

The CAPABILITY Project

I. Nippert

Trolleholm, Sweden
May 7 – 9th, 2007



International Partners



Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention:



**CAPABILITY: a 3 year model project
(2007-2009)**

Improving quality of genetic counselling, clinical validation and clinical utility

Public Health

Generating shared skills and knowledge about genetic testing

Education

**CAPABILITY is a Specific Support Action (SSA)
for EuroGentest units 3 (Public Health)
and 6 (Education)**

www.eurogentest.org



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Objectives

- **Establish a network of quality across Europe**
- **Promote research, proper utilization, quality control and assurance and adequate management of genetic services**



Objectives

- Establish procedures and guidelines for the validation of methods and technologies
- Provide genetic healthcare workers, the end-users and healthcare authorities with a portfolio of quality-assured information sources and informatic tools that are subject to validation and quality procedures

In addition, EuroGentest aims at becoming a model for similar initiatives in developing countries and will provide appropriate support for their development.



CAPABILITY is a 3-year model project developed jointly by units 3 & 6.

UNIT 3: CLINICAL GENETICS, COMMUNITY GENETICS AND PUBLIC HEALTH



Unit Leader: Ulf Kristoffersson, Head of the Department of Clinical Genetics at the University Hospital in Lund in Sweden.



Co-leader: Joerg Schmidtke, Director of the Institute of Human Genetics at Hannover Medical School.



CAPABILITY is 3-year model project developed jointly by units 3 & 6.

UNIT 6: EDUCATION



Unit Leader: Alastair Kent, Director of GIG and President of the European Alliance of Genetic Support Groups.



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CAPABILITY

- **Funded by FP6:** **EU Contract No. 037275**
- **Starting month:** **January 2007**
- **Kick-off meeting:** **May 7-9, 2007**
Trolleholm Castle,
Trolleholm ,Sweden



