

CAPABILITY Workshop III

TROLLEHOLM

November 30th - December 3rd 2009



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

Tentative programme Trolleholm CAPABILITY meeting November 30th - December 3rd 2009

Monday Nov 30	Tuesday Dec 1	Wednesday Dec 2	Thursday Dec 3
Arrival day Overnight at Hotel Concordia, Lund centre	8.30 Departure for Trolleholm 9.30 Morning coffee 10.00 CAPABILITY <ul style="list-style-type: none"> - Housekeeping, U. Kristoffersson - CAPABILITY overview, I. Nippert Demonstration projects/Final <ul style="list-style-type: none"> - R. Raouf - C. Barreiro - A. Christianson - J. Schmidtke - Lessons learned 	9.30 Strategy discussion CAPABILITY/GenTEE survey: Genetic Testing in Emerging Economies (GenTEE) <ul style="list-style-type: none"> - Content of the survey - Collaboration with the EU - Institute for Health and Consumer Protection (IHCP) - Timeline & meetings 	8.30 CAPABILITY 2nd report for EC <ul style="list-style-type: none"> - Auditing - Technical information
	13.00 Lunch	12.00 Lunch	12.00 Lunch
	14.00 CAPABILITY final report <ul style="list-style-type: none"> - Needs Assessment final recommendations; A. Christianson - Clinical Utility final recommendation; J. Schmidtke - Final report – Discussion - Final report - Dissemination 	13.30 Strategy discussion for CAPABILITY/GenTEE survey <ul style="list-style-type: none"> - Protocols - Contracts 15.45 Coffee break 16.15 CAPABILITY/GenTEE survey continued Legal aspects, what to address in the survey; M. Christianson	Departure
19.00 Get together and dinner	19.00 Dinner	19.00 Dinner	



CAPABILITY Workpackages 1-4

No.	Workpackage title	Lead contractor No.	Start month	End month	Deliverable(s) No.
WP1	Co-ordination centre	1	0	36	1, 2, 6, 12, 18
WP2	Establish Working Group/ Workshop I	1-7 All	2	5	3, 4, 5
WP3	Development of analytic framework for genetic test evaluation	1, 2, 3, 5, 7	5	12	7
WP4	Genetic needs assessment survey	1, 4, 5, 6, 7	5	12	8



CAPABILITY Workpackages 5-9

No.	Workpackage title	Lead contractor No.	Start month	End month	Deliverable(s) No.
WP5	Draft model approach/ Workshop II	1-7 All	10	17 (delayed)	9, 10, 11
WP6	Demonstration project	1-7 All	13	32 (delayed?)	13, 14, 15
WP7	Project outcome evaluation/ Workshop III	1-7 All	32	35/36 (delayed)	16, 17
WP8	Final model approach	1-7 All	33	36	19
WP9	International dissemination	1-7 All	36	36	20

CAPABILITY Deliverables months 1-18

No.	Deliverable title	Due date	Actual date
D1	Co-ordination centre fully established	M3	M4
D2	IT tools for communication implemented	M3	M4
D3	Working Group established (Workshop I)	M3	M5
D4	Protocols for developing an analytical framework for genetic test evaluation established	M5	M5
D5	Protocols for needs assessment survey established	M5	M5
D6	Workshop I proceedings/ presentations available on CAPABILITY website	M6	M6
D7	Report: Framework for test evaluation	M12	M13
D8	Report: Needs assessment survey and capacity building priorities	M12	M13
D9	Draft model approach	M13	M17
D10	Workshop II	M13	M17



CAPABILITY Deliverables months 19-36

No.	Deliverable title	Due date	Actual date
D11	Revised model approach	M14	M22
D12	Start: demonstration project	M13	M13
D13	Workshop II proceedings/ presentations available on CAPABILITY website	M15	M18
D14	Mid-term review demonstration project	M22	M27
D15	Demonstration project completed	M32	M32
D16	Demonstration project report	M33	M33
D17	Workshop III	M34	M35/36
D18	Model Approach Report: completed	M36	M36
D19	Report available on CAPABILITY website	M36	M36
D20	International dissemination of report	M36	M36



