45 Science Policy Briefing • September 2012

Implementation of Medical Research in Clinical Practice

Contents

Foreword

Medical care has improved beyond recognition over the past half century, underpinned by progress in clinical research. However, there is no room for complacency. New findings need to be taken into account in clinical practice as speedily and efficiently as possible so that patient–clinician encounters and policy decisions can be informed by up-to-date evidence.

Much clinical decision-making remains insufficiently informed by reliable evidence, and much research is not methodologically robust. Some treatments actually harm patients, while other, worthwhile, treatments are not used widely enough.

The Forward Look, 'Implementation of Medical Research in Clinical Practice', prepared by the European Medical Research Councils (EMRC) addressed the question: 'How can the treatment of patients be improved through better research and better use of research results?' The issues were thoroughly discussed and debated by more than 90 participants from around Europe and the rest of the world, culminating in a consensus conference. The resulting Forward Look has received widespread coverage and support in a range of media across Europe, and has been sent to over 2000 individuals and organisations.

The aim of this Science Policy Briefing is to encapsulate the main conclusions and recommendations of the Forward Look, and to ensure further dissemination. It identifies the stakeholder groups responsible for implementing the recommendations, and describes the steps needed to ensure that the recommendations are implemented for the benefit of the citizens of Europe.

We thank our expert group for their great effort and excellent support, and a warm thank you to Professor Kirsten Steinhausen and her EMRC Unit team.

Professor Liselotte Højgaard
EMRC Chair

Mr Martin Hynes
ESF Chief Executive

Introduction

Medical research has made a fundamental contribution to health and wellbeing over the last 50 years. Well-directed, high-quality research can answer important questions and provide evidence to inform decisions in clinical practice and policy. Nevertheless, it needs to be acknowledged that some research is not of sufficient quality or relevance, and that healthcare professionals, patients, citizens and policy-makers often make decisions without taking research evidence into account.

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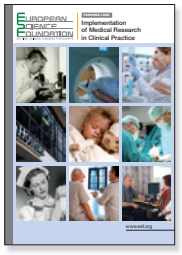

Figure 1. Table of Content of the Forward Look Report

To help address this unsatisfactory situation, in May 2011 the EMRC published the Forward Look report *Implementation of Medical Research in Clinical Practice*[1], upon which this Science Policy Briefing draws.

Broadly the conclusions of the Forward Look are as follows:

• Research questions should be framed to address more effectively problems known to be relevant to the end-users of research results – patients and the public. More high-quality studies are needed to test the comparative effectiveness of drugs and other healthcare technologies. When the evidence base for an invasive intervention, for example, is insufficient, the added value of the intervention versus non-invasive management should be studied. Resources should not be wasted on unwarranted duplication of research. Existing evidence should be reviewed systematically before additional research is embarked upon, and the protocols for on-going research should be registered and published.

• Research must be methodologically sound, so that the evidence it delivers can be viewed and replicated with confidence. This will require further development of education and training for clinical researchers and an increase in the numbers of professionals with expertise in methodology and an understanding of evidence-based medicine (EbM), health technology assessment (HTA), health economics, and the development and use of clinical practice guidelines. The results of all well-conducted research should be made publicly available, in unbiased reports providing adequate detail to enable patients and the public to benefit from them.

• Research aimed at meeting the needs of primary care must be increased, and there is too little research evidence on how to ensure that research results are used in practice to the benefit of the patient – a priority area for investigation.

• Finally, but crucially, there must be greater involvement of patients and the public at all stages of research and the use of research results. This will require healthcare professionals to communicate the importance of research to patients and citizens. Health professionals will need to be trained to communicate research findings, and they will need to have adequate numeracy skills to communicate accurately to patients and citizens about issues such as risk. Funding agencies should require researchers to report their plans for involving patients and the public in their research projects.

• Implementation efforts must not be restricted to physicians but include all healthcare professionals, health administrators and policy-makers. All these people play key roles and their interaction with patients and the public is vital.

• There is still a strong need for effective implementation strategies. Paulussen 1994[2] and Fleuren et al. 2004[3] observed a very low use of guidelines in innovations in schools and preventive child healthcare with only 7% out of 100% using the guideline as intended (Figure 2).

