



Guidelines
International
N e t w o r k
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ANNUAL REPORT

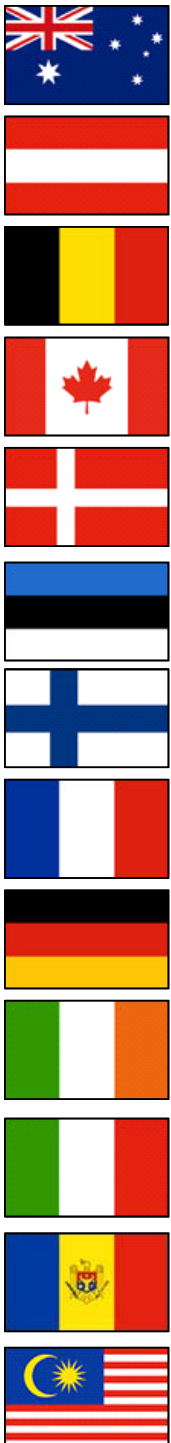
November 2003 – October 2004

Guidelines International Network

is a Scottish Guarantee Company, established under Company Number SC243691
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Registered Office: J. & H. Mitchell W.S., 51 Atholl Road, Pitlochry, Perthshire PH16 5BU, Scotland

Administrative Secretariat: Agency for Quality in Medicine, Wegely Str. 3, 10623 Berlin, Germany



**Guidelines
International
Network**

www.guidelines-international.net

**Membership
October 2004**



Agency for Health Research & Quality AHRQ, US
 Agency for Quality in Medicine AZQ, DE
 AGREE Collaboration
 Association of Scientific Medical Societies AWMF, DE
 Basque Office for HTA OSTEBA, ES
 Belgian Center for Evidence based Medicine CEBAM, BE
 Berlin Chamber of Physicians, DE
 Center for Health Policies and Services CPSS, RO
 Center for Reviews & Dissemination York CRD, GB
 Clinical Epidemiology Center Lausanne CapiC, CH
 Danish Center for Evaluation and HTA DACEHTA, DK
 Directorate for Health and Social Affairs, NO
 Dutch Association of Comprehensive Cancer Centres ACCC, NL
 Dutch College of General Practitioners NHG, NL
 Dutch Institute for Healthcare Improvement CBO, NL
 evidence.at - Austrian Ass. for Quality in Healthcare, AT
 Estonian Health Insurance Fund, EE
 Federal Committee of Physicians and Sickness Funds FCPS, DE
 Finnish Medical Society Duodecim, FI
 Finnish Office for HTA FINOHTA, FI
 Flemish College of General Practitioners WVVH, BE
 German Federal Institute for Quality Assurance, DE
 HTA Unit, Ministry of Health Malaysia, MY
 Institute for Quality in Healthcare IQS, PT
 Italian Evidence-Based Medicine Group GIMBE, I
 J. Briggs Inst. for Evid. Based Nursing & Midwifery, AU
 Josep Laporte Library Foundation, Barcelona FBJL, ES
 Ministry of Health-Refik Saydam Hygiene Centre Presidency, TR
 Moldovan Association of Perinatal Medicine, MD
 Nat. Agency for Accred., Eval in Healthcare ANAES, FR
 Nat. Board of Health and Welfare (Socialstyrelsen), SE
 National Federation of French Cancer Centres FNCLCC, FR
 National Institute for Clinical Excellence NICE, GB
 National Institute of Clinical Studies NICS, AU
 National Kidney Foundation NKF, US
 New Zealand Accident Compensation Corporation ACC, NZ
 New Zealand Guidelines Group NZGG, NZ
 Polish Institute for Evidence Based Medicine PIEBM, PL
 Program in Evidence-based Care, Cancer Care Ontario PEBC, CA
 Regional Health Agency Emilia-Romagna ASR, I
 Royal College of Nursing, GB
 Royal College of Surgeons in Ireland RCSI, IE
 Royal Dutch Ass. of Physiotherapy KNGF, NL
 Scottish Intercollegiate Guidelines Network SIGN, GB
 Slovene Guidelines Group SGG, SI
 Sowerby Centre for Health Informatics at Newcastle SCHIN, GB
 Spanish Network for Research on Guidelines REDEGUIAS, ES
 Swiss Medical Association FMH, CH
 Trimbos Institute - Neth. Inst. of Mental Health & Addiction, NL
 World Health Organisation Geneva WHO



Abbreviations

ACC	New Zealand Accident Compensation Corporation, NZ
ACCC	Dutch Association of Comprehensive Cancer Centres, NL
AEKB	Berlin Chamber of Physicians, DE
AGREE	Appraisal of Guidelines Research and Evaluation
AHRQ	Agency for Healthcare Research and Quality, US
ANAES	National Agency for Accreditation and Evaluation in Health, FR
AQuMed / AEZQ	Agency for Quality in Medicine, DE
ASR	Regional Health Agency Emilia Romagna, IT
AWMF	Association of Scientific Medical Societies, DE
BQS	German Federal Institute for Quality Assurance, DE
CBO	Dutch Institute for Healthcare Improvement, NL
CEBAM	Belgian Centre for Evidence-Based Medicine, BE
CepiC	Clinical Epidemiology Centre, University of Lausanne, CH
CPSS	Center for Health Policies and Services, RO
CRD	Center for Reviews & Dissemination, University of York, GB
DACEHTA	Danish Centre for Evaluation and Health Technology Assessment, DK
DUODECIM	Finnish Medical Society, FI
EHIF	Estonian Health Insurance Fund, EE
evidence.at	Austrian Association for Quality in Healthcare, AT
FBJL	Josep Laporte Library Foundation, ES
FINOHTA	Finnish Office for Health Care Technology Assessment, FI
FMH	Swiss Medical Association, CH
FNCLCC	National Federation of Cancer Centres, FR
GBA	Federal Joint Committee, DE
GIMBE	Italian Evidence-Based Medicine Group, IT
HM-Saglik	Ministry of Health – Refik Saydam Hygiene Center Presidency, School of Public Health, TR
HTA-DoH	HTA Unit, Ministry of Health Malaysia, MY
IQS	Institute for Quality in Healthcare, PT
JBI	Joanna Briggs Institute, AU
KNGF	Royal Dutch Society for Physical Therapy, NL
MAPM	Moldovian Association of Perinatal Medicine, MD
NHG	Dutch College of General Practitioners, NL
NHMRC	National Health and Medical Research Council, AU
NICE	National Institute for Clinical Excellence, GB
NICS	National Institute of Clinical Studies, AU
NKF	National Kidney Foundation, US
NZGG	New Zealand Guidelines Group, NZ
OSTEBA	Basque Office for Health Technology Assessment, ES
PEBC	Program in Evidence-based Care, Cancer Care Ontario, CA
PIEBM	Polish Institute for Evidence Based Medicine, PL
RCN	Royal College of Nursing Institute, GB
RCSEI	Royal College of Surgeons in Ireland, IE
REDEGUIAS	Spanish Network for Research on Guidelines, ES
SCHIN	Sowerby Centre for Health Informatics at Newcastle, GB
SGG	Slovene Guidelines Group, SI
SHDIR	Directorate for Health and Social Affairs, NO
SIGN	Scottish Intercollegiate Guidelines Network, UK
SOS	National Board of Health and Welfare Sosialstyrelsen, SE
TRIMBOS	Trimbos-Institute - Netherlands Institute of Mental Health & Addiction, NL
WHO	World Health Organisation
WVVH	Flemish College of General Practitioners, BE



