Strengthening the evidence base for a learning health system

Inspirations from good practice for capacity building in health services research and public health research



Ludwig Boltzmann Institut Health Technology Assessment

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Inspirations from good practice for capacity building in health services research and public health research



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Conflict of Interest

All contributing authors declare that they have no conflicts of interest according to the Uniform Requirements of Manuscripts Statement of Medical Journal Editors (www.icmje.org)

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List of Abbreviations

AUS	Australia	NO	Norway
ÄZQ	Agency for Quality in Medicine, Germany	NOK	Norwegian Kroner
BQS	Federal Office for Quality Assurance, Germany	NOKC	Norwegian Knowledge Center for Health Sciences
CAN	Canada	NOR	Norway
DG	Directorate General, European Union	NOWT	Netherlands Observatory of Science and Technology
DIMDI	German Institute of Medical Documentation and Information	NRW	North-Rhine Westphalia, Germany
DK	Denmark	NSW	New South Wales, Australia
DKK	Danish Kroner	NWO	Netherlands Organization for Scientific Research
DSI	Institute for Health Sciences Research, Denmark	PhD	Doctor of Philosophy
EU	European Union	PHR	Public Health Research
EUPHA	European Public Health Association	PHSF	Public Health Status and Forecasts Report, RIVM
EUPHIX	European Union Public Health Information and Knowledge System	PHSR	Public Health Services Research
EUR	Euro	PISA	Programme for International Student Assessment
EuSANH	European Science Advisory Network for Health	R&D	Research and Development
GBP	British Pound	RCN	Research Council of Norway
GR	Health Council of the Netherlands	RGO	Advisory Council on Health Research, Netherlands
HSPHR	Health Services Research and Public Health Research	RIVM	Netherland Institute of Public Health and the Environment
HSR	Health Services Research	RVZ	Council for Public Health and Health Care, Netherlands
НТА	Health Technology Assessment	sciQuest	Standard Evaluation for Public Research Organizations, Netherlands
ICT	Information and Communication Technology	SDO	Services Delivery and Organisation Programme, England
IQWiG	Institute for Quality and Efficiency in Health Care, Germany	SPHERE	Strengthening Public Health Research in Europe
ISO	International Organization for Standardization	SWOT	Strength – Weaknesses – Opportunities – Threats
KNAW	Royal Netherlands Academy of Arts and Sciences	UK	United Kingdom
LBI-HTA	Ludwig Boltzmann Institute of Health Technology Assessment	USA	United States of America
Mio.	Million	VSNU	Association of Universities in the Netherlands
МоН	Ministry of Health	VU	VU University Amsterdam
MSc	Master of Science	WHO	World Health Organisation
NICE	National Institute for Health and Clinical Excellence, England	WIdO	Scientific Institute of the General Regional Sickness Funds, Germany
NIHES	Netherlands Institute for Health Sciences	WRR	Scientific Council for Government Policy, Netherlands
NIPH	Norwegian Institute of Public Health	Zon	Health Research and Development Council, Netherlands
NIVEL	Netherlands Institute for Health Services Research	ZonMw	Netherlands Organization for Health Research and Development
NL	Netherlands		

Summary

Background

WHO published its "World Report on Knowledge for better Health – Strenghtening Health Systems" in 2004. The EU's 6th Framework Program for Research analyzed the status quo of public health research. The current 7th Program looks at health services research. Always of central importance is the question of how to translate theoretical knowledge into practical action.

transfer of knowledge to practice as focus of WHO and EU reports on health services research and public health research

Motivation

To stimulate the debate on enablers of high-quality health services research and public health research, LBI-HTA initiated a report on organization and governance of health services research and public health research. A successful system (organization and governance) of health services research and public health research enables institutional and human resources capacity building, which are foundations of high-quality research.

LBI-HTA report to stimulate debate on capacity building

Research questions

The report starts off by touching upon some of the conceptual and theoretical issues relating to knowledge gaps in health systems, capacity building for research and the interface of research and policy. Then concrete examples for good practice from the Netherlands, Denmark, Norway and the UK are presented to gain ideas and draw inspiration.

conceptual issues and good practice examples from NL, DK, NO, UK

Results

Not least due to a long standing and well funded research tradition and a culture open to evidence based policy debate, model organizations in the field of health services research and public health research are found in particular in the Netherlands and in the UK. Transparent processes of prioritizing research questions, of communicating research results and of evaluating research and its implementation are necessary to establish a research system positively impacting the practice of political decision making. Trust between decision makers and researchers, characterized by intensive interaction along the entire research process, is a prerequisite for ultimate user relevance of research. Scientific competence in the narrow sense on the part of the research organization needs to be coupled with the ability to actively communicate with decision makers and with network building skills. This can be enhanced by organizational structures in research commissioning, academia and independent research organizations. In addition to political will, organizational leadership and sustainable funding commitments, capacity building requires time for a culture of problem solving in mutual respect to develop between decision makers and researchers. A perspective on research that takes organizational and systemic perspectives on board, that understands the production of evidence as a shared process and that is sensitive to context offers the most promising way forward.

transparent processes, interaction and trust between researchers and decision makers result in user relevance of research

political will, organizational leadership, long term funding necessary for capacity building

success factors:

- ... system perspective
- ... generation of evidence as shared process
- ... context sensitivity

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Zusammenfassung

Hintergrund

Die WHO veröffentlichte 2004 den "World Report on Knowledge for better Health – Strengthening Health Systems". Im abgelaufenen 6. Rahmenprogramm für Forschung der EU wurde eine Bestandsaufnahme der Public Health Forschung in Europa gemacht. Im laufenden 7. Rahmenprogramm steht Versorgungsforschung im Fokus. Immer ist dabei die Frage nach dem Transfer von theoretischem Wissen zu praktischem Handeln von zentraler Bedeutung.

WHO-Bericht, EU Forschung widmen sich der Frage nach Link zwischen Forschung und praktischer Umsetzung

Motivation

Um die Debatte zu den Rahmenbedingungen hochwertiger Versorgungsund Public Health Forschung zu bereichern, führte das LBI-HTA ein eigeninitiiertes Projekt zu Fragen der Organisation und "Governance" von Public Health Forschung und von Versorgungsforschung durch. Ein erfolgreiches System (Organisation und "Governance") von Versorgungs- und Public Health Forschung gewährleistet den Aufbau von personeller und institutioneller Kapazität, und legt damit den Grundstein für hochstehende Forschung. Capacity Building für Versorgungs- und Public Health Forschung als Gegenstand eines LBI-HTA initiierten Berichts

Forschungsfragen

Nach dem Beleuchten theoretischer Fragen zu Forschungsbedarf, der Etablierung von Forschungskapazitäten und dem Verhältnis von Forschung, Politik und praktischer Umsetzung werden in dem Bericht konkrete institutionelle Beispiele für "Good Practice" aus den Niederlanden, Dänemark, Norwegen und England beschrieben, um aus ihnen Anregungen zu gewinnen und Inspiration zu ziehen.

konzeptuelle Fragen und konkrete Good Practice Beispiele aus NL, DK, NOR, UK

Ergebnisse

Insbesondere die Niederlande und England verfügen nicht zuletzt aufgrund langer gutdotierter Forschungstradition und einer Kultur evidenzbasierter Politikdiskurse über Institutionen mit Modellcharakter im Bereich der Versorgungs- und Public Health Forschung. Transparente Prozesse bei der Priorisierung von Forschungsfragen, bei der Vergabe von Forschungsaufträgen, bei der Qualitätssicherung in der Forschungsdurchführung, bei der Kommunikation der Forschungsergebnisse und bei der Evaluierung von Forschung und deren Umsetzung sind notwendige Bausteine eines die politische Entscheidungspraxis befruchtenden Forschungssystems. Ein Vertrauensverhältnis zwischen politischen EntscheidungsträgerInnen und ForscherInnen mit möglichst intensivem Austausch entlang der gesamten Forschungsprozesskette ist Voraussetzung für AnwenderInnenrelevanz. Fachliche Kompetenz im engeren Sinn auf Seiten der Forschungsorganisation muss mit der Fähigkeit zu aktivem Kommunizieren mit EntscheidungsträgerInnen und dem Netzwerkbilden in die Praxis gepaart sein. Dies kann durch institutionelle Strukturen in der Forschungsförderung, im akademischen Bereich und im Bereich außeruniversitärer Forschungsinstitutionen gefördert werden. Deren Aufbau erfordert neben politischem Willen und nachhaltiger Finanzierung der kritischen institutionellen Masse auch vom Zeithorizont her einen langen Atem. Nicht zuletzt das Reifen einer von gegenseitigem Respekt getragenen Problemlösungskultur zwischen EntscheidungsträgerInnen und ForscherInnen benötigt Zeit. Ein Forschungsverständnis, das in organisationalen und systemweiten Zusammenhängen denkt, die Produktion von Evidenz als einen gemeinsamen Prozess begreift und sensibel für Kontextualisierung ist, verspricht am ehesten Erfolg.