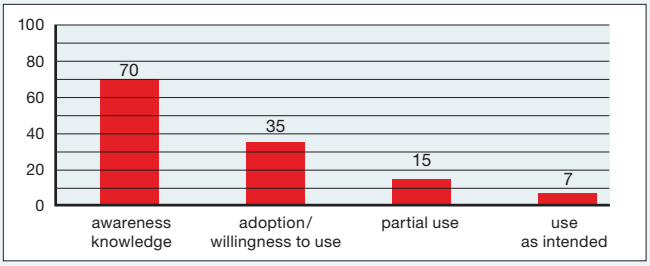

Figure 2.
Innovations in practice after one year (*Paulussen 1994; Fleuren et al. 2004*)

The 10 recommendations that follow summarise the recommendations made in the Forward Look to improve the quality of research and healthcare in Europe and beyond. Because of the distinct challenges of involving primary care and the public and patients in clinical decision-making and in framing research questions, these two areas have been addressed separately in detachable inserts that we hope readers will find useful.

1. European Science Foundation 2011; ISBN 978-2-918428-36-7

2. Paulussen TGWM: Adoption and implementation of AIDS education in Dutch secondary schools. PhD thesis University of Maastricht: 1994

3. Fleuren MAH et al. Tijdschrift voor Gezondheidswetenschappen (TSG), 2004: 82, 42-49.

Table 1: The ten main recommendations, the stakeholders responsible for implementing the recommendations and the actions needed

Recommendation	Actions needed	Stakeholder groups
1. Strengthen European coordination and collaboration in and funding of systematic reviews of existing evidence, comparative effectiveness research, health technology assessment (HTA) and clinical practice guidelines.	• Improve funding, collaboration and coordination at the European level. • Set up a pan-European interdisciplinary working group to develop effective implementation strategies. • Integrate existing groups and networks. • Develop a common international declaration for researchers, publishers and agencies to use or work with evidence-based medicine (EbM), HTA and clinical guidelines. • Establish a European Institute for Health Research to provide a forum where issues of common interest in Europe in healthcare research and policy can be debated and appropriate strategies formulated. Encourage medical associations to have EbM and HTA sessions during meetings to improve awareness and knowledge.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group) Group 4 ('patients and public' group) Group 5 ('communicators' group) Group 6 ('industry' group)
2. Foster transparency and require evidence on comparative effectiveness and costs of interventions to demonstrate added value before approval for use in publicly funded health services.	• Establish an approval and transparency system for medical interventions. • Evaluate the possibility of establishing mandatory registries (on cost effectiveness, use and patient safety) for new and existing medical technologies and interventions on a national and/or supranational level. • Set up a working group to discuss how to change the process of assessing a new medicinal product so that added value can be demonstrated before it is approved for use in the publicly funded health services. • Evaluate the possibility of establishing national systems for preapproval use and conditional reimbursement of medical innovation during the phase of evidence generation. • Organise dialogue-meetings between HTA/EbM leaders and political leaders, policy-makers and health administrators at the European, national, regional and local level.	Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group) Group 6 ('industry' group)
3. Improve the education, training and career structures for health professionals in prioritisation, funding, planning, conducting and reporting of clinical comparative effectiveness research and evidence-based medicine and policy.	• Provide best practice models for health professional training in critical appraisal. • Evaluate at the national level opportunities for developing curricula on the use and development of evidence in healthcare in university courses, postgraduate training and continuing development programmes. • Ensure adequate training in health research methodology, conduct, and reporting for health professionals involved in research with a particular focus on early career professionals. Initiatives such as EQUATOR[1] (Enhancing the QUAlity and Transparency Of health Research) and the planned Centre for Health Research Education – European Collaborative Education Network can play a key role. • Introduce and accept activities in the field of HTA, EbM, guideline production and implementation as part of the academic research career. • Introduce activity-based HTA processes, with support and quality control processes, in healthcare organisations to disseminate practical knowledge of these activities where healthcare is provided. • Establish at the national level Healthcare Knowledge Centres for improved access to and transfer of unbiased information on patient-oriented research.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group)

1. http://www.equator-network.org
2. http://www.lindalliance.org/
3. http://www.comet-initiative.org/
4. http://www.g-i-n.net/
5. http://www.partecipasalute.it/cms_2/node/966
6. http://consumers.cochrane.org/cochrane-groups
7. http://eppi.ioe.ac.uk/cms/
8. Chalmers, I & Glasziou, P. Avoidable waste in the production and reporting of research evidence. Lancet, 2009, 374, 86-89.
9. http://www.equator-network.org/resource-centre/library-of-health-research-reporting/