CONTENTS

Abbreviations.....	3
Chairpersons' Foreword	5
The route we have travelled	7
Origin of G-I-N.....	7
Membership	8
Activities 2003 - 2004	11
Congresses, Meetings and Workshops	16
Collaboration	18
Leadership and Administration.....	21
GIN Advisory Committee	22
Strategic Direction - The Road Forward.....	25
Financial Statements.....	27
1. Financial Report 2003	27
2. Budget 2004	28
Board of Trustees 2003-2004.....	30

Chairpersons' Foreword



It is a great pleasure to present the second Annual Report of the Guidelines International Network. Looking back, it is hard to believe how much the Network has grown in 2 years. We now have members from all corners of the world - including 51 organisational members and seven individuals who have chosen to join us.

We are delighted that over the last year we have been able to set up a strong administrative infrastructure for the organisation that will be a platform for further growth. We have appointed a dedicated Principal Administration Officer, Angela Maienborn, and over the last year our website has been hosted by AZQ and this function will now transfer to CRD in York. Our financial systems have been enhanced, centralised and moved to Germany and we have a more secure funding stream that will allow the network to continue to have an autonomous workforce committed to making this network a success. We would like to record our thanks to all the members of the Executive, Board and all of the contractors who have worked together to get the Network up and running to such a position of strength in such a short time.

We would also like to express our appreciation to all G-I-N members for their amazing contribution to the Network. Members provided us with a wealth of information about their activities in a very short time. The results now shown on our website are a fantastic achievement. By actively consulting the 2500 references within the website database, all members will have a great opportunity for learning from work that has gone before – and continuously improving the quality of our clinical practice guidelines in a more efficient and robust way.

We hope this Annual Report will demonstrate how much has been achieved this year, and also help to set out a strong and courageous future for the Guidelines International Network.



Günter Ollenschläger



Catherine Marshall

Box 1: Objectives and Aims of the Guidelines International Network

The objective of the network is to protect the health of the general public by seeking to improve the quality of healthcare.

Its aims are:

- To promote the systematic development, dissemination, implementation and evaluation of clinical practice guidelines.
- To promote international collaboration in guideline activities to avoid duplication of effort and to facilitate information sharing, education and knowledge transfer.
- To improve and, as appropriate, to harmonise methodologies for systematic guideline development, dissemination, implementation and evaluation.
- To identify priorities for and to support research relating to clinical practice guidelines and to facilitate the implementation of research findings into practice relative to the Object.
- To build links between relevant international organisations so as to improve co-ordination with clinical practice guidelines and other healthcare quality initiatives.
- To maintain a database of information of and relating to member organisations, their work programs, methodologies and background documentation.
- To prepare and organize, promote and implement training courses, exhibitions, lectures, seminars, conferences, events and workshops and to prepare, produce, edit, publish, exhibit and distribute articles.

The route we have travelled

Origin of G-I-N

In recent years, many countries have built up experience in the development, appraisal and implementation of clinical practice guidelines at professional, organisational, regional and national levels, recognising that guidelines are powerful tools to achieve effective and efficient health care [1].

A number of national agencies, institutions, experts, and health care providers specializing in the guideline field are involved in supranational networks. This is apparent in the guidelines activities taking place all over the world.

However, no established forum for communication on an international level existed until recently. Thus in different countries seeking similar goals and using similar strategies, efforts have been unnecessarily duplicated. As a consequence, financial and structural resources risk being wasted, and activities may be managed in a suboptimal way. Active cooperation between national and international guideline organisations could yield substantial synergies and even savings.

This triggered a proposal in 2001 for an international guidelines network built on existing partnerships.

A multinational group of guideline experts agreed with the initiative and evaluated in 2002 the level of interest in systematic networking on an international level. (2,3)

Based on the results of this survey a steering group consented to the main objectives, areas of interest, and possible working agenda for a not-profit organization aimed at promotion of systematic guideline development and implementation. (cf. Box 1)

In November 2002 the forum was founded under the name of "Guidelines International Network <G-I-N>". Information about the network as well as invitations to join the Network as founder members were issued to over 100 organisations in 34 countries.

The Guidelines International Network was formally constituted as a Scottish Guarantee Company under Company Number SC243691 and recognised as a Scottish Charity under Scottish Charity Number SC034047 and having its Registered Office in Scotland at J. & H. Mitchell W.S., 51 Atholl Road, Pitlochry, Perthshire PH16 5BU. It is managed by a Board of Trustees comprising representatives of many of the Member organisations.

The Guidelines International Network was formally established as a Charitable Incorporated Association registered in Scotland, managed by a Board of Trustees comprising representatives of many of the member organisations. The Memorandum & Articles of Association was signed at the Royal College of Physicians of Edinburgh on 4th February 2003.

1 Burgers JS, Grol R, Klazinga NS, Mäkelä M, Zaat J, for the AGREE Collaboration. Towards evidence-based clinical practice: an international survey of 18 clinical guideline programs. *Int J Qual Health Care* 2003; 15: 31-45

2 Guidelines International Network (2003) Annual Report November 2002-October 2003. www.g-i-n.net

3 Ollenschläger G, Marshall C, Qureshi S, Rosenbrand K, Burgers J, Mäkelä M, for the Board of Trustees 2002, Guidelines International Network G-I-N. Improving the Quality of Health care: Using international collaboration to inform guideline programmes - by founding the Guidelines International Network G-I-N. *Qual Saf Health Care*, in press

Membership

According to the Network's "Articles of Association" membership is open to:

(1) **Organisational Members:** any corporate body or unincorporated association (or equivalent internationally) which is

- a non-profit-distributing body or association;
- involved in developing, disseminating, implementing, or evaluating clinical practice guidelines, or otherwise active in the guidelines field;
- committed to adopting evidence-based practice as the guiding principle for its processes;
- working in accordance with international standards for clinical practice guidelines;
- transparent about its sources of funding.

(2) **Associate Members:** any other corporate body or unincorporated association which does not fall within clause (1) and any individual who is active in the field of clinical practice guidelines. Associate Members are not eligible either to stand for election to the Board or to vote.