transparente Prozesse bei Priorisierung, Forschungsvergabe, Qualitätssicherung, Ergebniskommunikation und Evaluation wichtig

Austausch
ForscherInnen,
PolitikerInnen schafft
Vertrauen für
gemeinsame
Problemlösung

strukturelle Maßnahmen bei Forschungsförderung, Forschungsorganisation en, Plattformen für Austausch helfen

offenes Forschungsverständnis erfolgsversprechend

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1 Introduction

1.1 Objectives

The utilisation of health research in policy making should contribute to policies that may eventually lead to desired outcomes, including health gains. Austria, like other countries, to date does not have a national research strategy for health services and public health. This LBI-HTA initiated and funded report intends to stimulate debate about the way to go forward in capacity building for health services research and public health research in Austria.

report to stimulate debate in Austria about capacity building in health services research and public health research ...

Learning from good practice in other countries is intended to inspire an inclusive and thorough development process of an Austrian strategy on how to build capacity for health services research and public health research. This strategy would include:

- The formulation of health services research and public health research priorities,
- Desirable governance principles for a health services research and public health research system,
- A plan for short and long term academic and institutional capacity building for health services research and public health research,
- An infrastructure mediating the interaction between research on the one side and policy on the other side,
- A roadmap towards a national data infrastructure necessary for high quality and multi facetted for health services research and public health research,
- Covenants between stakeholders on long term funding of capacity building and commissioning of health services research and public health research,
- A plan to implement strategies to bridge the divide between research and policy.

To inform the debate on health system learning this report begins with presenting a selective conceptual and theoretical background to this complex topic. Some of the central issues to be addressed in the course of drawing up a national health services research and public health research strategy are accentuated. The report then goes on to describe procedural and institutional good practice models realized in other countries to inspire the debate. It is very seldom that models of good practice are transferable 1:1 and this is not insinuated here. In conclusion, the report condenses suggestions from the theoretical literature and inspirations from examples of good practice into recommendations for Austria – or other countries interested in drawing up an agenda for building capacity in health services research and public health research.

... lessons from other countries to inspire development of Austrian research strategy

structure of report:

- ... selected conceptual and theoretical issues first
- ... then examples of good practice
- ... condensing into general recommendations

¹ Hanney (2003)

report does not

... analyze status quo of health services and public health research in Austria

> ... develop a detailed roadmap towards an Austrian research strategy

> > target audience of report:

... research funders

... research policy decision makers

... research community

This report does not aim to analyze the situation of health services research and public health research in Austria. A scoping study on strengths and weaknesses of the present implicit research priority setting for health services research and public health research in Austria, on research capacities at universities and government affiliated health services research/public health institutions, on research funding and on institutional mediation between research and policy in Austria would be an essential prerequisite for a later stage of the debate. Based on this additional detailed analysis of the status quo in Austria in the field of health services research and public health research a roadmap towards implementing a jointly formulated health services research and public health research agenda could eventually be implemented.

The target audience of this report consists primarily of health research funders, research policy decision makers and the research community, in particular those interested in a dialogue about the future of health services research and public health research in Austria.

Additionally this report is written for the broader group of health services research and public health knowledge users:

- Health policy administrators in government on national, state, regional and local level;
- Decision makers in health services research and public health administration and service delivery organizations;
- Practitioners in the fields of health care services and public health.

1.2 Research questions

research questions:

... concepts and theories important for strenghtening evidence

oase

... status quo of health services research and public health research in Europe

... good practice examples

The following questions guided the compilation of this report:

- 1.) What concepts and theories have to be considered when reflecting about strengthening the evidence base for a learning health system and the dynamics between evidence and policy on the way?
- 2.) What is the status quo of health service research and public health research in Europe?
- 3.) Which existing organizations delivering health service research and public health research can be considered good practice examples? Which structures and processes account for their model character? What are properties of the surrounding health services research and public health system that enable the success of research institutions?

The answers given to the initial two questions in this report are intended to set the stage for presenting the good practice examples providing answers to the last set of questions.

1.3 Methodology

The initial part of the report – dealing with the first of the above research questions – aims to briefly prepare the ground with conceptual and theoretical reflections taken from published literature on the following topics:

- * Knowledge gaps in health systems,
- Capacity building in health research,
- Relationship between evidence and policy,
- # Bridging the divide between research and policy.

The starting points for (unsystematic) literature searches were related reports funded by international organizations (WHO, EU).² In a snowballing system the literature sources of interest listed in these reports where further explored.

The second part of the report – addressing the second of the above research questions – gives an overview of the status quo of health services research and of public health research in Europe. For information it chiefly draws on scoping reports commissioned within the European Commission Research Programs:

- Strengthening Public Health Research in Europe SPHERE Sixth Framework Research Program of the European Commission: 2005 2007³
- * Health Services Research in Europe Seventh Framework Research Program of the European Commission: ongoing⁴

A closer look is taken at the situation in Germany. The German health system is characterized by organizational properties similar to Austria: federalist decentralization, corporatist administration and mandatory social health insurance.

The third and main part of the report describes good practice examples from expert organizations active in the field of health services research and public health research as well as good practice examples taken from institutions active in facilitating research, such as commissioning organizations. This is not to say that the organizations presented in this report show good practice in their entire range of activities and qualify as comprehensive organizational role models. Rather, distinctive practices of these organizations and selected experiences of these organizations, which are potentially worthwhile to learn from, are highlighted and presented. The choice of countries to screen for good practice examples to inform countries wishing to develop a learning health services and public health research system was guided by the following criteria:

- Tradition of evidence aware discourse about policy making in the field of health care and public health,
- Developed capacity in health services research and public health research,
- Information available on the internet in English.

When deciding on which lessons from abroad to learn from, the similarities and differences of the compared countries' political traditions and institutions on the one hand and those of its health care and public health sectors

unsystematic literature search on four conceptual / theoretical topics

2 scoping reports of European Commission Research Programs as basis for chapter on status quo in Europe

closer look at status quo in Germany

good practice examples from other countries ...

- ... with evidence aware political discourse
- ... with developed capacity for health services research and public health research

 $^{^2}$ WHO (2004) and www.healthservices research.eu, in particular Ettelt (2010)

³ www.ucl.ac.uk/public-health/sphere/spherehome.htm

⁴ www.healthservicesresearch.eu

on the other hand are important variables to be considered. These go beyond the scope of this report.

Initially screening countries and organizations in the field ... During the first stage of research, information about institutions relevant for health services research and public health research in a range of countries was gathered on the internet:

- Research funding institutions
- National research institutions, either independent or government affiliated
- Research centers at universities
- National Institutes of Public Health and the like
- Government bodies involved in health services research and public health research on national, regional and local levels

A list of initially screened institutions of interest not included in the report can be found in the appendix 8.5.

... selecting NL, DK, NOR, UK

... and NL for case study in overall "research – policy system"

information on good practice ...

... from institutions' websites

... from 13 senior to mid level expert telephone interviews The resulting choice of countries and institutions to be included in this report reflects in part aspects of convenience sampling. Eventually the Netherlands, Denmark and Norway and the United Kingdom were selected for further exploration. The Netherlands were chosen as the subject of an exemplary presentation of an entire "research – policy system". The case study on the Netherlands looks not only at individual institutions, but at the wider institutional interplay between stakeholders in research agenda setting, in research funding, in the commissioning of research and finally in the implementation of research and in policy making. It occupies the largest part in the good practice chapter.