EUROPEAN
COMMISSION

Community Research

FP6

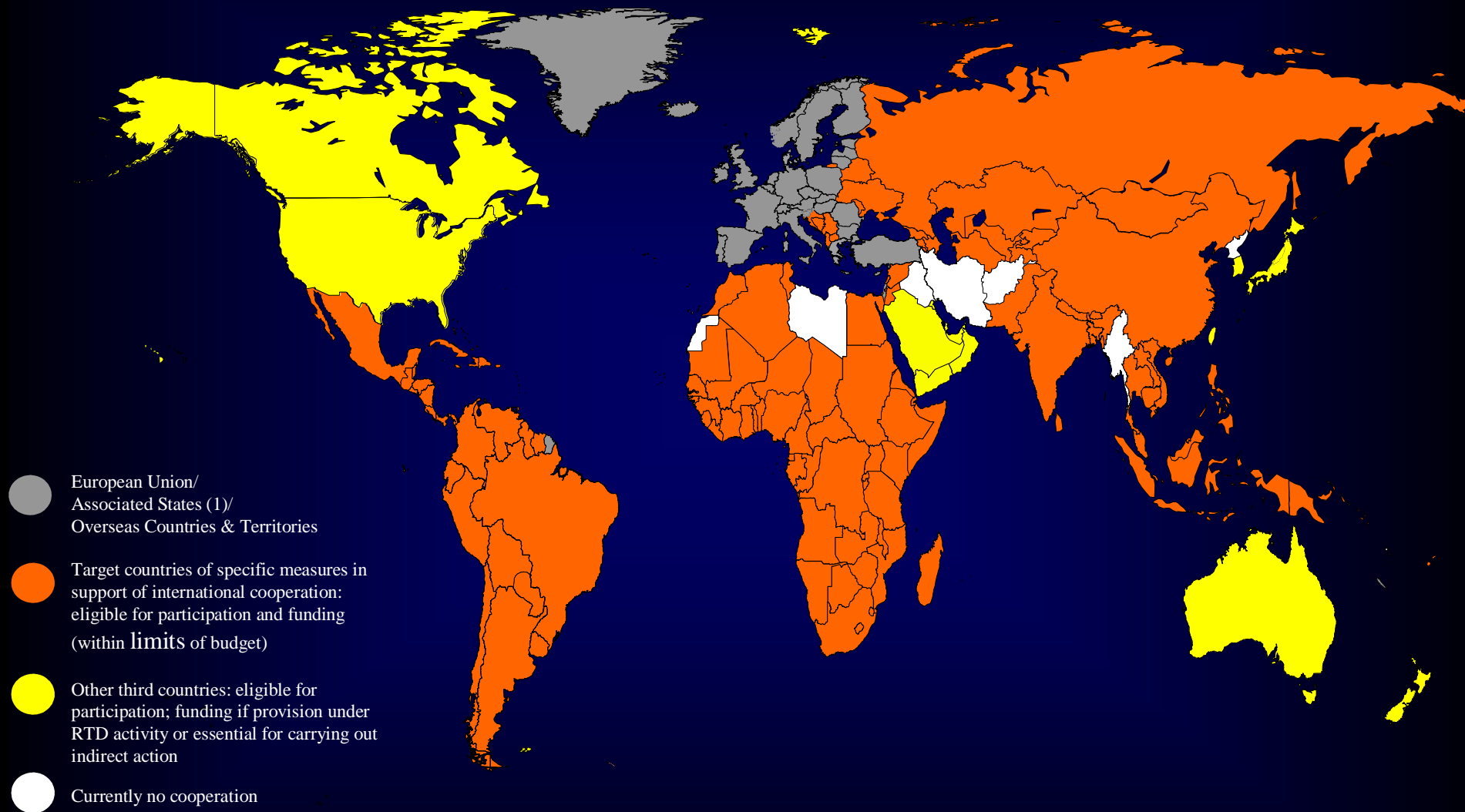
ALL RESEARCH TOPICS WERE OPEN FOR 3rd COUNTRY PARTICIPANTS

- **At least 3 organizations from EU and/or associated states**
- **In addition, “third country” participants were welcome**
- **Partners from the INCO target countries, could receive funding**



SIXTH FRAMEWORK PROGRAMME 2002-2006

Participation by legal entities from third countries



Workshop 1 serves several functions:

- it will host the 1st meeting of the Working Group
- it will present the CAPABILITY agenda to involved key stakeholders, observes from New Member States and other third countries
- participant 1 will prepare the proceedings of the workshop and publish them on the CAPABILITY website

CAPABILITY Participants...





INSTITUTE OF
LABORATORY MEDICINE
på svenska

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Ulf Kristoffersson, Head of the
Department of Clinical Genetics at the
University Hospital in Lund in Sweden.
(Participant 2)



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- Portrait
- Notfallrufnummern
- Informationen für Patienten und Angehörige
- Verkehrsanbindung
- Lageplan
- Spenden und Fördern
- Veranstaltungen
- Kliniken A-Z
- Institute A-Z
- Zentrale Einrichtungen A-Z

Aktuelle Informationen der MHH

weitere Presseinformationen finden Sie hier ▶

Neue Hoffnung im Kampf gegen Aids

MHH-Wissenschaftler entwickeln Wirkstoff / Minister Stratmann lobt Infektionsforschung

mehr... ▶

Volkkrankheit Depression: Was man wissen sollte und was man tun kann

Sonderveranstaltung der MHH-Patientenuniversität am 12. Mai für jedermann

mehr... ▶

Neue Hoffnung im Kampf gegen Aids

MHH-Forscher stellen Konzept bei Pressegespräch mit Minister Stratmann am 2. Mai vor

mehr... ▶

M_HH Servicebox

Suche 🔍
erweiterte Suche

Schnellzugriff für Zielgruppen

Blutspende in der MHH
 Blut spenden und Leben retten? Weitere Informationen finden Sie beim Blutspendedienst der MHH.
mehr...



Joerg Schmidtke, Director of the Institute of Human Genetics at Hannover Medical School.
(Participant 3)

Genetic Interest Group
Working to benefit all people affected by genetic disorders

EDUCATION VIDEO CLIPS INTERACTIVE ZONE

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LATEST NEWS FROM GIG

Find out what is happening in the world of genetics including: New genetic researches, Genetic conferences, Supporting aid activities, The latest genetic press releases and more

You can also get the latest genetic news at our live Google news page > [Latest News on Genetics](#)

Senior Policy and Research Manager

We need a Senior Policy and Research Manager to coordinate our project based activities, and to integrate these with our advocacy and strategic campaigning role. Do you want to make a real difference to the lives of those living with intractable disease? Can you work in a fast moving and sometimes controversial area of science and health policy? If so, this could be the job for you.