Any body or association which, or individual who, wishes to become a member of the Network must sign a written application for membership in the form prescribed by the Board of Trustees (cf. Box 2).

Organisational Members

As at October 2004 the Guidelines International Network had **51 Organisational Members:**

- Between December 2002 and October 2003 a total of 46 organisations had agreed to become Organisational Members of G-I-N.
- Until the end of September 2004, six further organisations joined the Network (cf. Box 2).
- One institution resigned its membership

Box 2: Categories for Information on G-I-N Member Organisation

- Organisation Description
- Activities
- Funding Information
- Mission Statement
- Geographic Extent
- Guideline Target Audience
- Average Number of Clinical Disciplines Involved
- Patient Involvement
- Methods for Evidence Collection
- Methods for Evidence Analysis
- Methods for Formulation of Recommendations
- External Endorsements
- Guideline Review Frequency
- Recent Guideline History
- Guideline Versions
- Dissemination Media
- Guideline Availability
- Implementation Strategies
- Quality Systems
- Current Research

Individual Members

During early 2004, the G-I-N Board of Trustees developed a policy for awarding the G-I-N associate membership: applicants are asked to disclose their expertise and affiliations in the guidelines field.

So far a total of 7 individuals from 7 countries joined the Network as **Associate Members**:

Marten Gerle (Sweden), Mary Hemming (Australia), Carla Herrerias (Spain), Minna Kaila (Finland), Nam Son Kim (Korea), Takeo Nakayama (Japan), Richard Shiffman (USA).

Organisational Members

Box 3: G-I-N Organisational Members 2004

Australia	<ul style="list-style-type: none"> • Joanna Briggs Institute • Nat. Health & Medical Research Council (NHMRC) - New Member • National Institute of Clinical Studies (NICS)
Austria	<ul style="list-style-type: none"> • Austrian Association for Quality in Healthcare (evidence.at)
Belgium	<ul style="list-style-type: none"> • Belgian Centre for Evidence-Based Medicine (CEBAM) • Flemish College of General Practitioners (WVVH)
Canada	<ul style="list-style-type: none"> • Programme in Evidence-based Care, Cancer Care Ontario (PEBC)
Denmark	<ul style="list-style-type: none"> • Danish Centre for Evaluation and Health Technology Assessment (DACEHTA)
Estonia	<ul style="list-style-type: none"> • Estonian Health Insurance Fund (EHIF) - New Member
Finland	<ul style="list-style-type: none"> • Finnish Medical Society (Duodecim) • Finnish Office for Health Care Technology Assessment (FinOHTA)
France	<ul style="list-style-type: none"> • National Agency for Accreditation and Evaluation in Health (ANAES) • National Federation of French Cancer Centres (FNCLCC) • Agency for Quality in Medicine (AquMed/ÄZQ)
Germany	<ul style="list-style-type: none"> • Association of Scientific Medical Societies (AWMF) • Berlin Chamber of Physicians (AEKB) • German Federal Institute for Quality Assurance (BQS) - New Member • Federal Joint Committee (GBA)
Ireland	<ul style="list-style-type: none"> • Royal College of Surgeons in Ireland (RCSI)
Italy	<ul style="list-style-type: none"> • Italian Evidence-Based Medicine Group (GIMBE) • Regional Health Agency Emilia Romagna (ASR)
Malaysia	<ul style="list-style-type: none"> • HTA Unit, Ministry of Health, Malaysia (HTA-DoH)
Moldova	<ul style="list-style-type: none"> • Moldavian Association of Perinatal Medicine (MAPM) – New Member
Netherlands	<ul style="list-style-type: none"> • Dutch Association of Comprehensive Cancer Centres (ACCC) • Dutch College of General Practitioners (NHG) • Dutch Institute for Healthcare Improvement (CBO) • Royal Dutch Society for Physical Therapy (KNGF) • Trimbos-Institute - Dutch Institute of Mental Health & Addiction
New Zealand	<ul style="list-style-type: none"> • New Zealand Accident Compensation Corporation (ACC) • New Zealand Guidelines Group (NZGG)
Norway	<ul style="list-style-type: none"> • Directorate for Health and Social Affairs (SHDir)
Poland	<ul style="list-style-type: none"> • Polish Institute for Evidence Based Medicine (PIEBM)
Portugal	<ul style="list-style-type: none"> • Institute for Quality in Healthcare (IQS)
Romania	<ul style="list-style-type: none"> • Centre of Health Policies and Services (CPSS)
Slovenia	<ul style="list-style-type: none"> • Slovene Guidelines Group (SGG) • Basque Office for Health Technology Assessment (OSTEBA)
Spain	<ul style="list-style-type: none"> • Josep Laporte Library Foundation (FBJL) • Spanish Network for Research on Guidelines (REDEGUIAS)
Sweden	<ul style="list-style-type: none"> • National Board of Health and Welfare Socialstyrelsen (SOS)

Switzerland	<ul style="list-style-type: none"> • Clinical Epidemiology Centre, University of Lausanne (CepiC) • Swiss Medical Association (FMH)
Turkey	<ul style="list-style-type: none"> • Ministry of Health – Refik Saydam Hygiene Center Presidency School of Public Health (HM Saglik) - New Member • Centre for Reviews & Dissemination, University of York (CRD)
United Kingdom	<ul style="list-style-type: none"> • National Institute for Clinical Excellence (NICE) • Royal College of Nursing Institute (RCNI) - New Member • Scottish Intercollegiate Guidelines Network (SIGN) • Sowerby Centre for Health Informatics at Newcastle (SCHIN)
United States	<ul style="list-style-type: none"> • Agency for Health Research and Quality (AHRQ) • National Kidney Foundation (NKF)
International	<ul style="list-style-type: none"> • The AGREE Collaboration • World Health Organisation (WHO)

Activities 2003 - 2004

Between November 2003 and October 2004, the G-I-N Board of Trustees have been prioritising the Network' issues and projects according to the needs and demands of guideline experts all over the world as expressed in the international survey which was performed in preparing G-I-N's foundation (cf. Box 3).

Box 4: Priority Issues and Projects for G-I-N – Results of the International Survey 2002 [3]

Issues	Projects
Information sharing	<ul style="list-style-type: none"> • Database of existing guidelines • Library of guideline methodologies, tools, templates • Database of background documentation • Database of patient guidelines
Education on guidelines methodology	<ul style="list-style-type: none"> • Promoting AGREE instrument for guideline development • Promoting use of clearinghouses etc. to avoid duplication
Collaboration between members	<ul style="list-style-type: none"> • Prospective sharing of evidence review work • Sharing implementation and audit tools • Use and/or updating of CPG/ evidence reviews by other members
Outreach of new or prospective member	<ul style="list-style-type: none"> • Sharing evidence reviews with other programmes • Advising on adaptation of existing guidelines

Within this framework last year's activities have been focusing on

- developing the G-I-N Website www.guidelines-international.net
- presenting the Network's aims and goals at international and national conferences – with special respect to education on guideline methodology
- facilitating collaboration between G-I-N members and

- consolidating the Network administration.