4. Involve patients and the public in making decisions about prioritisation, funding, planning, conduct and reporting of clinical comparative effectiveness research and EbM.	• Discuss strategies in interdisciplinary groups with patient representatives, researchers, funding agencies and media. • Instigate targeted media campaigns, harnessing new media such as Twitter, Facebook and YouTube, to improve the public's engagement with the research process and raise awareness of EbM and HTA principles. • Universities and journalist organisations to organise workshops on EbM, guideline use and HTA. Organisations such as the James Lind Alliance[2] and the Core Outcome Measures in Effectiveness Trials (COMET)[3] initiative in the UK, the Patient and Public Group of the Guidelines International Network (G-I-N)[4], and the PartecipaSalute project[5] in Italy should play a key role. • Relevant organisations, such as the Cochrane Communication and Consumers Group[6] and the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre)[7] in the UK, to gather evidence about the involvement of patients and the public in setting the healthcare research agenda. • Journal articles and medical curricula to stress the importance of active public/patient involvement.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group) Group 4 ('patients and public' group) Group 5 ('communicators' group)
5. Support and facilitate methodologically sound, high-quality clinical research inspired by gaps and uncertainties identified through systematic reviews that address the needs of patients, health professionals and society.	• Through broad discussion with representatives of the relevant stakeholders, develop dissemination and implementation strategies to improve quality in the different stages of medical research within Europe. • Funding structures to reflect the importance of independently instigated clinical research. • Set up research networks and ensure collaborative research between primary and secondary care. • Instigate more research on treatments and treatment pathways in primary care. • Implement mandatory registration of studies in ClinicalTrials.gov or similar to have a study published. Facilitate easy registration of all research studies.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group) Group 4 ('patients and public' group) Group 5 ('communicators' group) Group 6 ('industry' group)
6. Promote rigorous reporting of all clinical studies.	• Stakeholders must insist on implementing this recommendation as an ethical imperative. Over 50% of clinical studies are never published in full, and more than 30% of trial interventions are not sufficiently well described; there is too much biased under-reporting of studies that have disappointing results[8]. • Reports to be written taking into account the reporting standards identified and catalogued by EQUATOR in its online Library for Health Research Reporting[9].	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group) Group 4 ('patients and public' group) Group 5 ('communicators' group) Group 6 ('industry' group)
7. Strengthen shared national and international open access databases on protocols, data, reports, scientific publications, systematic reviews, health technology assessments and clinical practice guidelines.	• Initiate a broad discussion, involving researchers, methodologists, funding agencies and representatives from industry. • In order to facilitate discoveries and innovation in biomedical research, research stakeholders should collaborate to establish a Europe-wide repository in biomedicine as a partner site to the US equivalent PubMed Central (PMC). The recently rebranded Europe PMC represents a valuable means to achieving this goal, provided that the diverse European partners in terms of mandates and policies can be integrated. Use existing well-established local or national solutions as best practice models for open access and information sharing. • Develop strategies to define optimal methods and pathways to improve easy and understandable access to HTA and EbM reports and clinical practice guidelines for both healthcare professionals and patients/citizens.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group)

Recommendation	Actions needed	Stakeholder groups
8. Increase use and implementation of HTA reports and clinical guidelines in administrative processes including financing of technologies. Implement and improve guidelines in clinical practice through IT tools, audit and feedback, clinical indicators and continuous updates.	• Develop strategies to strengthen the role of HTA, EbM and clinical guidelines. • Increase awareness of HTA throughout the healthcare sector, especially in terms of the role it can play in funding and budgetary decisions and in disinvestment from outdated treatments and technologies. • Develop incentive systems for using and implementing evidence-based practice and policy at medical care level through national European guidelines or even regulations through ESF's Member Organisations and relevant learned societies. • Use existing well-established local or national solutions as best practice models. • The network of HTA agencies in Europe, EUnetHTA[10], to play an important role in implementing this recommendation.	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 4 ('patients and public' group)
9. Generate through multidisciplinary teams and with patient involvement, high-quality evidence-based clinical practice guidelines according to common standards and criteria.	• Develop incentive systems for using and implementing evidence-based practice and policy at medical care level through the Guidelines International Network (G-I-N) via ESF's Member Organisations and relevant learned societies. • Use existing well-established local or national solutions as best practice models. • Ensure guideline committees have a high representation of primary care practitioners. • Ensure that guidelines have consensus of all relevant stakeholders. • Define and promote national and international methodological standards for development and use of clinical guidelines ('guidelines for guidelines'), as used or promoted by the Guidelines International Network G-I-N, the US Institute of Medicine, as well as by several national healthcare agencies in Europe – for example the Scottish Intercollegiate Guidelines Network (SIGN) and the National Institute of Health and Clinical Excellence (NICE)[11] (UK); the German umbrella organisation of the Scientific Medical Societies (AWMF)[12] and the German Agency for Quality in Medicine (ÄZQ)[13] (Germany); Duodecim (Finland)[14]; and the Haute Autorité de Santé (HAS)[15] (France).	Group 1 ('researchers, professionals and teachers' group) Group 2 ('methodologists and assessors' group) Group 4 ('patients and public' group)
10. Strengthen the research evidence base for effective implementation strategies.	• Carry out systematic reviews of controlled trials of implementation strategies and further research to address uncertainties revealed by these reviews. • Make funding available to set up and promote European research groups on implementation research.	Group 2 ('methodologists and assessors' group) Group 3 ('funders and regulators' group)