[Job Advert](#)
[Job Description](#)

Please send your CV and covering letter to Cathrine Agnew, Office Manager cathrine@gig.org.uk

Patient Information Leaflets

New leaflets developed as part of GIG's role in the Eurogentest Project are now online and available. They cover topics surrounding genetic testing, and also basic genetic inheritance patterns.

How helpful is our site?
Comment:
Your email:
Add to mailing list:
Who are you?
Choose..
Send Feedback



Alastair Kent, Director of GIG and President of the European Alliance of Genetic Support Groups.
(Participant 4)



NATIONAL HEALTH
LABORATORY SERVICE

The Department of Human Genetics

School of Pathology, Faculty of Health Sciences,
University of the Witwatersrand



Arnold L. Christianson

The Clinical Diagnostic and Genetic Counselling
Division

Medical Genetic Services

(Participant 5)




جمهورية مصر العربية
وزارة الصحة و السكان

اتصل بنا
 خريطة الموقع
 ريدود

أدلة الوزارة | عن الوزارة | إحصائيات

MOHP
 بحث | أدوية | التثقيف الصحي | هيئات ومراكز الوزارة

الأخبار:

- ◆ 10 آلاف كتيبات من فرنسا لمصر
- ◆ إحتفال وإنشاء 59 مجمع طبي بالمعافظات
- ◆ خمس وحدات للمناظير وإفتتاحات بالمنيرة

الحركة الإستثنائية للترشيح
 للخصصات الطبية المختلفة مايو
2006

- ◆ جمعية الصحة العالمية الثامنة و الخمسين تنبج اللوائح الصحية و الدولية
- ◆ دراسة عناصر تدبير الخدمة
- ◆ نتيجة الممولين بالزمالة





**Randa Kamal Abdel-Raouf, Children with
 Special Needs Department.
 (Participant 6)**

Study sites in Egypt: Cairo & Alexandria



Hospital de Pediatría S.A.M.I.C.
"Prof. Dr. Juan P. Garrahan"

Buenos Aires
Argentina



Cristina Barreiro, Medical Genetics Service.
(Participant 7)



Co-ordinator: Irmgard Nippert,
Women's Health Research,
Department of Genetics.
(Participant 1)

Co-ordination Office Münster



Karina Bertmaring
Tel. +49 251 / 83 584 12

Secretariat



Luis Robles-Treviño
Tel. +49 251 / 83 584 65

**Website,
IT-Communication,
Documentation**



International Partners



CAPABILITY Advisory Board...



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The PHG Foundation has been established as a new charitable organisation to take the place and to continue the work of the Public Health Genetics Unit as from 1 April 2007.

The Foundation will be dedicated to the translation of biomedical sciences, but in particular of genome-based knowledge and technologies, in order to benefit the health of individuals and populations.



- Latest headlines change display >>
- EuroGenest draft recommendations on genetic counselling
 - Gene therapy for eye disorder
 - Study casts doubt on candidate genes for heart disease
 - European human embryonic stem cell registry
 - US moves closer to prohibiting genetic discrimination
 - Embryo screening for hereditary breast cancer
 - HFEA launches consultation on human-animal hybrid embryos
 - Launch of UK National Stem Cell Network

Recent highlights



Ron Zimmern, Director PHG Foundation, Cambridge, UK.



Pan American Health Organization
Regional Office of the World Health Organization

Vaccination
Vaccination Week in the Americas
21-28 of April 2007 *An Act of Love*

VEA ESTA PÁGINA EN ESPAÑOL

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PAHO Publishing

Welcome to PAHO Publishing, gateway to health care publications and information resources related to the Western Hemisphere's most pressing public health issues. The site pulls together scientific articles, books and book reviews, expert opinions, testimonials, statistical data, and links from authoritative sources, and puts them in the hands of health care workers and the general public in easy to use formats.