G-I-N Website

G-I-N being primarily a virtual network the website >>www.guidelines-international.net aka www.g-i-n.net <<< (cf. Box 4) is the key tool supporting most of the Network's activities and communication. Through combined visionary, technical and editorial efforts G-I-N's interim website was replaced by its final database-driven website in November 2003.

Since April 2004 an average of more than 9,200 unique visitors per month to the site have been registered, with a peak in May of more than 9,500 and in September with over 12,300 (detailed statistics overview see below). One major principle of the website is to provide members with the ability to manage their own content, i.e. information on their organisation and their guideline programmes.

Box 5: Contents of www.g-i-n.net (for members only parts are *highlighted*)

About GIN	<ul style="list-style-type: none"> ○ Organisation & Management ○ G-I-N Activities ○ Board of Trustees ○ Memorandum & Articles of Association ○ G-I-N History
Guideline Resources	<ul style="list-style-type: none"> ○ <u>International Guideline Library (for members only)</u> ○ Development Tools and Resources ○ Training Materials ○ Patient/Consumer Resources ○ Guidelines from Non-Members ○ Health Topics Collection
G-I-N Members	<ul style="list-style-type: none"> ○ Links to Websites of the G-I-N Membership with Search Mode
<u>Activities</u> <u>(for members only)</u>	<ul style="list-style-type: none"> ○ <u>Collaboration: The Virtual Workshop for G-I-N Members</u> ○ <u>Training for Members</u> ○ <u>Research</u> ○ <u>Notice Board for Members</u> ○ <u>G-I-N SOPs</u> ○ <u>Member Events Diary</u>

News	<ul style="list-style-type: none"> o Meetings / Events Diary o Newsletter o News from G-I-N Members
Related Links	<ul style="list-style-type: none"> o Guidelines o Evidence Research o Organisations o Healthcare Information o Consumer Resources o Knowledge Management in Health Care
Enquiries	<ul style="list-style-type: none"> o Enquiries – FAQ
Join G-I-N	<ul style="list-style-type: none"> o How to join, Fees, Benefit of Membership o Online application forms
AGREE Instrument	<ul style="list-style-type: none"> o <u>Posting of guidelines for evaluation</u> o Public evaluation of posted guidelines

The cornerstone of the website is the International Guideline Library - a searchable database which provides G-I-N Members with the ability to search and review the programmes for published and planned guidelines, systematic reviews, evidence reports, guideline clearing reports of all member organisations, as well as related documents (e.g., evidence tables, search strategies, patient information) – cf. Box 6.

Box 6: Categories for Information on G-I-N Member Programmes

- **Publication Title and URL**
- **Disease / Condition addressed** (based on the National Library of Medicine's (NLM) Medical Subject Headings (Mesh) classification.)
- **Date of Publication**
- **Languages published in**
- **Publication Scope** (Screening, Prevention, Assessment / Diagnosis, Management, Rehabilitation)
- **Publication Status** (published, in development, planned, under review)
- **Publication Type** (Guideline, Systematic Review, Evidence Report, Guideline Clearing Report, Guideline Methodology, Implementation Tool)
- **Organisation producing publication**
- **Countries that the publication applied to**
- **Planned Review**
- **Date of Review**
- **Primary Contact**
- **Associated Documents, Terms of reference, Key questions, Group membership, Search strategy, Critical appraisal documents, Evidence tables, Algorithms, Consultative drafts, Consumer resources, Considered judgement forms, Implementation tools and/or strategies, Economic analysis, Methodology description, including selection criteria, Video clips, Power Point presentations, Electronic tools / quizzes, Summary Document(s), Other, eg. indicators, remit, press releases)**

With a total of about 2,500 items of information (September 2004) from 17 language groups (cf. Box 5) the **Guideline Library** has grown to the largest web-based guideline database worldwide during the last 10 months.

As part of our commitment to sharing knowledge and information, a number of our G-I-N resources have been made freely available to the public. These include:

- Development Tools and Resources which inform about state-of-the-art techniques and instruments for developing evidence-based guidelines;
- Training Materials on producing and using clinical practice guidelines from G-I-N Members – assembled into different language collections (Dutch, English, French, German, Nordic, Roman, Slavic, Hungarian and Greek)
- Patient/Consumer Resources from G-I-N Members – assembled into different language collections (Dutch, English, French, German, Nordic, Roman, and Slavic – partially under construction)
- Guidelines from African, American, and Asian Non-G-I-N Members;
- The Health Topics Collection with guidelines and other resources from G-I-N members for specific health topics (by October 2004: Asthma, Breast Cancer, COPD, Colorectal Cancer, Dementia, Diabetes Type 2, Myocardial Ischemic Disorders, Pain, Schizophrenia)

Box 7: Number of Items of Information in the G-I-N International Guideline Library (by September 2004)

Language	Documents (n)	Language	Documents (n)
Danish	9	Dutch	223
English	1777	Estonian	8
Finish	19	French	90
German	195	Italian	3
Moldavian	2	Norwegian	6
Polish	5	Portuguese	5
Romanian	20	Slovenian	2
Spanish	19	Swedish	13
Turkish	11		