10. http://www.eunethta.eu/
11. http://www.nice.org.uk/
12. http://www.awmf.org
13. http://www.aezq.de;
14. http://www.duodecim.fi/web/english/home
15. http://www.has-sante.fr/portail/jcms/j_5/accueil

*** Key stakeholder groups:**

Group 1: Academic research (basic to patient-oriented research), learned societies, universities; healthcare providers/hospitals, healthcare professionals, i.e. clinicians, primary care practitioners, medical specialists including medical ethicists; teachers (undergraduate and postgraduate medical training, and continuous professional development).
Group 2: Methodologists, systematic reviewers, healthcare professionals; health economists; HTA and guideline agencies and Cochrane Collaboration; policy-makers and healthcare systems.
Group 3: National and EU funding agencies and research councils; ministries; national and EU regulators; ethics committees.
Group 4: Patients and general public; patient and consumer organisations; philanthropic organisations.
Group 5: Journal editors and peer reviewers; media (internet, journals, medical journalists, etc.).
Group 6: Private sector; pharmaceutical industry; medical devices industry, etc.

The involvement of patients and the public in medical research and its implementation

Either directly or indirectly, the public funds most medical research, and people can benefit from research if research evidence is used to inform decisions and choices in practice. For these reasons, patients and the wider public must be at the centre of any move to improve the quality of research and to ensure that new research evidence is taken into account in practice. Although patients are the principal 'end users' and potential beneficiaries of research, they are not often involved in the process of generating research, or in its funding and implementation. Involving patients actively in research requires a significant culture change and requires that a number of barriers be addressed, including people's attitudes and levels of awareness. Health research professionals need to recognise that important advantages can result from engaging the public in the research process.

Communication is an important aspect of engaging citizens with research. It is important that press releases covering research reports are produced with input from the researchers, and are worded suitably for a lay audience. They need to communicate numerical information using natural frequencies rather than odds ratios, for example, and without jargon. New social media will become increasingly important avenues for information – Twitter, Facebook and YouTube, for example.

Contributions from patients and citizens can be formal or informal, from individuals or from groups, using various methods to provide insights into the best ways to select and develop research questions. Patients can identify mismatches between research that gets done and research they would like to see done, thus contributing to research agenda setting. The James Lind Alliance is one example of an initiative that brings patients, their carers and clinicians together to identify and prioritise treatment uncertainties for research. Another initiative is the PartecipaSalute project of the Mario Negri Institute in Italy, which brings together consumer associations and the medical community. On an international level, the G-I-N Patient and Public Group, an initiative of the Guidelines International Network (G-I-N), develops and promotes methods and best practice models for participation of patients and the wider public in the production and use of evidence-based clinical practice guidelines.

Patients can help to provide a 'patient view' within a research team to illuminate what it is like to be involved, thereby helping to design trials that are 'patient friendly' and workable. They can help to refine research questions, prioritising and highlighting important factors. They can suggest important additions to questions, eliminate unimportant factors and help make a complex trial protocol comprehensible to lay people, thereby improving the readability, quality and style of information for potential participants. Patient and public involvement in trials can lead to improved recruitment and to successful completion of studies.

Knowledgeable and well-trained health professionals and involved lay people can together campaign strongly to ensure that resources – human and financial – are not wasted on futile, unnecessary or poorly conceived and executed research.

In the light of the issues outlined above, ESF makes the following recommendations:

- Best practices for involving patients and the public should be identified and promoted.
- Based on the available evidence, consideration should be given to involving patients and the public at all stages of the research process: priority setting, planning, executing, reporting, dissemination and implementation.
- Citizens should be educated about research concepts, and properly informed about the important discoveries made through patient participation in research and through secondary uses of patient data.
- Patient groups and citizen advocates should be independent and without affiliation to industry, and patient groups should declare all sources and amounts of funding and specify the role of funders and sponsors in the groups' activities.
- Statistical literacy modules should be introduced into school curricula.
- Health professionals and clinical researchers should receive training in patient involvement during their undergraduate and postgraduate training and as part of their continuing professional development. They should also be trained in communication skills, understanding and communication of risk, and communication of research concepts.
- Funders of clinical research should ask researchers to report on how patients have been involved in the development of their funding applications, and on how they plan to involve patients in the future. Funders should usually make genuine patient involvement a condition of funding.