"There is a need to look beyond formal arrangements if we wish to understand the relationship between research, policy and practice." To gain a little bit of this deeper understanding, the method of expert interviews was chosen to try to enrich insights. Allowing the readers of this report to "listen to the experts" in order to convey a "feeling" for the institution represented resulted in a lot of space given to the institutional presentations in chapter 5, making this chapter a little bit unbalanced in terms of length compared to the other chapters.

Building on the information available on the websites, institutions were chosen to conduct in-depth expert interviews on. Senior experts in these organizations were contacted via e-mail briefly describing the planned report. The senior experts were asked to either participate in person in a semi structured interview via telephone or to name another expert in their organization with relevant knowledge. Where necessary the e-mail was followed-up with a telephone call if there was no reaction within two weeks.

Expert interviews: 13 such interviews with durations of between 45 and 90 minutes were eventually conducted via telephone. Some with the initially contacted senior experts, some with mid-level experts suggested by their superiors in case they themselves did not avail themselves, because of time constraints or because they deemed the mid-level expert more competent to provide information on the topic of the report. Starting points of the interviews were individually calibrated sets of questions, guided by the general structure (see blueprint below). An example of such an interview guide for

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⁵ Nutley (2010), p. 141

the Netherlands Institute for Health Services Research NIVEL can be found in appendix 8.2.

Since the telephone interviews were meant to give as much room to the structuring of the questions at hand by the expert herself and to allow the expert to emphasize aspects of particular importance to her, the interview guide was not uniformly adhered to. This is why the presentation of good practice institutions in chapter 5 is not uniform and the level of detail provided is not consistent across institutions.

The telephone interviews were not recorded. Notes were taken during the conversation. Quotations from the interviews are therefore not verbatim. That is why no quotation marks are used when citing an interviewee's voice. Passages from expert interviews are presented in the report in either one of the two the following *italics* formats:

Politicians only want knowledge if it supports their position. 90% of decisions are being taken without knowledge/ evidence consideration. Knowledge is only one <u>small</u> factor in the process of policy making.

01

Politicians only want knowledge if it supports their position. 90% of decisions are being taken without knowledge/ evidence consideration. Knowledge is only one <u>small</u> factor in the process of policy making.

Eventually 15 institutions find themselves portrayed in this report, a few only briefly.⁶ The blueprint topical structure guiding the presentation and analysis of the chosen organizations in chapter 5 can be seen in table 1.3-1 below.

15 institutions presented

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⁶ A recent report for the Austrian Federal Ministry of Health on the organizational structures for health technology assessment in selected countries presented nine organizations in five countries, four of the countries European, compare Antony (2008)

Table 1.3-1: Blueprint topical structure for presenting and analyzing contacted organizations

Institution YZ

- 1. Fact sheet
- 2. Legal status
- 3. History
- 4. Funding
 - Share of non earmarked free funding
- 5. Setting the research agenda
- 6. Interaction with stakeholders
 - Decision makers
 - Research project stakeholders
 - General public
 - Internationally
- 7. Cooperation with the academic field
 - Research schools
 - Staff exchange
 - o Part time professorships
 - o Shared researchers
 - o Senior lecturers
 - o Internships/ stages
- 8. Quality assurance of research
 - ISO certification
 - Peer review
 - Evaluation
 - Quality of technical infrastructure
 - Interlinking of lines of research in-house
- 9. Research data
- 10. Implementation of research
 - Including dissemination of knowledge as a first step
- 11. Evaluation of research impact
- 12. Human resources policy
 - Qualifications looked for at recruiting
 - Long-term career development
 - Standing of natural vs. social sciences
 - Staff flows to and from other institutions
- 13. Looking to the future
- 14. A question beyond: Playing god for one day: what would you change in your work environment?

The fact that an institution is included as a "good practice" example in chapter 5 is not a judgment about the general effectiveness of the institution.

1.4 Limitations

The scoping of the report, the methods for information gathering for the report and the way results are presented in the report were chosen in line with the aim to initiate a debate on a national health services research and public health research strategy amongst a larger stakeholder group.

As mentioned in the section on objectives above, the conceptual and theoretical issues presented serve to accentuate and offer only a selective background to the topic of health systems learning. This report did not undertake a systematic review of the literature on the conceptual and theoretical questions involved (gaps in the evidence base necessary for health care systems, capacity building, conceptualization of the relationship between evidence and policy, strategies to successfully bridge the divide between research and policy). The choice of good practice examples presented does by no means purport to cover the most important (on whatever scale) or to be exhaustive. The good practice examples are meant to inspire and to make curious.

The presentation of individual good practice institutions relies on material taken from the institutions' websites and on a single (in one case two) telephone expert interview(s) within the institutions. The institutional portraits were strongly influenced by the views of the experts contacted. These experts express opinions about their own institutions. In this report, the presentation of their inside views is not balanced with critically reflective views from outsiders, who might have a different perspective on the organization discussed. Inside views may have a certain tendency to paint rosy pictures. In this sense this report does not purport to contain a selection of thorough and balanced academic case studies of the contacted institutions. In addition, when reading this report, the methodological limitations of telephone interviews as opposed to e.g. personal interviews on site or participatory observation should be born in mind.

What is true in terms of limitations of this report in the study of individual good practice organizations is even more true for the description of complex institutional interactions in the field of health services research and public health research funding, commissioning, undertaking, communicating of results and trying to bridge the divide between research and policy on a national level in the case study of the Netherlands: The telephone interviews for this report focussed on experts from research commissioning bodies, health services research and public health institutes, universities and administrative layers of government. Elected and unelected decision makers on government policy were not interviewed, neither were "end users" of research evidence in field of health (care). The Austrian author of this report was possibly to a degree influenced by the phenomenon of "the grass always looking greener on the other side of the fence". This should be taken into account when reading the report.

Finally, a caveat about the basic premise of this report: "Any evidence that increases in research use have indeed made the world a better place is at best partial and contested, and some would say is largely absent."

selective conceptual background

<u>not</u> systematic review of literature on theoretical issues involved

good practice portraits rely on

- ... one single
- ... telephone interview
- ... with organizational insider

No interviews with

... government policy decision makers

... users of research

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⁷ Nutley (2007), 297

2 Definitions

Health Services Research HSR

"Health Services Research in Europe" is a European Union funded project within the current seventh research framework program.⁸ The initiative aims at identifying, evaluating and improving the contribution of health services research to the health policy process in Europe. The project uses the following working definition of health services research as a

"multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being".

broad definition of health services research HSR from EU project used for report

Using a system theory model of health services research these distinct research areas – amongst others – are suggested to make up the field:¹⁰

- ♣ Input (resources)
 - Research on needs for health services
 - Utilization research
- Through-put (health services structures and processes)
 - Organizational research
 - Research into structural and outcome quality
- Output (health services)
 - Health economics
 - Health care management
- Outcome (result)
 - # Health technology assessment
 - # Health economics
 - Research into outcome quality
 - Effectiveness research

A concrete conceptualization of health services research domains developed by the Netherlands Institute for Health Services Research NIVEL can be found in figure 5.1-3 further below. NIVEL attaches particular importance to the area of primary care research. This is grounded in evidence on the utilization patterns of health care services such as a study using 1996 data from the USA:¹¹

importance of primary care research for HSR

⁸ www.healthservicesresearch.eu

⁹ Lohr (2002)

¹⁰ Pfaff (2004)

¹¹ Green (2001)

Every month, out of 1.000 persons

- 113 visit a primary care physician's office,
- ♣ 104 visit a specialist's office,
- 65 visit a complementary or alternative medical care provider,
- 21 visit a hospital outpatient clinic,
- ♣ 14 receive home health care,
- 13 visit emergency departments,
- * 8 are hospitalized,
- 1 (in fact even less: 0.7) is hospitalized in an academic medical center.