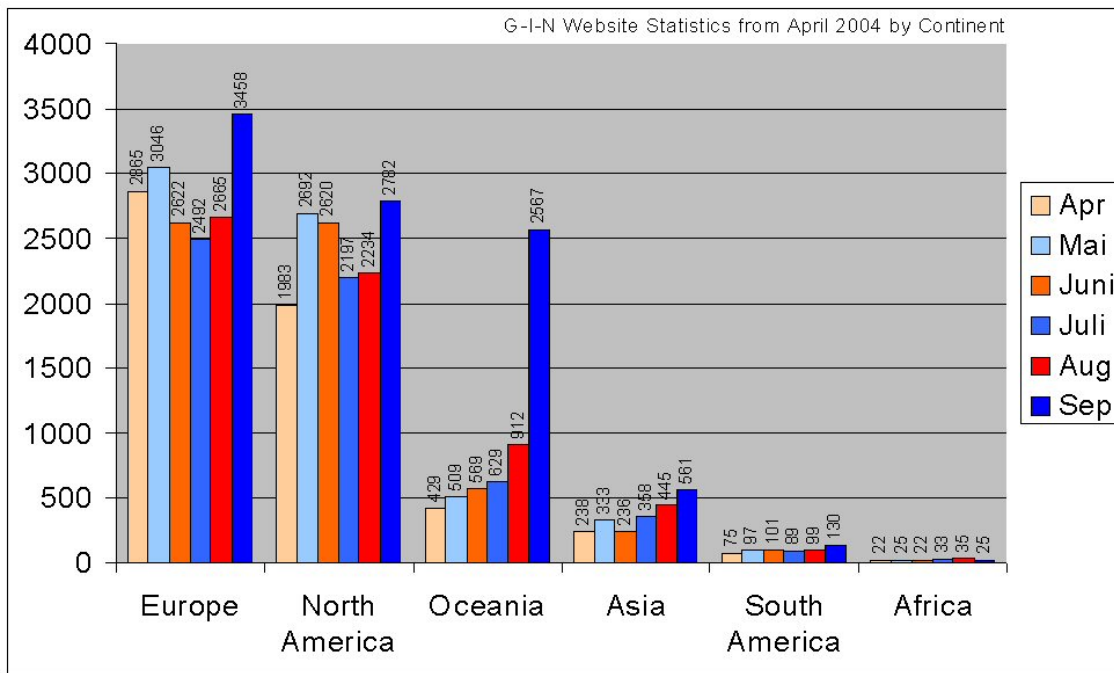
Member database – The increase in membership of G-I-N is reflected in a continuous enlarging and updating of the site's Member Database. Especially, access to the restricted sections of the site has been established for many individuals working closely with members, such as experts in working groups. Administration of the member database is aided by automatic feeding of information from the online application forms.

Collaboration – One of the sites major objectives is to provide a platform for international collaboration. An example for this is the setting up of a discussion forum for the project “Clinical Guidelines Reference Architecture” (details see Collaboration – Working Group on Guideline Reference Architecture (CPG-RA)).

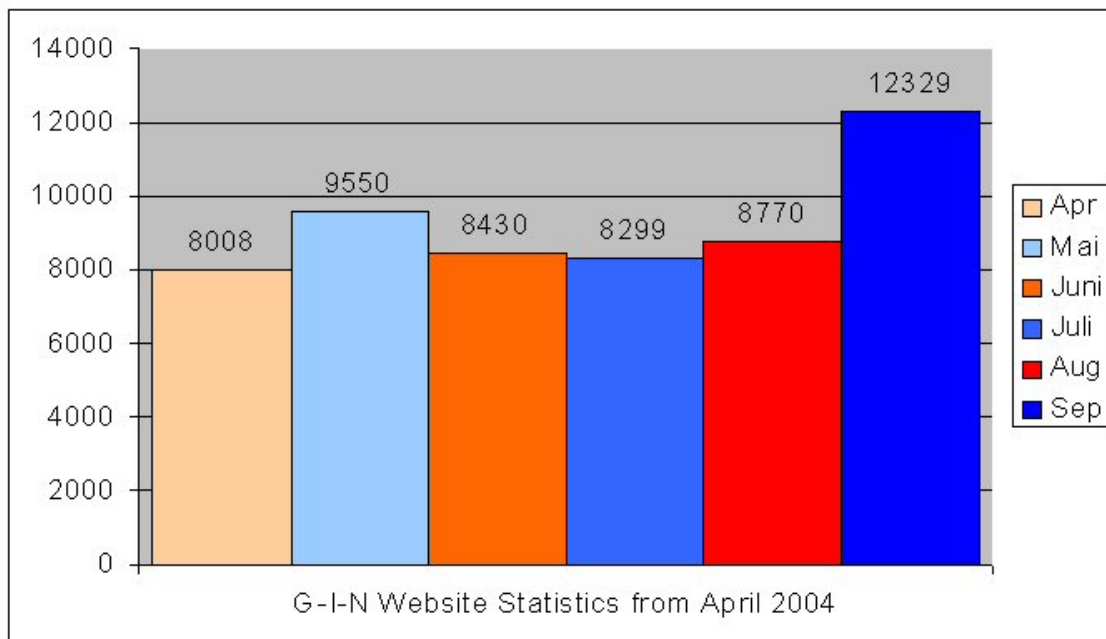
Another example is the online AGREE Instrument which allows members to post their guidelines for public evaluation.

G-I-N Website statistics – an overview from April 2004

Unique visits by continents



Total of unique visits



Congresses, Meetings and Workshops

The Network was represented at the following events this year (including November 2003):

- **Edinburgh (UK) 14th – 15th November 2003 - Annual General Meeting**

Edinburgh Meeting – some reflections from SIGN

148 delegates from 46 countries braved the fabled Scottish weather to attend the joint G-I-N / AGREE meeting on 14 and 15 November 2003. To ensure maximum exposure to Edinburgh's proud medical heritage the meeting was held in both Edinburgh Royal Colleges.

Friday saw delegates at the Royal College of Surgeons of Edinburgh attending either the G-I-N symposium or the AGREE meeting, coming together for coffee breaks and lunch. The G-I-N symposium had a few technical hitches but provided a good overview and prompted considerable debate. Especially important for the SIGN contingent was a personal tribute to our founder, the late Professor James Petrie, by Professor John Cash. We were delighted that Jim's widow and son were also able to attend. The day finished with a tour of the College's gruesome museum (remember that Edinburgh provided Burke and Hare bodysnatchers!) and a fine dinner.

Saturday dawned without the predicted storm, denying our international visitors the chance to sample Edinburgh rain and wind, and action shifted to the Royal College of Physicians of Edinburgh. This was 16

another hugely successful day with excellent presentations and debate. G-I-N's AGM went off without a hitch and the new Board of Trustees was announced. The whole meeting ended in grand style with a traditional dinner and ceilidh.

So what did we discover from the experience? Well, the I and N of G-I-N are well established, whoever could forget our International visitors Networking furiously on the dance floor to great Scottish music? As for the G, this still needs some work - guidelines are urgently required on:

- how to dance the Dashing White Sergeant
- how to avoid collisions on the dance floor
- how should the chairman of SIGN be dressed?

Many thanks to you all for making the whole meeting so successful, but special thanks to Lesley Forsyth, Safia Qureshi and Mel Chesnokov for really making it happen.

- **Prague (CZ), 14th – 15th April 2004 - Euromise**

The symposium tried to identify use cases for guideline-base applications in healthcare, pressing issues and promising approaches for developing usable and maintainable vehicles for guideline delivery. The symposium was organized in co-operation with the University of Economy in Prague and the Czech Society for Cybernetics and Informatics.

G-I-N has presented part of its activities during the symposium: Catherine Marshall: Transforming Written Guidelines into Electronic Formats – International Perspectives, Günter Ollenschläger and Kitty Rosenbrand: Bridging the gap between the medical guideline- and computer science worlds: will Future Guidelines be Living Guidelines.