Many documents are available in full-text and free of charge. Other documents feature a detailed synopsis and ordering information. New documents and materials are added periodically.

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World Health Day 2007

Publication: Well-Being

Pan American Journal of Public Health

- » www.journal.paho.org
- » [Past Issues](#)
- » **Information for Authors:**
- [Books](#)
- [Journal](#)



Victor B. Penschazadeh, Program on Genetics in Public Health and Human Rights, Pan American Health Organization (PAHO)



MARY SEACOLE
1805 - 1881

VOTED THE GREATEST BLACK BRITON

ABOUT MARY SEACOLE | STATUE APPEAL | CENTRE FOR NURSING PRACTICE | CONTACT | RESOURCES

MARY SEACOLE WAS A NURSE AND CARER WHO WENT TO WAR IN THE 1850'S. Her *adventures* took her far from home, the island of Jamaica in the Caribbean. She met members of the *British Royal Family*, and was *cheered by thousands* of people in London. She wrote a book about her life, telling how she helped soldiers during the Crimean War.

LATEST NEWS
FORTHCOMING EVENTS

MARY SEACOLE 1805-1881
Jamaican Nurse, Victorian Heroine and Crimean War Heroine

PLACES WHERE MARY SEACOLE IS REMEMBERED

RACE IN VICTORIAN BRITAIN

USA ATLANTIC OCEAN JAMAICA

MEDICINE IN THE VICTORIAN AGE

HISTORY OF THE CRIMEAN WAR

1805
TIMELINE
1881

MARY'S JOURNEY: [interactive map]
MEDICINE IN THE VICTORIAN AGE
HISTORY OF THE CRIMEAN WAR
GALLERY



Elizabeth Nneka Anionwu, RN HV Tutor PhD CBE, Professor of Nursing, Head of Mary Seacole Centre for Nursing Practice, Thames Valley University, London, UK.



Advisory Board



Hilary Harris, MD, is the senior partner in a South Manchester general practice, UK.



International Partners



The Advisory Board will

- Participate actively in all international workshops & some meetings,
- Comment the draft versions of the reports, the demonstration project design, its outcome data and advise on the final model approach

Evaluator

March of Dimes, Global Programs White Plains, USA



Represented by Christopher Howson – Vice President

<http://www.marchofdimes.com/professionals/>



Observers

- **World Alliance of Organizations for Prevention and Treatment of Genetic and Congenital Conditions (WAO) - Ysbrand Poortman**
- **Central Europe and Eastern Countries Genetic Network Gdansk, Poland (Member of the *EuroGentest* Advisory Board) - Grzegorz Wegrzyn**
- **Instituto de Biomedicina Universidad Católica de Santiago de Guayaquil, Guayaquil, Ecuador (Advisor to unit 3 *EuroGentest*) – Peter Chedraui**

Observers



- **Clinical Genetic Service Centre, Department of Health, Hong Kong Special Administrative Region – Stephen T.S. Lam**

CAPABILITY Working Group

15 experts:

- clinical genetics
- genetic epidemiology
- health service research
- health technology assessment
 - evidence-based medicine
 - molecular genetics
- parent and patient organisations
- primary care providers
- public health genetics
- ethics