Public Health Research PHR

"Strengthening Public Health Research in Europe SPHERE" was a European Union funded project within the Sixth Framework Research Program of the European Commission, 2005 – 2007. Its two broad objectives were to describe public health research literatures and to determine priorities for research among European stakeholders. SPHERE used the following definition of public health research 13:

broad definition of public health research PHR from EU project used for report "Public health research refers to the organized quest for new knowledge to protect, promote and improve people's health.

- It is undertaken at population or health services level, in contrast to laboratory (cellular) or clinical (individual) health research;
- It differs from public health practice (which also uses scientific methods), as it is designed to obtain knowledge that can be generalized rather than to address specific programs for service delivery;
- It is usually goal-oriented, addressing questions of policy relevance, and may be published in either academic journals or reports; and
- tuses a range of observational methods, including surveys, registers, data sets, case studies and statistical modeling, and draws on disciplines including14 epidemiology, sociology, psychology and economics, and interdisciplinary fields of environmental health, health promotion, disease prevention, health-care management, health-services research and health-systems research."

definitions not clear cut and mutually exclusive

Public health research includes population level and health systems research but not clinical or biomedical research. Research fields include disease control, health promotion and health services.¹⁵

... public health systems research included

Apart from health services research and public health research, a third field of research has entered the stage lately, staking a claim for data and methods: public health <u>systems</u> research PHSR. ¹⁶ It defines itself as follows:

¹² www.ucl.ac.uk/public-health/sphere/spherehome.htm

¹³ McCarthy (2007a)

¹⁴ see also McCarthy (2007b)

¹⁵ McCarthy (2009)

"Public health systems research is a field of study that examines the organization, financing, and delivery of public health services within communities, and the impact of these services on population health." ¹⁷

Concept of HSR and PHR/ HSPHR used in this report

The definitions of HSR, PHR and public health systems research above are not distinct and mutually exclusive. In this report an inclusive and pragmatic definition is used, incorporating all the three above. The abbreviation HSPHR will be used for health services research and public health research in this broad understanding.

HSPHR can take place in a wide variety of settings within the health system, such as health policy decision making processes, health impact assessment, health equality assessment, community level public health initiatives, primary care, hospital care and many others.

broad and inclusive definition of health services research and public health research HSPHR used in this report

¹⁶ Holve (2010), AcademyHealth initiative Public Health Systems Research PHSR see also at

www.academyhealth.org/programs/ProgramsDetail.cfm?ItemNumber=2077&navItemNumber=524

¹⁷ Mays (2003)

3 Conceptual and Theoretical Aspects

Complex systems like the health (care) system need a regularly updated evidence base of descriptive and reflective knowledge. To continuously develop this base and to enable a system to become a learning system, a constant flow of knowledge inputs is required. A balance between basic research, user-oriented research geared towards solving problems, system research and learning from successes and failures through evaluation is needed. For health (care) systems this knowledge input comes from a wide array of public health and health services research.

learning system needs regularly updated evidence base

This chapter addresses the following conceptual and theoretical questions:

- Chapter 3.1: In what areas lie the current knowledge gaps in health systems?
- Chapter 3.2: In order for HSPHR to perform its tasks of producing evidence to help fill these gaps in knowledge, HSPHR capacity is necessary. How is capacity for HSPHR built, educating and training qualified researchers and creating organizational underpinnings for an environment conducive to the undertaking of high quality HSPHR?
- Chapter 3.3 looks at the interface of research and policy and asks how the implementation of findings from HSPHR is to be facilitated? What is the relationship between evidence and practice?

conceptual/theoretical questions addressed in this report

- ... knowledge gaps in health systems
- ... capacity building in HSPHR
- ... interface of research and policy with its relevance for implementation

3.1 Knowledge Gaps in Health Systems

In 2004 the World Health Organization published its "World Report on Knowledge for Better Health: Strengthening Health Systems". In the report WHO pointed out areas in need of answers from research in health systems in the field of financing, health information, service delivery and human resources. This list of challenges for HSPHR proposed by WHO, which could of course be itemized differently and elaborated on in more detail, should begin to give an idea of what knowledge HSPHR should contribute towards improving health systems:

WHO report on knowledge for better health points out knowledge gaps in health systems

Financing

- Inputs to health systems
 - Strengthening national health accounts
 - Development and testing of methods to track expenditures by use
- ♣ Financing function revenue collection and pooling
 - Financing schemes and equity
 - The sustainability of health financing
 - Health insurance schemes financial, administrative and technical aspects
 - Co-payments, user fees and exemptions
 - Public and private mix

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¹⁸ WHO (2004)

- ⇔ Financing function purchasing
 - The costs, effectiveness and impact on equity of interventions (taking into account interactions between different interventions)
 - Human resources, incentives and the rationalization of health services
- Measurement of key health system outcomes
 - Routine monitoring and assessment of the impact of the health financing system on access to services

Health Information

- Results generated by health information systems are needed to guide and complement health research
- Need to develop a set of practical "core metrics" to monitor the status and capacity of health systems with special attention given to equity issues
- Research into improving data accuracy

Health Services Delivery

- Research on how to scale up health services rapidly in the face of urgent public health problems
- Research to integrate single-disease programs into the broader health system
- Development of effective and efficient approaches to dealing with populations that have special needs, focusing on access
- Research on improving drug supplies, including cost-recovery schemes and interventions to improve prescribing and dispensing
- Evaluation of strategies to ensure quality in the health system setting
- Research into how to better manage chronic diseases (facilitating continuity of care, support of self-management)
- Providing decision support for health professionals that is consistent with scientific evidence and patient preference
- Research into system of feedback on performance to health-care providers

Human resources

- How does one assess the state of the health workforce?
- ♦ What is the optimal skill mix?
- How many workers are migrating and where?
- What types of recruitment and incentive packages work for attracting and retaining workers in remote areas?

Now that some of the questions for HSPHR are explicitly on the table, the question of how HSPHR is supposed to come up with answers poses itself. What needs to be taken care of in a health system for HSPHR capacity to develop in human resources, organizational and financial aspects?

3.2 Capacity Building

For HSPHR to flourish, capacity has to be in place on many levels:

- Researchers have to be trained at universities to enable them to conduct high quality research.
- State of the art methodological skills are essential for HSPHR.
- Practitioners in the field, administrators and policy decision makers need to be educated to be "HSPHR literate" in order to formulate research questions that lend themselves to being addressed by research and to later on make sense of research results and discern the parts lending themselves to outcomes relevant policy implementation.
- University based research centers need to be established alongside independent research organizations and government affiliated or government integrated research teams.
- Networks between these centers and with the international research community have to be established.
- Sunding for initial capacity building in HSPHR and long run sustained funding streams for research activities have to be made available.

A mechanism for determining the agenda of HSPHR and for commissioning, implementing and evaluating research has to be put in place, accompanied by the necessary institutional arrangements.

A generic conceptual framework for building capacity is helpful, determining the specific needs of capacity building. With these requirements in mind embarking on a voyage to build HSPHR-specific capacity within the health system arrangements and political context of a certain country will be better informed.