- **Krakow (PL), 30th May – 2nd June 2004 - HTAi**

G-I-N has presented its activities during the Annual Congress of HTAi (Health Technology Assessment international) - Workshop on "Networks in the field of HTA" (Günter Ollenschläger)

- **Ottawa (C), 2nd – 6th October 2004 –**

A workshop on the Network's activities was organized during the 12th Cochrane Colloquium of the Cochrane Collaboration. - more detailed.

- **San Francisco (US) September 2004 –**

At the **Medinfo** Conference in San Francisco in September 2004, Catherine Marshall represented the Guidelines International Network. She was part of a panel session entitled "*Requirements for and Work towards an international Standard for representing Clinical guidelines*". Other panel members included Enrico Coiera (Australia), Martin Entwistle (NZ), Rick Shiffman (US) and Robert Jenders (US).

The panel examined various aspects of the need for an agreed international standard or standards; the key elements of a standard/s; and the process for achieving international consensus on a standard. The session was well attended and generated a lot of discussion, it was particularly useful to have the range of perspectives from vendors, to guideline developers, network organisations and standards development organisations represented. The conference also provided an opportunity to informally discuss ways the G-I-N Network could build an online web-based evidence table database, and to meet other organisations interested in ways of implementing online evidence.

- **Wellington (NZ), 1st - 3rd November 2004** – The second international Conference of the Network will be held. The theme is “Evidence in Action”. The G-I-N Annual General Meeting will take place on Tuesday 2nd November 2004.

Collaboration

One of the first activities of the Network in 2003 was to establish working groups to take forward different aspects of G-I-N's work and to facilitate collaboration between member organisations. (cf Annual Report 2003).

The groups on **Website Development** and **Programme Information, Background Documentation and Resources** completed their activities by having implemented its recommendations in the content structure of the G-I-N website.

The **Research Registry Group** postponed its activities according to the working plan from 2003 (cf. Annual Report 2003) until 2005. This re-prioritisation resulting from lack of funding was endorsed by the Board of Trustees.

Working Group on Grading Harmonization

During the last 5 year, a group of experts familiar with one or more systems for grading evidence and recommendations. (the **GRADE group** - led by Andy Oxman of the Nordic Cochrane Centre) had been working to look at how systems for evaluating the quality of evidence and grading recommendations can be improved, simplified, and harmonised. From G-I-N member organisation participated Cindy Farquhar (NZGG), Robin Harbour (SIGN), Margaret Haugh (FNCLCC), and Jacek Mrukowicz (PIEBM).

The results of the GRADE group discussions were published in a BMJ article this year (<http://bmj.bmjournals.com/cgi/content/full/328/7454/1490>). More publications of GRADE are available on: <http://www.gradeworkinggroup.org/publications/index.htm>.

Working Group on Guideline Reference Architecture (CPG-RA)

Background:

Sharing guidelines remains a difficult task – there is a lack of commonality of document structure and subtle differences in guideline elements remain implicit. By making guidelines that conform to a standard in architecture will not only enable sharing but can also improve clarity and implementation. XML is a technical standard that can be used to represent such an architecture and has the added advantage of being able to view documents in local structures (using style sheets) yet still conform to an international standard.

Scope:

During the Euromise Meeting in Prague (14/15 April 2004) representatives from several G-I-N Members (i.e. SCHIN, NZGG, RCNI, CBO, ÅZQ) agreed on a project, which will investigate what the guideline community does with studies, citations, evidence tables and evidence statements with considered judgments and look at how they are currently represented by GIN members. Its aim will be to create a general model encompassing the needs of the community.

Under the leadership of Ian Purves and Sharon Smart from SCHIN, a work-programme was set up and confirmed by the G-I-N Board of Trustees, aiming at the following products:

Products:

- 1/ Documented use cases for guideline community actors (authors, evaluators and implementers)
- 2/ Repository of current representations
- 3/ XML Schema of the data elements found

The working group finally got going towards the end of July. The web site www.cpg-ra.net was initiated with draft use cases, a model for studies/citations and a model for evidence tables. Some members found the syntax of the documentation foreign to understand and clearly some meetings are going to be necessary as well a virtual working group. A good meeting took place in San Francisco during the MedInfo conference (early Sept) and a lot of progress was made on the evidence table model.

Guidelines adaptation working group

Adaptation is a most important and timely issue. Most agencies and other groups developing guidelines are struggling to keep guidelines updated and to develop new ones. In addition, although interest in evidence-based health care and evidence-based guidelines is increasing, funding of such activities is difficult in most countries.

Beyond developing the rationale for guidelines adaptation, the word and the concept of adaptation requires definition. Indeed, many definitions have been found in the literature as well as among members of the working group. There is an overlap between the concepts of adaptation and implementation. In addition, several steps in the adaptation process are similar to steps in the development process. A literature search was conducted about the process of guidelines adaptation (J. Burgers, M. Haugh, N. Mlika Cabanne, B. Burnand, B. Fervers).

The activities in guidelines adaptation have been developed mostly within a France – Québec “mission” aimed at developing a methodology to adapt oncology guidelines from one side of the Atlantic to the other. This project has received financial support from an existing collaborative France – Québec entity. Four members of the GIN adaptation subgroup have been participated to this project in collaboration with other scientists (noted with a * in the list of participants below). So far, several steps have been identified in the adaptation process: defining the clinical question(s) and the target groups of both patients and health care professionals, systematic search and appraisal of source guidelines, customizing the adapted guideline to the target context (e.g., a region, a country, a province, an hospital or a health care network), followed by external review, diffusion, implementation and an updating process. In the framework of defining and pilot testing a model for the guideline adaptation process, an instrument (PIPOH) has been developed in order to help defining the clinical question and target patient groups.

The process and the PIPOH instrument will be presented and discussed during the workshop of guideline

adaptation at the annual GIN meeting in Wellington. A protocol will be prepared to validate the process and PIPOH instrument among guideline developing organisations.

A brief position paper will be prepared for G-I-N and a manuscript will be drafted to be submitted for publication.

Other Collaborative Activities

• evidence.at and ÄZQ: Austrian Guideline Manual

As joint activity of ÄZQ and evidence.at together with international experts and experts from Austria a concept for an Austrian Guidelines Manual was published. With the strong support of Günter Ollenschläger and its ÄZQ, the final draft of an Austrian Guidelines Manual could be presented to interested experts in Austria in late spring 2004. The Manual is actually the basis for a starting national consensus-process combining the interests of the health system stakeholders: For the near future the Austrian Guidelines Manual will serve as guidance:

- a) for the development of rehabilitation guidelines starting in winter 2004,
- b) for a guidelines-conference at the Ministry of Health in November 2004 and
- c) for the development of an national Austrian Guidelines Development Standard in 2005.

