

MEETING TNO-PREVENTION and HEALTH, NVvHP & EUROLIGHT

25 November 2008, 15.30 hrs.

TNO Leiden, Wassenaarseweg 56

Representatives:	TNO	Dr. Astrid Chous Prof. Dr. Stef van Buuren Dr. Nico van Meeteren	Epidemiologist Section Physical Activity & Health Statistician & Consultancy Head Department Physical Activity & Health
	Eurolight	Colette Andrée,	CRP Santé Luxembourg, project coordinator Eurolight
	NVvHP	Peter Vriezen	Scientific Advisory Committee NVvHP Project Steering Committee Eurolight

Minutes of meeting

Meeting objectives: To establish whether and if so under which conditions TNO Prevention & Health can support the Nederlandse Vereniging van Hoofdpijnpatiënten in executing the Dutch 'branch' of the Eurolight national survey.
Further, to discuss possibilities for acquiring additional funding.

1. Introduction

TNO, NVvHP and Eurolight representatives introduced themselves and their role in the respective organisations. Details on the NVvHP (the Nederlandse Vereniging van Hoofdpijnpatiënten) can be found at www.hoofdpijnpatienten.nl; while all information on the Eurolight project can be found at www.eurolight-online.eu.

Colette Andrée initiated the Eurolight project and acts as project coordinator for the Luxemburg Centre de Recherche Publique (CRP) Santé. The project carries 40% subsidie from the EU Public Health Executive Agency (PHEA), recently renamed into Executive Agency for Health and Consumers. One of the key deliverables of the project is: to develop and validate an instrument (questionnaire) for gathering information on the (physical, emotional and socio-economic) impact of headache disorders, on patient's treatment satisfaction and their needs. Further, to pilot this instrument in ten EU countries.

As past president of the NVvHP, Peter Vriezen represents this organisation in several international activities. In this context he is member and rapporteur of the Eurolight project steering committee (PSC). Equally, he is responsible for the organisation of the Dutch 'branch' of the project. Over and above the original scope of the Eurolight project - which was limited to piloting the questionnaire amongst a representative sample of the members of the NVvHP - it has been decided to aim for piloting the questionnaire on population-based representative samples of some 6000-8000 persons in the age of 18-65 in all ten EU-countries. The current discussion is aimed to establish if and under what conditions TNO can execute this latter investigation.

2. Eurolight questionnaire

The design of the questionnaire has recently been completed. In its final form it is ready for a language validation into Dutch. During the meeting TNO received a copy of the (©copyright protected) final text. Colette Andrée mentioned that it can not be used by any other body without official permission of the Eurolight Steering Committee and the EAHC

CRP Santé will produce the required number of copies of the questionnaire for a Dutch survey..

3. Survey requirements

The following requirements were discussed:

- population-representative sample,
- resulting in a minimum of 400 to 500 completed questionnaires from headache patients aged 18-65 (estimated headache prevalence \geq 50%), preferably from migraine patients (estimated prevalence some 15-20%),
- equally sized control group
- estimated number of questionnaires to be sent out (if population based): 6000-8000 randomized population or region based addresses
- minimum response rate 30% should be opted for

- encoding of the completed questionnaires & quality assurance (double encoding or single encoding with controlled checking).
- timing of the survey: targeted starting point latest March 2009; targeted delivery of the encoded data to be submitted by end May 2009.

4. TNO services & cost aspects

TNO are invited to provide the following services:

- provide a population based /regional)representative sample of 6000-8000 people
- using questionnaires printed by CRP-Santé, to send these out,
- keep track of returns, send one reminder,
- encode the completed questionnaires using the CRP-Santé provided encoding mask and to the encoding 'rules' handbook delivered by CRP
- encode the data with an adequate quality control, preferably by double coding or single encoding with controlled checking
- return the encoded data via a CRP delivered software for submitting the encoded data to CRP
- optional : propose data analysing specified data analysing for the Netherlands and produce respective publications this

5. Opportunities for additional funding

Although previously TNO (Mr. S. Dhondt).had suggested that TNO might be able to find additional sources for funding, the current TNO representatives saw little or no opportunities at this point. Consequently, the NVvHP will have to make all efforts to find funding, either from VWS, or from other sources that might have an interest in the results from this project (**action PV**).

6. Any other aspects

- TNO will advise on the need, if any, for ethical and or data protection approval.
- Eurolight will provide the covering participant information letter and - if required - a consent form.
- The NVvHP will act as contract party for TNO.
- The Eurolight project develops this measuring instrument; which is foreseen to be used by the EU as a standard instrument for the future analysis.in the field of neurological headache disorders.

7. Where do we go from here?

TNO (Stef van Buuren) are to provide an initial cost estimate by Friday 28 November, in time for NVvHP to include this in their application for extra VWS-funding within the framework of the new strategic planning for patient organisations (deadline early December).

TNO stressed that a firm order should be received by early January in order to fit this time schedule.