The following framework was originally drawn up for the area of health promotion, drawing on inputs from many sectors of society.¹⁹

Capacity building in the health system can be defined as "an approach to the development of sustainable skills, organizational structures, resources and commitment to health improvement in health and other sectors, to multiply health gains." It occurs more broadly within entire systems or within smaller programs and niches. Capacity building leads to greater capacity of people, organizations and entire (sub) systems. Three prominent dimensions of capacity building were identified in developing infrastructure, in enhancing sustainability and in fostering problem solving capabilities. Taken together with the overarching importance of contextual factors, this framework for capacity building is illustrated in figure 3.2-1 below.

capacity building needs

- ... trained researchers
- ... knowledgeable in state of the art methodological skills
- ... HSPHR literate policy and user community
- ... research institutions
- ... networks
- ... funding for initial capacity building

plus sustainable funding of research

mechanisms needed for

- ... setting research agenda
- ... commissioning research
- ... implementing and evaluating

greater capacity of

- ... people
- ... organizations
- ... entire (sub)systems

¹⁹ NSW Health Department (2001)

²⁰ NSW Health Department (2000)

²¹ Hawe (1997)

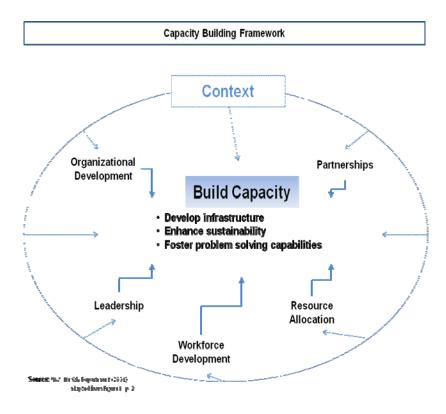


Figure 3.2-1: Capacity Building: Framework

interdependent areas of capacity building need to be developed together An additional positive effect of capacity building is fostering a system's ability to support change.²² For each of the three above dimensions of capacity building, interrelated key action areas were defined. The individual dimensions are not to be dealt with in isolation trough a piecemeal approach. Instead they reach their potentials only as part of the overarching capacity building effort. The key action areas are interlinked and influencing each other. They need to be developed in a coordinated and balanced way. The key action areas for building capacity are presented in figure 3.2-2 below.

²² NSW Health Department (2001)

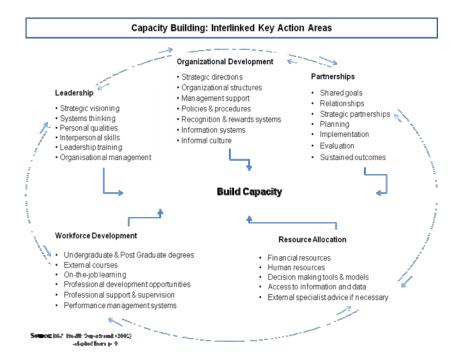


Figure 3.2-2: Capacity Building: Key Action Areas

Again the importance of taking contextual factors into account at all time should be stressed along with the need for giving respect and value for pre-existing capacity, the development of trust and well planned integrated strategies.²³

contextual factors important for capacity building

3.3 Evidence and Policy

Imagining that capacity for HSPHR was either already in place or has been developed successfully, and in this way high quality HSPHR-evidence has become potentially available, the question arises, how to best make it useful in practice. This leads to the reflection about the relationship between research and knowledge users or between evidence and policy. A more elaborate conceptualization closer to the complex reality of learning systems than underlying this report would also consider models of the interplay between evidence and practice.²⁴ On the outset of these reflections a warning is posted, a warning of "the dual follies of assuming, firstly, that research can provide objective answers to policy questions and, secondly, that policy making can become a more rational process"²⁵. With those caveats in mind, how can the interaction between research and policy be conceptualized?

limitations of research to provide answers to policy questions

policy making process messy

²³ NSW Health Department (2001)

²⁴ compare e.g. Nutley (2007), chapter 4

²⁵ Clarence (2002) and Parsons (2002) cited in Nutley (2003) p. 3

Models of interaction between evidence and policy

Weiss²⁶ reviewed social science research to explore the different models of how knowledge is transferred into policy. She came up with the following widely cited grouping of research utilization:²⁷

- * The knowledge-driven model research generates knowledge that impels action.
- The problem-solving (or engineering) model involves the direct application of the results of a specific study to a pending decision.
- The interactive/ social interaction model utilization occurs as a result of a complex set of interactions between researchers and users which ensures that they are exposed to each other's worlds and needs.
- The enlightenment (or percolation) model research is more likely to be used through the gradual 'sedimentation' of insight, theories, concepts and perspectives.
- The political model research findings are ammunition in an adversarial system of policy making.
- * The tactical model research is used when there is pressure for action to be taken on an issue, and policy makers respond by announcing that they have commissioned a research study on the matter.

linear assumptions on relationship between research and policy unrealistic The traditional linear assumptions about the nature of research and policy interaction, categorized under "knowledge-driven" and "problem solving" in Weiss' terminology, suppose straightforward relationships between research and policy and between knowledge and action. In these traditional models researchers undertake research, having chosen the topic either on their own initiative or having been commissioned to research a certain question by policy makers. This research is undertaken in accordance with the high academic standards of the research community. Once the research conducted yields results, these are passed on to the decision makers who frame policy decisions accordingly and the research is implemented in practice. Many voices do not consider this model to represent the actual interaction between research and policy very well:

"This is too simple, too rational, too linear, too one-directional, too individualized, too unproblematic, too asocial and acontextual." ²⁸

"A linear model of research-policy relations misses the often unstructured and ambiguous nature of many policy problems. Such problems are not easily tackled through unmediated research advice." 29

policies and science get shaped in mutual interaction Rather than focusing on the instrumental use of science in and by policy, it makes sense to analyze the ways in which both science and policies get shaped in their mutual interaction.³⁰

²⁶ Weiss (1979)

²⁷ Nutley (2003), Box 6 p. 11, adapted from Weiss (1979)

²⁸ Davies (2009)

²⁹ Bijker (2009)

³⁰ Bekker (2010) p. 238

"Simple models of the policy – research relationship, where evidence is created by research experts and drawn on as necessary by policy makers, fail as either accurate descriptions or effective prescriptions." ³¹

Simple, linear models seem particularly reductionist in the sphere of the complex health system with its high profile on the public's agenda, its multiple vested interests and the large share of industrialized nations' wealth distributed through it. One might envision another model introduced by Weiss as relevant for the health system interaction between research and policy. Perhaps, even probably, not too close to reality, but never the less attractive to strive towards in democratically founded societies: the interactive/social interaction model. It entails sharing in many forms:³²

social interaction and sharing as influential factors in progressive HSPHR

- Sharing the formulation of core questions,
- Sharing the creation of knowledge from diverse perspectives,
- Sharing the knowledge validation and application in use,
- Sharing the assessments of contextual effects and science impact,
- Shared spaces and co-producing knowledge.

Figure 3.3-1 below gives a graphic illustration of this transition.

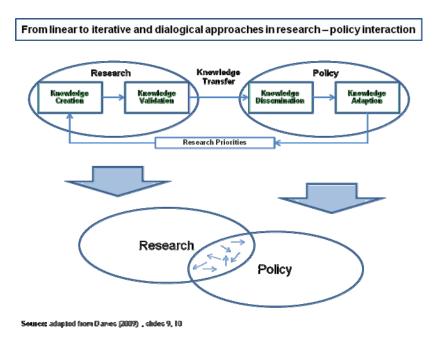


Figure 3.3-1: From linear to iterative and dialogical approaches in the interaction between research and policy

³¹ Nutley (2003) p. 16

³² Davies (2009)

Plausibly, the process of research utilization in practice shares properties with Weiss' "enlightenment" model, with her "political" model and with her "tactical" model.

"Policy making is an inherently political and often messy process where research gets used in a variety of ways, including the use of research as ammunition in an adversarial system of policy making. This is not a bad thing, particularly if useful knowledge (including research knowledge) is distributed more widely among members of policy and practice communities than is presently the case."³³

The changing conceptualization of the relationship between knowledge and action has also been put into a historical or even fashion context: Accordingly *linear models* with "knowledge transfer" and "dissemination" were prevalent from the 1960s to the 1990s, *relationship models* with "knowledge exchange" from the mid 1990ies to the present and *systems models* with "knowledge integration", "translation" and "mobilization" more recently. ³⁴

interaction between science, mediating institutions and policy of interest "Rather than focusing on the instrumental use of science in and by policy, it makes sense to analyze the ways in which both science and policies get shaped in their mutual interaction." So taking a closer look at the interaction between science, science mediating institutions and policy in the realm of HSPHR would be warranted. Taking inspirations from good practice models of these interactions practiced in other countries when reflecting on capacity building for HSPHR in Austria therefore seems to be worthwhile, too. Before doing this in the form of the presentation of good practice organizations in chapter 5 below, the nature of the divide between research and policy and how it may be narrowed will be considered.