- Researchers should fully report key information in their journal publications to raise the quality and transparency of reporting about the involvement of patients and the public. The GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist provides guidance on what should be included.

January 2010:
First brainstorming meeting, Copenhagen

↓ **Workshop planning**

May 2010:
3 workshops:
1) Production & Dissemination: How is medical research data produced, published and further disseminated?
2) Analysis & Translation: How is medical research data analysed and reflected in guidelines?
3) Implementation: How is medical research data implemented in clinical practice?

↓ **Draft report written**

October 2010:
Consensus conference: final decision about report content and recommendations

↓ **Report finalised**

May 2011:
Launch of the report, first discussion about implementation

↓ **Report disseminated**

September 2011 & March 2012:
Implementation meetings, 3 working groups
1) Patient & Public
2) Primary Care
3) Knowledge Generation and Transfer

Figure 3. The different steps of the Forward Look

Implementing medical research in primary care practice[4]

Primary care practitioners – family doctors and others – encounter a wide cross section of the population. They therefore have a central role in ensuring that relevant medical research is done, and that the results are taken into account in practice. A number of issues remain to be resolved, however, not least that medical research is currently only guided to a modest degree by questions relevant to primary care. As a consequence, specialist-driven research results may be of questionable relevance in primary care practice.

Primary care practitioners see six broad categories of people:

- healthy people;
- people who are suffering but have no objective signs to explain symptoms;
- people who feel ill and for whom the doctor can identify objective signs of disease;
- people who may or may not feel ill with long-term progressive conditions (chronic diseases), for example, diabetes;
- people who feel healthy but in whom asymptomatic signs or risk factors for future disease are identified;
- people who have been diagnosed as palliative care/end-of-life care patients with progressive diseases.

Many patients have objective signs of diseases, risk factors and symptoms without an objective explanation, resulting in multimorbidity, and are therefore not restricted to any one of the above categories.

A number of issues derive from this broad spectrum of patient types. Medical knowledge gained in secondary care may not be helpful in primary care. Some definitions of medical risk potentially define everybody as in need of medical control – with potential destabilising effects on healthcare systems. Objective medical research results do not provide adequate explanations about functional diseases. Comorbidities represent a considerable challenge for individual patients, the healthcare system and society at large, and may not have been taken into account by researchers and so cannot be taken into account in systematic reviews of research.

An editorial in the British Medical Journal commenting on the EMRC Forward Look, *Implementing Medical*

4. For the purposes of this Science Policy Briefing, "primary care practice" is synonymous with "family medicine", "general practice" and "primary healthcare".

Research into Clinical Practice, noted that "Improvement requires health services research and evidence-based leadership in healthcare, with a strong focus on the clinical management of the total disease trajectory. This demands independent public funding of health services research that looks at how to implement and sustain change in clinical practice and the training of doctors in evidence-based leadership and decision making."[5]

Medical research should therefore be context-oriented to reflect the decision-making circumstances. In other words, appropriate knowledge for primary care needs to be generated at this level. Medical knowledge ought to mirror, in a comprehensive and consistent way, the converging findings from a number of disciplines, documenting the interconnectedness between human biology and biography.

Systematic research needs to be carried out into evidence-based prevention, diagnostic and treatment procedures. For dissemination and transfer of high-quality healthcare knowledge, clinical practice guidelines and treatment pathways should become standard procedures in primary care. This will involve health services research and clinical research that is context-dependent. There are two main topics of research in primary care that have received far too little attention: how do we best handle the issue of risk factors and how do we deal with people who have symptoms with no objective explanation? These questions need to be addressed.

Education and training also needs to be addressed. Most medical students receive the majority of their training in hospitals, but this does not reflect the balance of where most citizens meet the health service, which is in primary care. Career pathways for doctors who wish to pursue research are usually ill-defined or non-existent.

Primary care is an important learning arena and there should be more teaching in the primary care setting, but with the key provision that quality of teaching is maintained. There should also be movement of GPs to teach in a secondary care environment. Intermediate clinics, where hospital specialists come into primary care to share their expertise, could make a useful contribution to this 'crossover'. There needs to be better academic input into primary care research, and this needs well-defined career paths for GP-PhDs. More PhD studentships in primary care should be made available.

The organisations responsible for implementing these changes need to have in place a model for providing strong and effective leadership for the change management process. In addition, there should be parallel research surveying the changes, to ensure that any change that is instituted is effective and achieves what it was designed to achieve.