D1

Co-ordination Office



Karina Bertmaring
Secretariat



Christoph Ries
IT & Communications
riesc@uni-muenster.de

New address:
Niels-Stensen-Str. 14
48149 Münster
Germany



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

D2 IT tools for communication implemented



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



[Home](#) | [Participants](#) | [Expert Advisors](#) | [Working Group](#) | [Demonstration Project](#) | [Meetings & Proceedings](#) | [Documents](#)

[About us](#)
[Links](#)
[Contact](#)
[Legal Notice](#)

HIGHLIGHTS

Available now on CAPABILITYNET

"Genetic Services in Egypt - Current Situation and Needs Assessment"
[click here](#)

CAPABILITY

CAPABILITY is a 3-year model project developed jointly by units 3 (Clinical Genetics, Community Genetics and Public Health) and 6 (Education) of the Network of Excellence: Genetic Testing in Europe Network for test development, harmonization, validation and standardization of services (EuroGenTest) and by leading experts from: Argentina, Egypt and South Africa, the latter being currently engaged in major development projects to integrate genetic services in primary care and prevention in their countries.

CAPABILITY will:

- develop an analytic framework for evidence-based genetic test evaluation including the domains: efficacy (evidence of utility in controlled settings) and effectiveness (evidence of utility in real settings), identify priorities for capacity building by a systematic needs assessment survey and
- validate the project's approach by means of a demonstration project.

CAPABILITY's overall objectives are to contribute to the efforts to establish and sustain a worldwide harmonisation process for quality standards for the integration of genetic test/genomic knowledge applications into practice and prevention and to serve as a model project for successful, sustainable collaboration between EU research centres and centres from developing countries.

The following challenges are common to both EU and middle income countries:

1. The need to develop an evidence-based evaluation process for genetic tests or other applications of genomic knowledge in transition from research into practice.
2. The need for capacity building to enable health care systems to integrate adequately genetic/genomic applications with proven clinical utility into practice and prevention.
3. The need to establish an evidence-based implementation process for genetic/genomic knowledge from research into routine practice, including the review of testing practices, to ensure quality standards of services

CAPABILITY is a first step to address these challenges.

News



CAPABILITY
Third workshop
December 1 - 3 2009
Trolleholm Castle
Trolleholm Sweden



CAPABILITY was presented at the 4th International Conference on Birth Defects and Disabilities in the Developing Countries. The Conference was held in New Delhi, India from Oct 4th to Oct 7th, 2009.

[Programme](#)

Copyright CAPABILITY Project 2007. Legal Notice - EC Contract no. - FP6-037275



D3

CAPABILITY Workshop I



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



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



Home
Participants
Expert Advisors
Working Group
Demonstration Project
Meetings & Proceedings
Documents

DNA

About us

Links

Contact

Legal Notice

CAPABILITY Workshops



Capability Evaluation Meeting
Place: Johannesburg and Honeyguide Camp (Mpalanga Province), South Africa
Date: March 25-30, 2009

[Agenda](#)
[Presentations](#)



CAPABILITY workshop II
Place: Oxford, UK
Date: May 21-23, 2008

[Agenda](#)
[Presentations](#)



CAPABILITY workshop I
Place: Trolleholm Castle, Sweden
Date: May 7-9th, 2007

[Agenda](#)
[Presentations](#)

DRAFT REPORT



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



CAPABILITY Subcommittee 1 Draft Report

Framework for test evaluation

A comparison of criteria for clinical validity and utility in various national and international frameworks

Jörg Schmidtke on behalf of Subcommittee 1

Hannover Medical School, Institute of Human Genetics, Carl-Neuberg-Str. 1, 30625

Hannover, Germany

Schmidtke.Joerg@mh-hannover.de



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

D8 *Report: Needs assessment survey and capacity building priorities*

HEALTH CARE NEEDS ASSESSMENT FOR MEDICAL GENETIC SERVICES IN MIDDLE- & LOW-INCOME NATIONS

ARNOLD CHRISTIANSON

Division of Human Genetics, National Health Laboratory Service &
University of the Witwatersrand,
JOHANNESBURG, South Africa.
arnold.christianson@nhls.ac.za