The divide between Research and Policy

policy makers and researchers work in different societal subsystems governed by distinct logics Politicians don't understand and value researchers (lack of familiarity with research methods and processes, expectations of what research projects can achieve). Researchers don't understand and value politicians (limited time for preparation and reflection, consideration of other kinds of evidence, need to reconcile conflicting interests, values, ideas, ideologies). Both act in normatively powerful sub-systems of society: Politicians in the sphere of (democratically legitimized) power and decision making, researchers in the sphere of (searching for) truth and progress. Although this divisions of worlds between researchers and politicians is not universally true, helpful inferences can be drawn from juxtaposing them in a slightly reductionist "black and white" manner. Table 3.3-1 below lists conflicting interests of policy makers and researchers.

³³ Nutley (2003) p. 15

³⁴ Best (2008) cited in Nutley (2010), p. 135f.

³⁵ Bekker (2010) p. 238

Table 3.3-1: Conflicting interests of policy makers and researchers

Policy makers	Researchers
Complex policy problems	Simplification of the problem to arrive at researchable question
Focused solutions	Interest in related but separate issues
Reducing uncertainties	Finding the truth
Speed	Time to think
Control and delay	Publish or perish
Instrumentalization	Explanation
Feasible and pragmatic solutions	Thoughtful deliberations

Source: adapted from Bensing (2003) p. 606

Understanding the different professional environments of policy makers and researchers, understanding the respective constraints and resulting needs, allows reflection on circumstances, which would be favorable for the two worlds to get in touch.

A review of 24 studies reporting on a total of 2.041 interviews on health policy-makers' perceptions of their use of evidence, underlines both the importance and the complexities of personal contact between researchers and policy makers: The most commonly reported facilitators were personal contact. The most commonly reported barriers were absence of personal contact. "Two-way personal communication, the most common suggestion, may improve the appropriate use of research evidence, but it might also promote selective (inappropriate) use of research evidence." ³⁶

Attention is more likely to be paid to research findings when:³⁷

- The research is timely, the evidence is clear and relevant, and the methodology is relatively uncontested.
- The results support existing ideologies, are convenient and not contentious to the powerful.
- Policy makers believe in evidence as an important counterbalance to expert opinion and act accordingly.
- The research findings have strong advocates.
- Research users are partners in the generation of evidence.
- The results are robust in implementation.
- Implementation is reversible if needed.

developing an understanding for each other's worlds necessary

policy – research: two way personal communication as way forward with caveats

attention paid by policy makers depends on scientific and contextual properties of research and on current political environment

³⁶ Innvaer (2002)

³⁷ Nutley (2003), Box 5, p. 10

measures to improve interaction between policy making process and research required on three levels ...

... government

... research organization

... individual researcher

Recommendations to overcome the divide between policy and research given in the literature are grouped according to their addressees: government, research organizations and individual researchers. Deciding which of these general recommendations will be helpful in the context of a specific country and a specific subsystem (such as HSPHR) would require taking the context into consideration and entail in depth calibration.

General recommendations for government³⁸

Build capacity within government.

- Train staff in formulating questions to researchers, in assessing the quality of research, and in spotting the policy relevance of generated evidence.
- Integrate analytical staff at all stages of the policy development process.

Create for afor interaction between policy makers and researchers.

- Co-locate policy makers and internal analysts.
- Co-locate government staff and external researchers.
- Co-locate government staff and university staff.

Cast external researchers more as partners than as contractors.

Raise role of evidence in daily running of affairs.

- Require performing impact assessments of proposed legislation.
- Require providing a supporting evidence base when spending budgets.

Raise general standards of transparency.

- Require the publication of the evidence base for policy decisions.
- Provide open access to information leading to more informed stakeholders and citizens.

Give researchers responsibility for policy implementation.

General recommendations for research organizations³⁹

- Collaborate with other organizations.
- Establish strong links with policymakers and involve stakeholders in the work.
- Be independent and manage conflicts of interest among those involved in the work.
- & Build capacity among those working in the organization.
- use good methods and be transparent in the work.
- Start small, have a clear audience and scope, and address important questions.
- Be attentive to implementation considerations even if implementation is not a remit.

³⁸ with Input from Nutley (2003) p. 10

³⁹ Moynihan (2008) p. 6

General recommendations for researchers⁴⁰

- Provide accessible summaries of research.
- & Keep the research report brief and concise.
- Publish in journals or publications that are user friendly.
- Use language and styles of presentation that engage interest.
- use visualization to communicate research results.
- Target material to the needs of the audience.
- Extract the policy and practice implications of research.
- Tailor dissemination events to the target audience and evaluate them.
- Use a combination of dissemination methods.
- # Use the media.
- & Be proactive and contact relevant policy and delivery agencies.
- Understand the external factors likely to affect the uptake of research.

The following quote sums up the above reflections about the relationship between research and policy: "The relationships between research, knowledge, policy and practice are always likely to remain loose, shifting and contingent. Initiatives to improve the linkages between policy and research need to be designed with this in mind."

The last part of this chapter on conceptual and theoretical issues to be taken into account when thinking about developing HSPHR is meant to start the transition from theory to practice: first the status quo of HSPHR in Europe in chapter 4, then individual "good practice" organizations and interorganizational arrangements in chapter 5. The Netherlands will be the country most extensively covered in chapter 5.

relationship between policy making and research does not lend itself to optimization

... rather ongoing context sensitive and incremental improvement efforts are warranted

⁴⁰ Nutley (2003), Box 7, p. 12

⁴¹ Nutley (2003) p. 16

4 Status Quo of HSPHR in Europe

Health Services Research in Europe

Presenting the status quo of health services research in Europe is not a straightforward matter. For the field of health services research and its utilization in practice "even descriptive information on activities and institutional arrangements is lacking." The above mentioned ongoing project "Health Services Research in Europe" funded by the European Union therefore "aims to identify, evaluate and improve the contribution of health services research to policy-making in countries in Europe".

only little information on HSR available

"Health Services Research in Europe" so far published draft scoping reports on the following sub-areas:

- # Health systems research in Europe
- Health services research in Europe and Its Use To Inform Policy
- Health Technology Assessment
- Health services research related to Benchmarking and Performance Indicators
- Health Care Organizations in Primary and Secondary Care in Europe

Health services are an established area for research in some countries. Great Britain with its National Health System may come to mind first. "Arguably, England and Scotland, share a long tradition of health services research, supported by government funding." The Netherlands, from the background of a differently organized health care system, developed a comparable tradition. Beyond Europe it is the United States, Canada and Australia who have longer standing traditions of systematic health services research. In many countries on the other hand, this field of research is still emerging.

tradition of HSR in England, Scotland, Netherlands ...

... beyond Europe in USA, CAN, AUS

Funding for HSR

Information about the level of funding available for health services research is not available for most European countries. Available data usually do not distinguish between funding for health services research and other health-related research.⁴⁷ Data suggest that the level of funding varies dramatically between countries, with England likely to be the largest spender in absolute terms at &174 million⁴⁸. The Netherlands may be next at &60⁴⁹ million.⁵⁰

research funding in EU varies greatly between countries ...

... England, NL largest spenders

⁴² Ettelt (2010) p. 8

⁴³ www.healthservicesresearch.eu

⁴⁴ Ettelt (2010) p. 9

⁴⁵ Ettelt (2010) p. 16

⁴⁶ Advisory Council on Health Research (2008)

⁴⁷ Ettelt (2010)

⁴⁸ value for 2004, Ettelt (2010)

⁴⁹ value for 2006, Advisory Council on Health Research (2008)

⁵⁰ An example of a health services research commissioning organization with implementation orientation featuring prominently in its remit is the Netherlands Organization of Health Research and Development, ZonMw. It is described in the good practice chapter five below.

The European Commission is a key funder of health services research projects in many countries of the European Union.⁵¹ Country specific statistics on these funding streams are not readily available, though.