**Multidisciplinary
International**

CAPABILITY Components

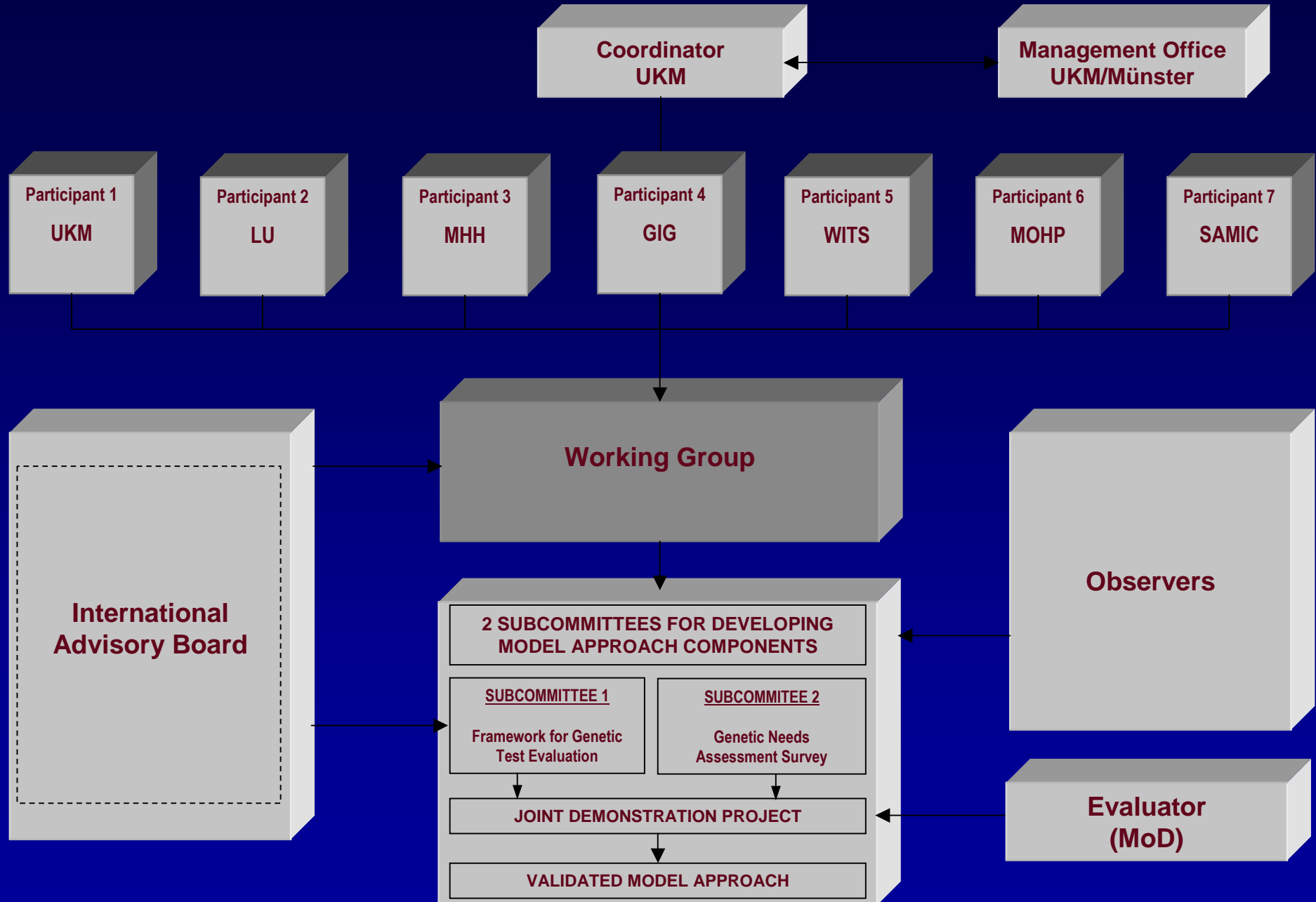


