of a national structure we should initiate a European wide action to help remedy this deficit.

10. Best Practice guidelines for methodology, minimum services and QA should be produced by ERNDIM/EUGT to provide the basis for local justification of increased budgets.

11. The advised recommendations and issues should be a Directive of the European Commission.

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