NEEDS ASSESSMENT CAPABILITY ARGENTINA

CHRISTINA BARREIRO

Hospital de Pediatria Juan P. Garrahan, S.A.M.I.C.
Buenos Aires, Argentina
cbarreiro@garrahan.gov.ar

all available
on website

GENETIC SERVICES IN EGYPT: CURRENT SITUATION AND NEEDS ASSESSMENT

RANDA KAMAL A. RAOUF

Professor of Pediatrics,
Institute of Postgraduate Childhood Studies
Ain-Shams University
Cairo, Egypt



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

D10

CAPABILITY Workshop II



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

CAPABILITY
South African Report
Greater Sekhukhune Capability Outreach
Project

(GraSCOP)

Arnold Christianson

Division of Human Genetics

National Health Laboratory Service

&

University of the Witwatersrand

Johannesburg, South Africa.





EGYPT

Community Education in Health Aspects of Genetics/ A Capacity Building Project



Randa Kamal A. Raouf

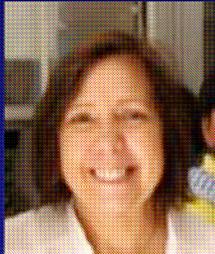
Prof. of Pediatrics – Institute of PGCS

Ain Shams University



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

CAPABILITY Argentina



Barreiro C.



Bidondo MP



Torrado MV



Garrido J.



Teiber ML



Luna A.



Acevedo E.



Elmeaudy P.



Rodriguez J.



Deurloo J.



Corvoisier J.



De Castro F.



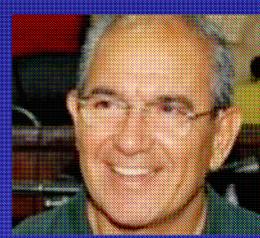
Gutierrez E.



Dellamea C.



Picón Cl.