5. F Olesen. Putting research into primary care practice. British Medical Journal, 2011, DOI: 10.1136/bmj.d3922.

Implementing research: examples of best practice

Knowledge transfer

In the Netherlands knowledge generation and transfer on effective implementation is stimulated by positioning implementation fellows in the various university medical hospitals throughout the country. These implementation fellows function as interconnectors between practice and research to initiate, stimulate and execute research in the field of implementing new knowledge on quality of care and patient safety. The Implementation Fellowship Programme is funded by the Dutch Organisation for Health Research and Development (ZonMW)[6].

In Germany generation and transfer of evidence-based healthcare knowledge is stimulated by the legal obligation to reimburse primarily those technologies within the framework of social health insurance for which patient-oriented benefit has been assessed according to the standards of evidence-based medicine (Federal Social Code Book). Furthermore, social sickness funds and physicians' organisations are now contracting healthcare programmes based on evidence-based guidelines.

Several national agencies are active in the field of knowledge generation, appraisal and transfer, such as the German Cochrane Centre and the Institute for Quality and Effectiveness in Healthcare (IQWiG). Responsible for safeguarding the development and dissemination of high-quality clinical practice guidelines are the umbrella organisation of the Scientific Medical Societies (AWMF[7]) and the Agency for Quality in Medicine (ÄZQ[8]).

On the European level, WHO/Europe addresses the need for trustworthy sources of evidence on which to build health policy with the Health Evidence Network

6. http://www.zonmw.nl/nl/
7. http://www.awmf.org
8. http://www.aezq.de

(HEN)[9], which gives access to independent and reliable health information and evidence. HEN produces policy briefs and policy summaries related to implementation strategies.

Education and training

In the Netherlands a new master's degree in Quality and Safety of Patient Care is being developed as an integrated master's programme for professionals, to which the eight Dutch university medical centres will contribute by giving a three-day course on a specific subject, including, for instance, EbM and implementation. This postgraduate master's programme is initiated and supported by the consortium Quality of Care of the Dutch Federation of University Medical Centres.

In Region Västra Götaland in Sweden, and now spreading to other healthcare regions, activity-based HTA with support and quality control processes is used[10]. Clinicians who want to introduce a new technology must perform, with support and quality control processes, a systematic review/HTA demonstrating the evidence for the technology. More than 50 such HTA reports have been produced in the Region in recent years, informing decisions by administrators and heads of clinics. Another important output in the activity-based HTA process is training of clinicians in systematic review/HTA processes ('learning by doing') – today more than 200 clinicians have had such training and can spread their knowledge where they work.

In Germany the Network for Evidence Based Medicine (Deutsches Netzwerk Evidenzbasierte Medizin), a multiprofessional scientific association, coordinates the development and implementation of national student and postgraduate curricula for evidence-based healthcare[11].

Public engagement

The Karolinska Institute in Sweden runs courses in popular science reporting. One example of a useful textbook is *Medical Journalism – Exposing Fact, Fiction, Fraud* by Ragnar Levi[12].

The book *Testing Treatments: Better Research for Better Healthcare*[13] is written in a language accessible to the broader public to raise awareness of the importance of fair (unbiased) tests of treatments.

A project in the Netherlands has examined the use of Wiki technology to engage the public in the prioritisation of key questions and generation of guideline recommendations. A Wiki is a website-based collaboration tool where anyone can contribute, read, edit and organise the contents – the best known example being Wikipedia[14].

Guideline-developing organisations that use public involvement strategies and discuss effective methods and develop standards include NICE (UK), ÄZQ and AWMF (Germany), G-I-N (Guidelines International Network) and GuíaSalud (Spain).

Patient involvement is considered a quality criterion within the appraisal of Guidelines for Research and Evaluation (AGREE) Instrument for assessing guidelines[15] and within the different Grading of Recommendations Assessment, Development and Evaluation (short GRADE) Working Group[16].

9. http://www.euro.who.int/en/
10. http://www.sahlgrenska.se/hta-centrum
11. http://www.dnebm.de

12. Lund: Studentlitteratur, c2000, ISBN 0-8138-0303-9
13. http://www.jameslindlibrary.org/testing-treatments.html
14. http://www.g-i-n.net/document-store/abstracts-and-presentations-conference-lisbon-2009/abstracts-participants-conference-lisbon-2009/monday-1-november-2009/O24-A-new-method-for-patient-participation-in-the.pdf
15. http://www.agreetrust.org/
16. http://www.gradeworkinggroup.org/index.htm

Abbreviations

COMET: Core Outcome Measures in Effectiveness Trials

EbM: Evidence-based medicine

EPPI-Centre: Evidence for Policy and Practice Information and Co-ordinating Centre