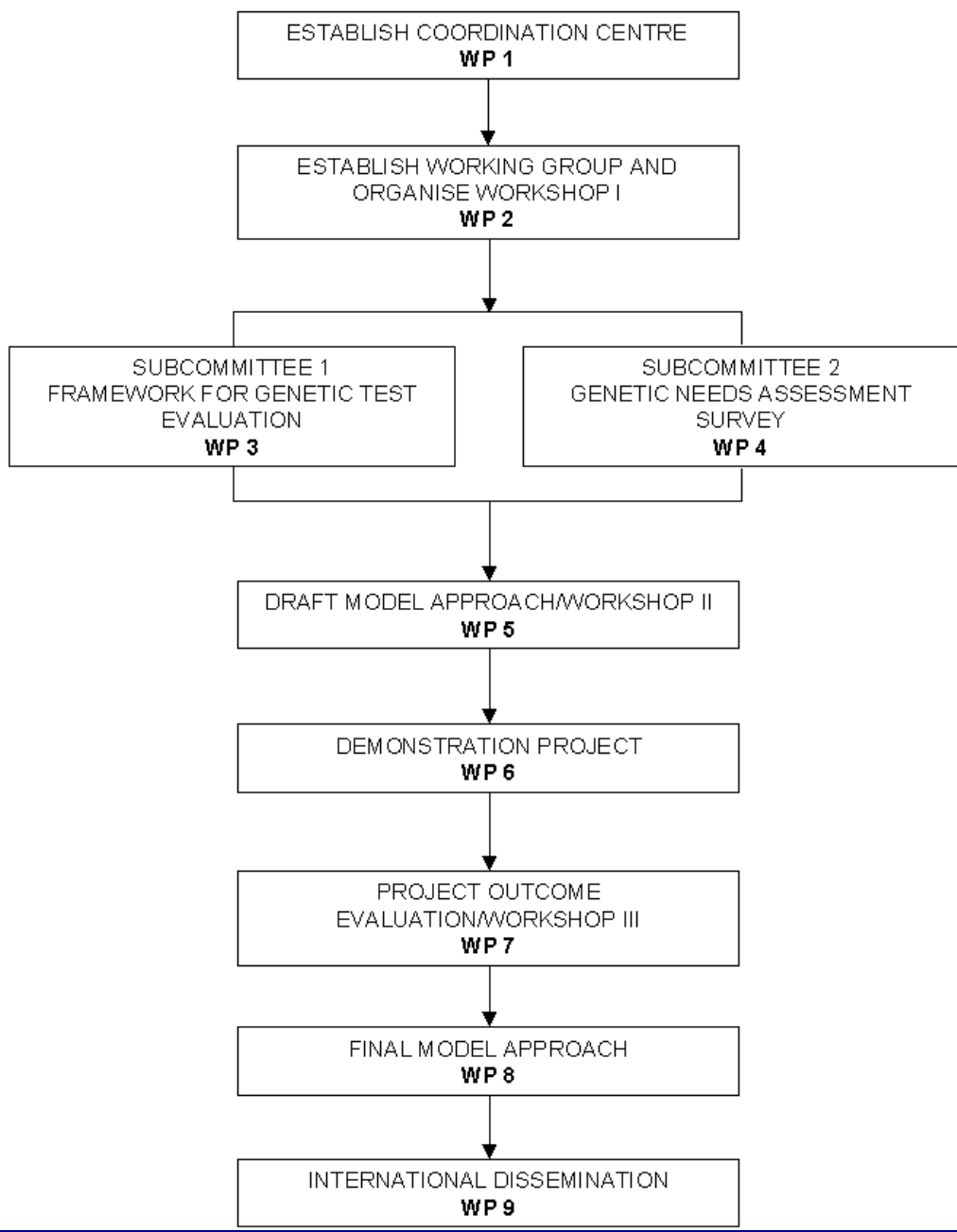
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Project Management and Structure