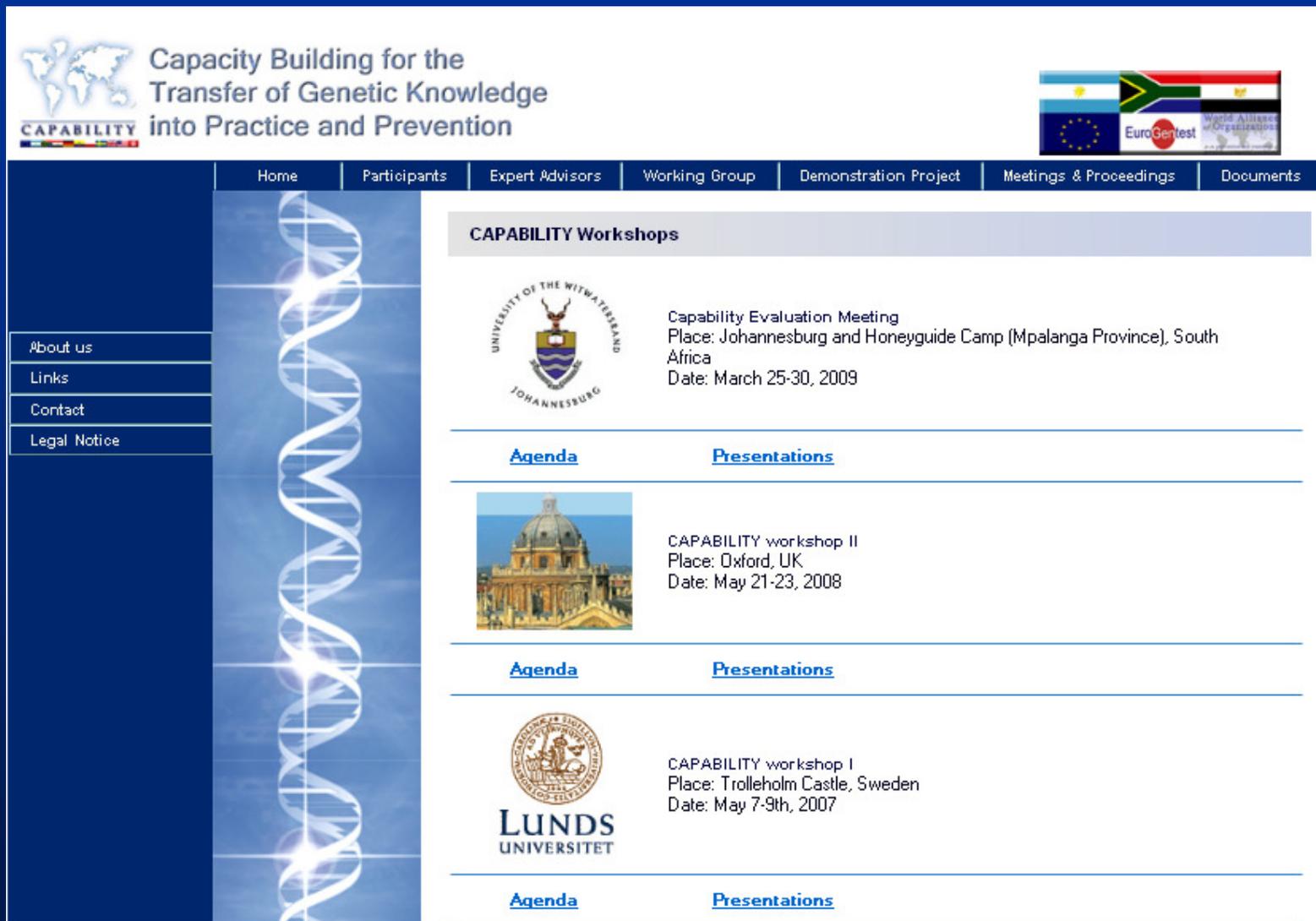
Picón Ce



Torres K.



D13 Workshop II proceedings/ presentations available on CAPABILITY website



The screenshot displays the CAPABILITY website interface. At the top left is the CAPABILITY logo, which includes a world map and the text "Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention". To the right of the logo are flags for Argentina, South Africa, and the European Union, along with logos for EuroGenest and the World Alliance of Organizations. A navigation menu below the header includes links for Home, Participants, Expert Advisors, Working Group, Demonstration Project, Meetings & Proceedings, and Documents. On the left side, there is a vertical DNA double helix graphic and a sidebar menu with links for "About us", "Links", "Contact", and "Legal Notice". The main content area is titled "CAPABILITY Workshops" and lists three workshops:

- Workshop 1:** CAPABILITY workshop I, Place: Trolleholm Castle, Sweden, Date: May 7-9th, 2007. Includes logos for the University of Witwatersrand and Lunds Universitet. Links for [Agenda](#) and [Presentations](#) are provided.
- Workshop 2:** CAPABILITY workshop II, Place: Oxford, UK, Date: May 21-23, 2008. Includes a photograph of a building. Links for [Agenda](#) and [Presentations](#) are provided.
- Workshop 3:** Capability Evaluation Meeting, Place: Johannesburg and Honeyguide Camp (Mpalanga Province), South Africa, Date: March 25-30, 2009. Includes the University of Witwatersrand logo. Links for [Agenda](#) and [Presentations](#) are provided.

D14 *Mid-term review demonstration project*



D14 *Mid-term review demonstration project*

Evaluator

The CAPABILITY consortium will implement an external independent audit to evaluate the mid-term outcome of its demonstration project. The March of Dimes' Global Programs unit has agreed to act as evaluator. To keep its independence from the CAPABILITY project, MoD Global Programs will cover its own expenses for personnel costs and travel necessary to conduct the evaluation. The evaluation report will be available for the CAPABILITY consortium and the European Commission.



Christopher Howson
[March of Dimes - Global Programs](#)



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

CAPABILITY Deliverables months 19-36

No.	Deliverable title	Due date	Actual date
D11	Revised model approach	M14	M22
D12	Start: demonstration project	M13	M13
D13	Workshop II proceedings/ presentations available on CAPABILITY website	M15	M18
D14	Mid-term review demonstration project	M22	M27
D15	Demonstration project completed	M32	M32
D16	Demonstration project report	M33	M33
D17	Workshop III	M34	M35/36
D18	Model Approach Report: completed	M36	M36
D19	Report available on CAPABILITY website	M36	M36
D20	International dissemination of report	M36	M36





Thank you for your attention!



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