• SIGN and others: Living Guidelines

It has long been recognised that guidelines can be out of date as soon as they are produced, as new research findings are continuously published. One way that this can be minimised is by clearly identifying a 'shelf life' for a guideline. These may be date limited (or have a statement that the review date will be determined by the availability of new evidence. An alternative option – the living guideline - is now being considered. A living guideline is one that is remains under review on an ongoing basis, with updates published at set intervals, e.g. annually.

SIGN and the British Thoracic Society jointly published a guideline on the management of asthma in 2003. The guideline development group has remained in place since that time and have already published one web only update.

The living guideline offers many advantages such as the possibility of worldwide collaboration and the possibility of a truly up to date guideline. There are, however, new challenges to be faced, including motivation of guideline development groups over an extended period and also an exit strategy.

Leadership and Administration

The affairs of the Network are directed and managed by a Board of Trustees, which was appointed in term of G-I-N' Articles of Association during the first Annual General Meeting held in Edinburgh – Scotland on 15th of November 2003.

The day-to-day activities have been planned, prioritized and supervised by the Executive Committee (Chair, Vice-Chair, Treasurer, 3 other Trustees and Principal Officer). The whole Board (the Executive Committee) convened on a bi-monthly (monthly) base by teleconference. We would like to thank all for the time and work they spend on working for the Network and especially the Executive Committee for their extraordinary contribution:

Regina Kunz (DE), Catherine Marshall (NZ), Najoua Mlika-Cabanne (F), Günter Ollenschläger (DE), Kitty Rosenbrand (NL), Jean Slutsky (US), Bernard Burnand (CH), Béatrice Fervers (FR), Finn Børllum Kristensen (DK), Marjukka Mäkelä (FI), Roland Schaffler (A), Melissa Brouwers (CA), Heather Buchan (AU), Jako Burgers (NL), Jos Kleijnen (UK), Sara Twaddle (UK).

In order to build up the administrative infrastructure of the organisation, the G-I-N Board of Trustees has elected a new Principal Officer on the basis of an international call for tenders.



The successful candidate, Dr. Angela Maienborn has taken over the management of the network in July 2004 and will coordinate the administrative and content work.

She is a trained anaesthesiologist and quality manager, with a long expertise in health organisation administration.

Dr. Maienborn was educated in both Germany and Ecuador. She studied and received her PhD in medicine at the University of Goettingen, Germany. From 1991 until 1998 she worked in several hospitals in Germany and Bolivia, and from 1998-2004 she managed the bureau for consumer and patient information at the Medical Chamber of Westfalia in Muenster, Germany.

She has special interests in quality management, the intensification of the relationships to Latin America, and the importance of consumer/ patient involvement in developing and promoting of clinical guidelines.

Angela looks forward to meeting Network members at the conference to know better about the different needs and expectations of the members and how to provide a good service to everybody. She is planning to run a membership survey to identify priority areas for work over the next two years.

We would also like to express our appreciation to all those who helped us this year to make G-I-N more than a Website. Henrike Trapp our dedicated webmaster, Sylvia Sängner who supported the Network in a sedulous way and Sabine Bauer our administration secretary, who left the Network in June. At this place we would like to welcome Martina Westermann a foreign language secretary; she is going to support the administration office of the network.

Our thanks also go to New Zealand to the NZGG – team – particularly Leonie Brunt and Paula Bell for doing an excellent work in setting up the Wellington conference.

GIN Advisory Committee

The Advisory Committee will provide strategic advice to the Guidelines International Network and support its work of improving the quality of health care by promoting systematic development of clinical practice guidelines and their application into practice, through supporting international collaboration. The Advisory Committee will be comprised of invited participants from different areas of expertise. Members of the Advisory Committee will be appointed as honorary members for up to 2 years.

It is a pleasure for the Network to announce the first appointments to G-I-N's Advisory Committee, six renowned experts who are willing to support the Network's activities:

ANDREA RITA HORVATH MD, PhD, EurClinChem, FRCPath (UK), Professor of Clinical Chemistry, University of Szeged, Hungary



Professor Horvath is Head of Department of Clinical Chemistry at the University of Szeged in Hungary. Currently she is the president of the Hungarian Society of Clinical Pathology and founding member of the medical laboratory committee of the Hungarian Accreditation Body. She spent altogether 8 years in Britain, first as a scientist in London (1988-1990), later as a chemical pathologist trainee in Sheffield (1993-1994), and subsequently as lecturer in clinical biochemistry at Oxford University (1995-1998). She has been a member (1999-2002) and since 2003 the chair of the Committee on Evidence-based Laboratory Medicine of the International Federation of Clinical Chemistry and Laboratory Medicine. In the last five years she has been active in running a national evidence-based health care programme and network, called TUDOR, in Hungary, initiated by the support of the Department for International Development of the British Government. Her main interests are evidence-based guideline development, evidence-based diagnosis and EBM training. She has held several Central-Eastern European EBM workshops with the support of DFID and the AGREE Collaboration.

Minna Kaila, MD, PhD
Paediatric Allergist
Chief Physician, Department of General Practice

Pirkanmaa Hospital District, Finland



Dr. Kaila is Chief Physician of the Department of General Practice at Tampere University Hospital's District, responsible coordinator of clinical cooperation between primary and secondary care and development of seamless care and implementation of guidelines. Currently she is President of the Allergy Section of Finnish Paediatric Society, Editor of the National Current Care Guidelines 2000-2001 and 2004, Chief Editor 2002-2003. Member of GIN Founding Committee. Member of the Advisory Committee of Finnish Office for Health Technology Assessment. Member of the Committee of Education of the Finnish Medical Society Duodecim.

Dr. Kaila is married; she has 4 children, 1 grandchild.

Dave Davis, MD, CCFP, FCFP
Chair, Ontario Guidelines Advisory Committee
Associate Dean, Continuing Education,

Faculty of Medicine, University of Toronto, Canada



Dr Davis is a Professor in the Departments of Health Policy, Management and Evaluation and Family and Community Medicine, and Associate Dean, Continuing Education (CE), Faculty of Medicine, the University of Toronto. He is also chair of the Guidelines Advisory Committee of the Ontario Medical Association and the Ministry of Health, Ontario and is the leader of the Knowledge Translation Program of the Faculty of Medicine.

Dr Davis has served as chair of the CME Committee of the Ontario Council of the Faculties of Medicine; president of the Standing Committee on CME for the Association of Canadian Medical Colleges; the president of the Alliance for CME, the largest organisation of CME providers in the US and Canada; and the president of the Society of Medical College Directors of CME, a North

American organisation of medical school deans and directors of CME), now called the Society for Academic CME.