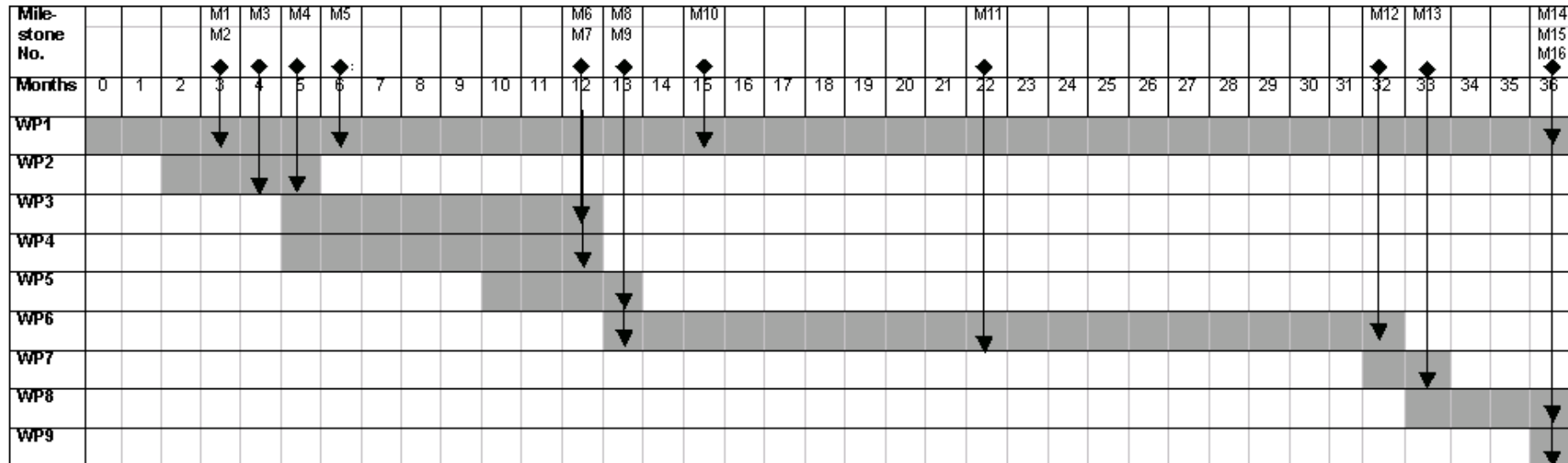
Specific Support Action
CAPABILITY





7.2 Work planning and timetable

Specific Support Action
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Agenda Milestones

- M1 = Set-up coordination centre
- M2 = Website
- M3 = Workshop I
- M4 = Working protocols for subcommittees
- M5 = Workshop I presentations/proceedings published on CAPABILITY website
- M6 = Draft report: Framework for genetic test evaluation
- M7 = Draft report: recommended capacity building
- M8 = Workshop II
- M9 = Start demonstration project

- M10 = Workshop II presentations/proceedings published on CAPABILITY website
- M11 = Mid-term review demonstration project
- M12 = Demonstration project completed
- M13 = Workshop III
- M14 = Report: completed
- M15 = Final Report available on CAPABILITY website
- M16 = International dissemination of report

Workpackage 3: Subcommittee 1

Subcommittee 1:

- will systematically review existing approaches genetic test evaluation with an emphasis on clinical utility of tests with a high potential to be implemented in general practice care and prevention
- included in the review will be genetic test evaluation approaches developed in the USA such as ACCE and EGAPP and the approaches of the United Kingdom Genetic Testing Network

Workpackage 3: Subcommittee 1

- will draw on the reviews done so far by Unit 3 of EuroGentest. R. Zimmern will act a special advisor to this committee
- will draft an analytic framework (=questions that need to be addressed) for evaluating genetic test application in different settings
- Participant 3 will prepare the report for the CAPABILITY Working Group

Subcommittee 1

- **Chair:** J. Schmidtke
- **Special Advisors:** R. Zimmern, N.N
- **Participants:** A. Christianson
I. Nippert
- **Deliverable:** Draft Report
(month 12)

Workpackage 4: Subcommittee 2

Subcommittee 2:

- will develop criteria for a systematic needs assessment survey
- will identify priorities for capacity building by needs assessment survey
- will recommend capacity building mechanisms
- Participant 5 will prepare the report for the **CAPABILITY Working Group**

Subcommittee 2

- **Chair:** A. Christianson
- **Special Advisors:** E. Anionwu, H. Harris
V. Penschaszadeh,
N.N.
- **Participants:** C. Barreiro, A. Kent
I. Nippert, R. Raouf
- **Deliverable:** Draft Report
(month 12)

CAPABILITY Methods

- Bring together key stakeholders for the systematic transfer of genetic testing from research into clinical practice by means of frameworks for an evaluation process agreed by academics, clinicians and policy makers
- Seek agreement on standards

CAPABILITY Objectives

- Identify priorities for capacity building for providing appropriate services by systematic needs assessment surveys
- Evaluate the approach via demonstration projects to be conducted at 4 target sites