EQUATOR: Enhancing the QUAlity and Transparency Of health Research

HTA: Health Technology Assessment

EMRC: European Medical Research Councils

ESF: European Science Foundation

EU: European Union

Europe PMC: Europe PubMed Central

G-I-N: Guidelines International Network

PMC: PubMed Central

SIGN: Scottish Intercollegiate Guidelines Network

This ESF Science Policy Briefing has been written by the following experts:

Chair

- **Professor Liselotte Højgaard**
  EMRC Chair, Director, Professor, Clinical Physiology, Nuclear Medicine & PET, Rigshospitalet, University of Copenhagen and Danish Technical University, Denmark

Working group: Public and patient involvement

- **Sir Iain Chalmers**
  Coordinator, The James Lind Initiative, National Institute for Health Research, United Kingdom
- **Dr Trish Groves**
  Deputy Editor, British Medical Journal, United Kingdom
- **Dr Line Matthiessen-Guyader**
  Head of Unit, Infectious Diseases and Public Health, DG Research & Innovation, European Commission, Belgium
- **Dr Paola Mosconi**
  Head of Laboratory for Medical Research & Consumer Involvement, Department of Oncology, Mario Negri Institute, Italy
- **Corinna Schaefer M.A.**
  Head of Patient Information Department, German Agency for Quality in Medicine, Chair of G-I-N PUBIC (Guidelines International Network Patient and Public Involvement Working Group), Germany
- **Mrs Hazel Thornton**
  Independent Citizen Advocate for Quality in Research and Healthcare/ Honorary Visiting Fellow, University of Leicester, United Kingdom

Working group: Primary care practice

- **Professor Rodger Charlton**
  GP and Associate Clinical Professor, Nottingham University Medical School, UK, Honorary Professor, College of Medicine, Swansea University, UK
- **Professor Irene Hetlevik**
  Department of Public Health & General Practice, Norwegian University of Science and Technology (NTNU), Norway
- **Professor Frede Olesen**
  Professor in Family Medicine/GP, Department of Public Health, Aarhus University, Denmark
- **Professor Stig Slørdahl** (Chair)
  Dean, Faculty of Medicine, Norwegian University of Science & Technology / EMRC Core Group, Norway
- **Professor Jørund Straand**
  Department of General Practice/ Family Medicine, Institute of Health and Society, University of Oslo, Norway
- **Dr David Tovey**
  Editor in Chief, *The Cochrane Library* The Cochrane Collaboration, United Kingdom
- **Professor Veronique Verhoeven**
  Researcher, Primary and Interdisciplinary Care, Faculty of Medicine, University of Antwerp, Belgium

Knowledge Generation and Transfer

- **Professor Gerd Antes**
  Director, German Cochrane Centre, University Medical Center Freiburg, Germany
- **Ms Allison Hirst**
  Research Fellow, EQUATOR Network, Centre for Statistics in Medicine, United Kingdom
- **Dr Gro Jamtvedt**
  Executive Director, Norwegian Knowledge Centre for the Health Services, Norway
- **Professor Lennart Jivegård**
  Assistant Professor, HTA-centrum, Sahlgrenska University Hospital, Sweden
- **Dr Ragnar Levi**
  Scientific Communications Director, The Swedish Council on Health Technology Assessment, Sweden
- **Professor Günter Ollenschläger**
  Director, German Agency for Quality in Medicine, Germany
- **Dr Gera Welker**
  Implementation Fellow/Quality Consultant, Health Technology Assessment, University Medical Centre, The Netherlands

Science Writer

- **Mr Simon Hadlington**, United Kingdom

ESF-EMRC Standing Committee Members consulted

Austria

- **Austrian Academy of Sciences (ÖAW)**
  Professor Hans Lassmann, Brain Research Institute, Vienna

Belgium

- **Fund for Scientific Research (FNRS)**
  Professor Pierre Gianello, Catholic University of Louvain, Woluwe-St-Lambert

- **Research Foundation Flanders (FWO)**
  Professor Roger Bouillon*,
  Laboratory of Experimental Medicine and Endocrinology, Leuven

Bulgaria

- **Bulgarian Academy of Sciences (BAS)**
  Professor Bogdan Petrunov,
  National Center of Infectious and Parasitic Diseases, Sofia

Croatia

- **Croatian Academy of Sciences and Arts (HAZU)**
  Professor Krešimir Pavelic,
  Rudjer Boskovic Institute, Zagreb