Priority setting for HSR

strategic approach to setting research priorities generally lacking "In most countries, no structured process of identifying priorities for health services research was reported, mirroring the absence of a comprehensive strategic approach. Health technology assessment appears to be an exception in some countries, with processes of priority-setting often being more explicit and more clearly attuned to the preferences and interests of health system decision-makers." 52

Research capacity for HSR

availability of specialized training for HSR generally limited "In most countries, universities play the major role as producers of health services research, yet institutional capacity to undertake research varies greatly. Although most countries offer some form of training in health services research (though with very variable capacity), this is often part of public health training programs or training in particular sub-disciplines such as health economics or epidemiology. Only three countries (England, the Netherlands and Scotland) appear to offer bespoke training in health services research." 53

Versorgungsforschung in Germany as an example of late development

HSR or "Versorgungsforschung" is a young discipline in Germany ... The term "health services research" does not exist in some languages and has only recently been created in others.⁵⁴ German language would be an example with the comparatively recently coined term *Versorgungsforschung* for health services research.

... with only limited funding available

Funding for health services research independent of special interests is scarce in Germany.⁵⁵ The established systems of funding basic and applied research with public money – German Research Foundation, *Deutsche Forschungsgemeinschaft*⁵⁶, Max Planck Society for the Advancement of Science, *Max-Planck-Gesellschaft*⁵⁷, Helmholtz Association of German Research Centres, *Helmholtz Gemeinschaft*⁵⁸ – do not address health services research's needs: interdisciplinary research into the quality and efficiency of medical and nursing care.⁵⁹

The German Network for Health Services Research – *Deutsches Netzwerk Versorgungsforschung*⁶⁰ – was initiated in 2006 by associations of medical specialties, nursing sciences, public health, health economics, organizational research, medical sociology, medical psychology etc.. The network has published three memoranda on health services research in Germany so far:

⁵¹ Ettelt (2010)

⁵² Ettelt (2010) p. 17

⁵³ Ettelt (2010) p. 44, 45

⁵⁴ Ettelt (2010)

⁵⁵ Pfaff (2004)

⁵⁶ www.dfg.de

⁵⁷ www.mpg.de

⁵⁸ www.helmholtz.de

⁵⁹ Pfaff (2004)

 $^{^{60}\,\}mathrm{www.netzwerk\text{-}versorgungs} for schung. de$

- 1. On the status quo, on action required and on strategies⁶¹ (in 2003)
- 2. On conceptual, methodological and structural prerequisites of health services research⁶² (in 2005)
- 3. On methods of health services research (part one in 2009^{63} and part two in 2010^{64})

The initial memorandum paints a sobering picture of health services research in Germany: "Efficient and internationally acknowledged health services research is to be found only sporadically in certain research institutes and university hospitals (e.g. running major registries) and via government funded research projects with very tight budgets." Making matters worse: "Lack of continuous financing endangers what has so far been achieved." Lack of continuity of funding for HSPHR is an issue in many settings, compare e.g. the organizational presentation of Holland's ZonMw in chapter five below.

Health services research as an interdisciplinary science is seen as not well established at German universities. In the traditional departmental logic of German universities the reputation of health services research is low.⁶⁷ Proponents of health services research at German universities outlined the necessities for advancing *Versorgungsforschung* in Germany.⁶⁸ An integrating vision for health services research was found lacking in Germany. The vision of a "learning health care system"⁶⁹ is proposed as such an integrating vision. The authors also pointed to the lack of available data for longitudinal health services research in Germany and to the difficulty of putting together existing data from various sources for research. Cooperation and established networks in the following areas were found underdeveloped in Germany:

- Among medical specialties internal medicine, surgery etc.;
- Among the other health related sciences public health, medical sociology, medical psychology, health economics, nursing etc.,
- Among the methodological sciences bio-informatics, statistics, epidemiology, quality research;
- Between health sciences, medicine and methodologically oriented disciplines.

The initial memorandum mentioned above gives six recommendations to improve the situation, first among them the call on federal government to establish a long term funding program for health services research. The making available of routine process data from the German health care system (mainly from Germany's social health insurance funds) for use in health services research is another demand.

internationally recognized HSR scarce in Germany

lack of continuity of funding

interdisciplinary field of HSR not well established at German universities

Integrating vision such as "learning health care system" needed

routine process data generally not available for HSR in Germany

⁶¹ Badura (2004)

⁶² Schrappe (2005)

⁶³ Pfaff (2009a), Glaeske (2009), Pfaff (2009b), Koller (2009)

⁶⁴ Neugebauer (2010), Icks (2010), Müller (2010)

⁶⁵ Badura (2004)

⁶⁶ Badura (2004)

⁶⁷ Pfaff (2004)

⁶⁸ H. Pfaff, University of Cologne, N. Schmacke, University of Bremen, M. Schrappe, University of Marburg, see Pfaff (2004)

⁶⁹ Pfaff (2004), p. 7

On the other hand – in order not to paint too bleak a picture of the situation of health services research in Germany – it should be mentioned that Germany features relatively prominently in the recent publication from "Health Services Research in Europe". In Germany, like in Austria, decision-making in the area of health care is largely devolved to corporatist bodies of self governance at arm's length from government. Corporatist bodies like regional associations of physicians, associations of sickness funds or hospital associations may operate their own research institutes. German institutions featuring in the survey on health services research and its use to inform policy in Europe are:

- Scientific Institute of the General Regional Sickness Funds Wissenschaftliches Institut der Allgemeinen Ortskrankenkassen WIdO⁷¹.
- Institute for Quality and Efficiency in Health Care *Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen* IQWiG⁷², established in the course of Germany's Health Care Reform 2004, anchored in the German Social Code Book⁷³.
- Agency for Quality in Medicine Ärztliches Zentrum für Qualität in der Medizin – ÄZQ⁷⁴, jointly owned by the German Medical Association and the National Association of Statutory Health Insurance Physicians.
- Federal Office for Quality Assurance Institut für Qualität und Patientensicherheit BQS⁷⁵ jointly established by the German Medical Association, the German Hospital Federation, several Federations of Social Health Insurance Funds and the Federation of Private Health Insurance Funds.
- Health Services Research Clearinghouse of North-Rhine Westphalia Clearingstelle Versorgungsforschung NRW⁷⁶, jointly run by local universities (Bielefeld, Bochum, Düsseldorf, Duisburg-Essen, Cologne, Münster) and the State Ministry for Labor, Integration and Social Affairs (Düsseldorf), which operates a data base on health services research projects.
- German Institute of Medical Documentation and Information Deutsches Institut für Medizinische Dokumentation und Information DIMDI⁷⁷, an institute within the scope of the Federal Ministry of Health (Berlin), which operates a data base on health technology assessments.

⁷⁰ Ettelt (2010)

⁷¹ Homepage in German only: www.wido.de

⁷² www.iqwig.de

⁷³ www.iqwig.de

⁷⁴ www.aezq.de

⁷⁵ Homepage in German only: www.bqs-institut.de

⁷⁶ Homepage in German only: www.versorgungsforschung.nrw.de

⁷⁷ www.dimdi.de

Public Health Research in Europe

"Strengthening Public Health Research in Europe SPHERE"78, as mentioned above, was a European Union funded project within the Sixth Framework Research Program of the European Commission, 2005 – 2007. Its two broad objectives were to describe the public health research literature and to determine priorities for research among European stakeholders which lead to broad recommendations to the European Union.

only limited information on status of PHR available in Europe

This is a synopsis of the project's findings: ⁷⁹

Public Health Research

- There is no common approach to support for public health research across Europe.
- The funds actually available for public health were not easily identifiable. Only two countries could state the allocation to public health research within their Ministry's annual budget.
- There are significant gaps in the organization and funding of public health research.
- Better processes are needed for priority-setting, and the accumulation, dissemination and implementation of scientific knowledge.

Public Health Research Literature

- The annual number of public health research publications in Europe has been rising. Over the 10 years between 1995 and 2005 the number of European public health research papers averaged 7,000 a year, compared with a global total average of 20,000 public health research papers.
- Nordic countries have the highest rates of public health research output per capita.
- Public health social science literature is less likely than literature from biomedical sciences to be published in journals or identified through medical science literature searches.

Recommendations for the European Union

- To achieve a European Research Area for public health, there should be a clearing-house and register of public health research calls, researchers and institutes.
- © Comparative research, using policy and practice variations across Europe, should be prioritized by EU funding.