**CAPABILITY will use knowledge
gained from previous evaluation
projects**



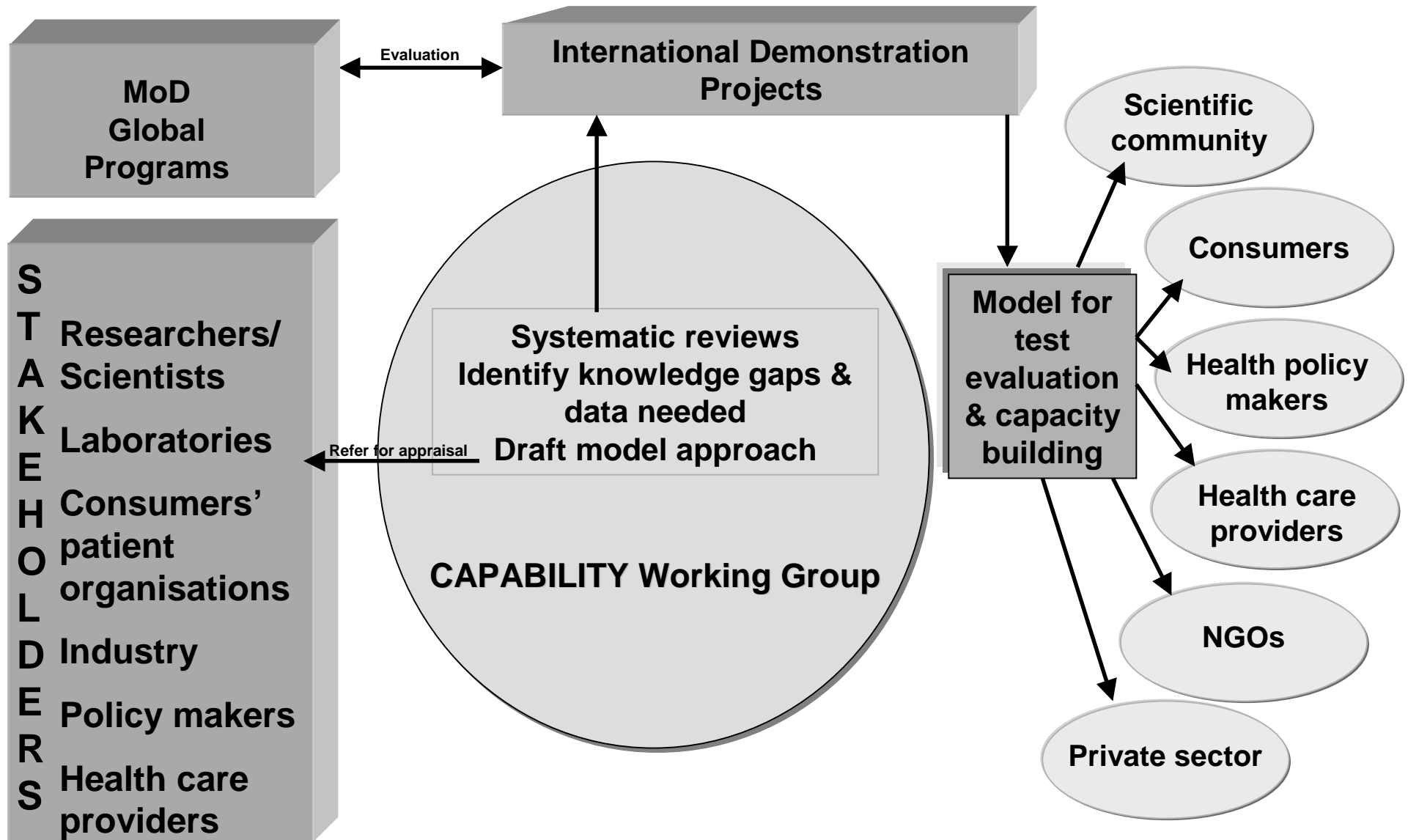
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**A key objective of CAPABILITY is
to engage the interest of a wide
range of stakeholders**



CAPABILITY Overview



CAPABILITY Networking Goals

- To promote an internationally shared set of basic quality standards for genetic testing and the provision of appropriate genetic services in primary care and public health
- To lay the foundation for a sustained collaboration, that will continue and be open for international partners
- To start collaboration by joint projects

CAPABILITY will help

- To promote proper implementation of new genetic knowledge, quality assurance and adequate provision of genetic services at a global level
- To identify present and future needs for capacity building mechanisms

CAPABILITY will help

- To avoid the opportunistic introduction of underevaluated technology driven genetic testing and concentrating on those areas where greatest gain for health is to be secured

CAPABILITY will help

- To create the expectation at all levels of health care systems that genetic tests should be subject to a systematic evaluation process prior to translation into general practice

Thank you
for your attention!



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