Cyprus

- **Cyprus Research Promotion Foundation (RPF)**
  Not represented

Czech Republic

- **Academy of Sciences of the Czech Republic (ASCR)/Czech Science Foundation (GAČR)**
  Professor Josef Syka*,
  Institute of Experimental Medicine, Prague

Denmark

- **Danish Council for Independent Research – Medical Sciences (FSS)**
  Professor Niels Frimodt-Møller,
  University of Copenhagen, Hvidovre

Estonia

- **Estonian Research Council (ETAG)**
  Professor Raivo Uibo,
  University of Tartu, Tartu

Finland

- **Academy of Finland**
  Professor Tuula Tamminen,
  University of Tampere, Tampere

France

- **National Centre for Scientific Research (CNRS)**
  Dr Emmanuelle Wollman, Paris
- **French National Institute of Health and Medical Research (Inserm)**
  Dr Claire Giry*, Inserm, Paris

Germany

- **German Research Foundation (DFG)**
  Professor Martin Röllinghoff*,
  Nuremberg University, Nuremberg

Greece

- **National Hellenic Research Foundation (NHRF)**
  Professor Andrew Margioris,
  School of Medicine, Heraklion

Hungary

- **Hungarian Academy of Sciences (MTA)/Hungarian Scientific Research Fund (OTKA)**
  Dr János Réthelyi,
  Semmelweis University, Budapest

Iceland

- **Icelandic Research Council (RANNIS)**
  Dr Jona Freysdottir,
  University Research Hospital, Reykjavik

Ireland

- **Health Research Board (HRB)**
  Professor Catherine Godson,
  University College Dublin, Dublin

Italy

- **National Research Council (CNR)**
  Professor Giovanni Pacini*, Institute of Biomedical Engineering, Padova

Lithuania

- **Research Council of Lithuania (LMT)**
  Professor Limas Kupčinskas, Lithuanian University of Health Sciences, Kaunas

Netherlands

- **Netherlands Organisation for Scientific Research (NWO)**
  Professor Marcel Levi,
  Academic Medical Centre, University of Amsterdam, Amsterdam

Norway

- **The Research Council of Norway**
  Professor Stig Slørdahl*,
  Norwegian University of Science and Technology, Trondheim

Poland

- **Polish Academy of Sciences (PAN)**
  Professor Anna Czlonkowska, Institute of Psychiatry and Neurology, Warsaw

Portugal

- **Foundation for Science and Technology (FCT)**
  Professor Isabel Palmeirim, Department of Medicine, University of Algarve, Faro

Romania

- **National Council for Scientific Research (CNCS)**
  Professor Simona-Maria Ruta,
  Carol Davila University of Medicine, Bucharest

Slovakia

- **Slovak Academy of Sciences (SAV)**
  Dr Richard Imrich, Centre for Molecular Medicine, Bratislava

Spain

- **Council for Scientific Research (CSIC)**
  Professor Isabel Varela-Nieto*,
  Instituto de Investigaciones Biomédicas 'Alberto Sols', Madrid
- **Ministry of Economic Affairs and Competitiveness (MINECO)**
  Dr Carlos Segovia, Institute of Health Carlos III (ISCiii), Madrid

Sweden

- **Swedish Research Council (VR)**
  Professor Mats Ulfendahl,
  Swedish Research Council, Stockholm

Switzerland

- **Swiss National Science Foundation (SNF)**
  Professor Stéphanie Clarke,
  Centre Hospitalier Universitaire Vaudois, Lausanne

Turkey

- **The Scientific and Technological Research Council of Turkey (TÜBITAK)**
  Professor Haluk Topaloğlu,
  Hacettepe Children's Hospital, Ankara

United Kingdom

- **Medical Research Council (MRC)**
  Dr Mark Palmer*,
  Medical Research Council, London

* The delegate is also a Core Group member

This ESF Science Policy Briefing has been prepared under the responsibility of the Standing Committee of the European Medical Research Councils (EMRC):

- **Professor Liselotte Højgaard**
  EMRC Chair, Director, Professor, Clinical Physiology, Nuclear Medicine & PET, Rigshospitalet, University of Copenhagen and Danish Technical University, Denmark
- **Professor Kirsten Steinhausen**
  Senior Science Officer,
  ESF, Strasbourg, France
- **Dr Stephane Berghmans**
  Head of Biomedical Sciences Unit,
  ESF, France
- **Ms Janet Latzel**
  Biomedical Sciences Unit Coordinator,
  ESF, Strasbourg, France

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European Science Foundation
1 quai Lezay-Marnésia • BP 90015
67080 Strasbourg cedex • France
Tel: +33 (0)3 88 76 71 00
Fax: +33 (0)3 88 37 05 32
www.esf.org

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