Niek S. Klazinga, Prof. Dr.
Professor of Social Medicine, AMC – UvA, Dept. of Social Medicine

Amsterdam, The Netherlands



Niek Klazinga has since 1985 been involved in quality improvement initiatives in the Dutch health care system as (chief) scientific officer of the Dutch Institute for Health Care Improvement, CBO. His PhD thesis in 1996 was on quality management of medical specialist care. After holding a post as associate professor at the department of health policy and management at the Erasmus University Rotterdam he was appointed at his present post in 1999.

Between 1990 and 1996 Niek Klazinga was project leader of a Biomed project on quality assurance in European hospitals. Teaching activities include lecturing at the Netherlands School of Public Health and programme directorship of the master programme for Health Services Research at the Netherlands Institute for Health Sciences (Nihes). Niek Klazinga was board member of the Dutch

Medical Association for a period of six years and is at present involved in various national committees on health policy and health care reform.

J. A. Muir Gray, CBE, MD, FRCP (Glas & Lond)
Director, National electronic Library for Health
Director, National Screening Committee

Institute of Health Sciences, Oxford, UK



Muir was born and educated in Glasgow. From surgery he moved to public health and has worked in all aspects of public health. In the vanguard of the evidence-based health movement [UK section], he established the Centre for Evidence-Based Medicine at Oxford.

In his recent book *The Resourceful Patient*, Muir argues for a radical shift in balance between the knowing professional and the unknowing patient.

Paul Shekelle, M.D., Ph.D.
Director, Southern California EPC-RAND

Santa Monica, CA, USA



Paul G. Shekelle (M.D., Duke University, 1982; Ph.D., University of California, Los Angeles, 1993) is associate Professor of Medicine at the UCLA School of Medicine, and a staff physician at the VA Medical Center in West Los Angeles. His research focus has been in the application of innovative methods to the assessment and improvement of the quality of care. He spent 6 years as a Career Development Awardee of the VA Health Services Research and Development Service. Dr. Shekelle spent 1996-1997 in the United Kingdom as an Atlantic Fellow in Public Policy studying how quality of care was being assessed in the National Health Service. Since 1997, Dr. Shekelle has been the Director of the Southern California Evidence-Based Practice Center, and has led numerous systematic reviews and meta-analyses in that capacity. Dr. Shekelle also co-directs the Assessing Care of the Vulnerable Elderly project, which seeks to develop a comprehensive set of quality tools to assess care for this population.

Strategic Direction - The Road Forward

Over the next two years, the Guidelines International Network will work together on the following priority areas:

Promoting the systematic development, dissemination, implementation and evaluation of clinical practice guidelines.

This will involve developing:

- Standards and procedures for guideline development and promotion
- Standards for setting up evidence tables
- Code of Conduct for Network members
- Framework for standardised G-I-N training sessions in member organisations

Promoting international collaboration in guideline activities to avoid duplication of effort and to facilitate information sharing and knowledge transfer.

The Network will take responsibility for:

- Continuously updating and enhancing the www.g-i-n.net website to ensure that member programme information is kept up to date and accurate
- Developing standards for the adaptation of guidelines between countries
- Developing programmes for the international working groups to collaborate on the following topics:
 - Background documentation
 - Consumers/ patients and evidence
 - Dissemination and Implementation of guidelines
 - Electronic decision support and standards for guideline formalism
 - Guideline Research
 - Integrating HTA and economic analysis

Building links between member organisations to improve co-ordination and learning.

- One annual meeting will be held for all Network members. The proposed annual meetings are:
 - 2005 Lyon, France
 - 2006 America
 - 2006 Asia
 - 2007 Africa
- Decentralised Workshops with G-I-N Member presentations will be encouraged.

The proliferation of guidelines and concerns about their quality has led to the development of international collaboration between organisations and individuals active in the field of guidelines. The fast growth of the Guidelines International Network confirms that structured international partnership is needed.

It is important to note and learn from the challenges experienced in the first years of the Network. The diversity and cultural differences in guideline development programs and their support have continued to present obstacles that are necessary to overcome. Many current and potential Network members are supported under different funding mechanisms, some more stable than others. Issues such as the role of Industry in supporting guideline programs are challenging not only to the Network but also to other international consortiums such as the Cochrane Collaboration and Health Technology Assessment International (HTAi).

The Network has decidedly moved toward supporting developing organisations through training, partnerships and subsidized fees to conferences, to reduce the need for industry support. Language barriers continue to be a challenge but can be overcome. The lingua franca is English but resources are provided in multiple languages when possible. It is imperative that the true meaning or validity of a guideline or supporting document transcends translations, and care has been taken to ensure this.

Some Network members come from more mature programs with long experience. The challenge of the Network is to provide a useful forum and resource for these more evolved programs.

The Network Working Groups have met this challenge by convening around topic areas that are complex and ripe for investigation, harmonization, or evaluation (electronic architecture of guidelines, guideline adaptation, optimal issues in guideline updating, evidence grading, etc.).

Finally, implementation of guidelines is a global issue. The Network recognizes the importance of this crucial area and the work that needs to be done to increase the uptake and use of guidelines.

This will be a continued focus of the Network for years to come.

Financial Statements

1. Financial Report 2003

Statement of Financial Activities

Period from 10 February 2003 to 31 December 2003

	Euro	Euro
INCOMING RESOURCES		
Membership subscriptions		207,500
TOTAL INCOMING RESOURCES		207,500
RESOURCES EXPENDED		
Costs of generating funds:		
Fundraising and publicity		3,427
Management and administration		163,137
TOTAL RESOURCES EXPENDED		166,564
NET INCOMING RESOURCES FOR THE PERIOD		40,936
Balances carried forward		40,936
CURRENT ASSETS		
Debtors	25,000	
Cash at bank	145,793	
	170,793	
CREDITORS: Amounts falling due within one year	(-129,857)	
NET CURRENT ASSETS		40,936

TOTAL ASSETS LESS CURRENT LIABILITIES		40,936
NET ASSETS		40,936
FUNDS		
Unrestricted		40,936
TOTAL FUNDS		40,936

2. Budget 2004

Budget 2004

EUR

I. Costs

1.	Fees	
	1a) Principal Officer	35.000
	1b) Admin. Secretariat (*1)	30.000
	1c) Webmaster	10.000
	1d) Office Secret. Scotl. / Fin. Controlling	3.000
2.	Website develop., maintenance	20.000
3.	Conferences	30.000
4.	Administration (Supplies, Postage)	8.000
5.	Travel expenses (*2)	25.000
6.	Promotion	5.000
7.	Representation	1.000
8.	Bank Costs	1.500
9.	Other Costs	6.495
	Total costs	174.995

II. Income

1.	Organisational Member Fee	125.000
2.	Associate Member Fee	5.000

Annual Report 2003-2004

3.	Interest	100
4.	Income 2003	19.895
5.	Other income (Congress Sponsorship)	25.000
	Total income	174.995

Board of Trustees 2003-2004

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