A recent report on the status quo of public health in Austria also addresses public health research and capacity building for public health. 80

PHR generally lacks ...

- ... funding
- ... transparent research commissioning processes
- ... coherent processes of research priority setting

European share of published literature is growing

Nordic countries publish most

PHR is not yet close to playing in the same league as biomedical sciences

⁷⁸ www.ucl.ac.uk/public-health/sphere/spherehome.htm

⁷⁹ Conceição (2009) und McCarthy (2007b)

⁸⁰ Ladurner (2010)

5 Good Practice in selected Countries

The initial conceptual and theoretical considerations in chapter 3 highlighted, among others, the importance of interaction between research and policy. This interaction is considered important starting from capacity building for HSPHR through the whole process of priority setting for research, research commissioning, research quality assurance, research communications, research implementation and research impact evaluation. Chapter 4 introduced the status quo of HSPHR in Europe. Against this abstract background information, concrete good practice examples from different countries are presented in this chapter. As stated in the introduction, it is only very seldom that models of good practice can be transferred 1:1 to other settings. A review of the literature argues that European countries have different traditions of dealing with knowledge in the area of policy making. These traditions are influenced by the size of the country, by the administrative arrangements, the political structures and the cultural preferences.⁸¹ Developing personal relationships between researchers and policy-makers is easier in smaller countries. The way in which policy is made and the culture of governance are linked to broader social and cultural values. 82 The supply of research is influenced by research capacity, the volume and type of research funding and the nature of research agendas. Also if researchers have incentives to engage in activities to foster research use matters.83

The intention of presenting good practice examples is therefore modest: to draw cautious inspirations to guide the process of developing an Austrian HSPHR agenda and to guide the building of capacity in Austria. A possible future Austrian research commissioning organization for HSPHR and a future HSPHR institute might be inspired by a synthesis of good practice examples from abroad, always taking the unique aspects of the Austrian health system and that of its governance culture into account. "Different approaches will thus need to be combined, in nuanced ways, that are sensitive to their local contexts for implementation."84

As mentioned above, the fact that an institution is included as a "good practice" example below is not a judgment about the general effectiveness of the institution. Neither does the fact that the detail of presentation varies across institutions have a signaling function in that regard. As also mentioned above, the detail of presentation results to a large degree from the variance in the expert interviews with the respective member of the depicted institution.

models of good practice only very rarely suitable for 1:1 transfer to different health system setting ...

... but useful to collect inspiration

⁸¹ Delvaux (2008) cited in Nutley (2010), p. 134

⁸² Nutley (2010), p. 137

⁸³ Nutley (2010), p. 139

⁸⁴ Nutley (2010), p. 308

5.1 Netherlands: Taking a closer Look

longstanding HSPHR tradition in NL

developed capacity for HSPHR

sophisticated research commissioning processes For a continental European country the Netherlands have a long tradition of HSPHR. The Netherlands institutionalized a comparatively sophisticated system of HSPHR commissioning for its relatively well developed capacity in HSPHR. Since individual high quality (research, research commissioning and policy decision making) organizations are as important for developing a successful system of HSPHR as is their interaction, the Netherlands are presented below not only through organizational portraits but also through glimpses at the dynamics of their interactions. As Nutley (2010) points out, the Netherlands have established a rich landscape of sophisticated institutional and procedural linkages between research and policy: Research insights are introduced to policy processes via advisory councils and planning bureaus. Social and policy demands on the other hand are relayed to researchers via mechanisms for research funding and wide spread research audits.

5.1.1 Health Research in the Netherlands

increasing emphasis on social relevance of research The relative level of spending for overall research and development R&D in the Netherlands is 1.71% of gross domestic product. That is below the average of the European Union. The growth rate of real R&D expenditures is also below average. The Netherlands is falling behind the world's leading countries in terms of R&D expenditure. In spite of this fact, the Netherlands are "generally viewed to 'punch above their weight' in research terms". In the Netherlands are "generally viewed to 'punch above their weight' in research terms".

recent health sector reforms drive need for knowledge on performance Research policy in the Netherlands since the 1970s has increasingly emphasized the social relevance of scientific research.⁸⁷

The governmental need for specific knowledge on the performance of healthcare services drives the policy rationale for socially relevant research in health and health care.⁸⁸

NL annually spend 800 Mio. on biomedical research and 60 Mio. on HSR The annual level of health services research in the Netherlands is estimated at €60 million. 89 This is a high figure in the context of the European Union. 90 "The total budget for health services research is – compared to that in other countries – adequate. "91 To put this investment into health services research into perspective: annually the Netherlands spend €800 million in public funds on biomedical research. 92

Ensuring the social relevance of Dutch research has been institutionalized through a diversified infrastructure:

⁸⁵ NOWT Netherlands Observatory of Science and Technology (2010)

⁸⁶ Nutley (2010), p. 138

⁸⁷ Wachelder (2003)

⁸⁸ Bekker (2010)

⁸⁹ value for 2006, Advisory Council on Health Research (2008)

⁹⁰ Ettelt (2010)

⁹¹ Advisory Council on Health Research (2008) p. 16

⁹² Health Council of the Netherlands (2010b)

- Institutions that mediate research insights to policy makers, e.g. advisory councils and the planning bureaus presented below.
- Institutions that mediate policy and social demands to researchers, e.g. the research funding organizations Netherlands Organization for Scientific Research NWO and the below discussed Netherlands Organization for Health Research and Development ZonMw.
- Research audit methodologies such as "sci-Quest", which is also described in more detail below.

No structured process of identifying priorities for health services research and public health research is in place on a national level in the Netherlands. However, priorities may be set for specific research programs or streams of research funding. For example, the Ministry of Health, Welfare and Sport defines the priorities for health and health services research for the Netherlands Organization for Health Research and Development, ZonMw. "These priority setting procedures are often indirect or ex post, for example through the selection, review and approval of research proposals after scientific review by members of the research community."

no national system for defining HSPHR priorities in place

Advisory councils

An important element of Dutch infrastructure that mediates the interaction between research and policy is the advisory council. Advisory councils analyze specific policy issues, gather information, formulate answers to policy problems and generate support for these solutions.

Presently, there are 42 national advisory councils, of which three specifically focus on healthcare issues:⁹⁴

- Health Council of the Netherlands *Gezondheidsraad* GR advising on scientific issues related to health and healthcare,
- GR's Advisory Council for Healthcare Research Raad voor Gezondheidsonderzoek RGO advising on research needs in health and healthcare,
- Council for Public Health and Health Care Raad voor de Volksgezondheid & Zorg – RVZ focusing on health system policy.

Additionally, the Scientific Council for Government Policy WRR is an independent council of researchers that provides advisory reports and analyzes broader trends in Dutch society, including in health and health care. Organizational profiles of WRR, GR and RGO with additional information can be found below.⁹⁵ For a graphic illustration of the role of advisory councils compare figure 5.1-1 below.

The Dutch parliament relies heavily on advisory councils for independent analyses of social and sectoral policy issues.⁹⁶

independent Advisory councils at arm's length from government as important mediators between science and policy making

Health Council of the Netherlands GR

Advisory Council for Health Research RGO

Scientific Council for Government Policy WRR addresses wider societal developments in a future oriented way

⁹³ Ettelt (2010) p. 17

⁹⁴ Bekker (2010)

⁹⁵ for RVZ compare www.rvz.net

⁹⁶ Bekker (2010)

Planning bureaus

as part of the governmental apparatus Planning bureaus undertake original policy research The work of the advisory councils is complemented by so called planning bureaus. They undertake independent analysis and assessments of government policy proposals in debate and provide the government with both solicited and unsolicited advice on specific policy fields. They differ from advisory councils in that they do original policy research, are part of the governmental apparatus and are mandated to deliver analyses and evaluations:⁹⁷

- 1. The Netherlands Bureau for Economic Policy Analysis
- 2. The Social and Cultural Planning Office
 - publishing a report on the macroeconomic development of the healthcare sector every three years⁹⁸

For a graphic illustration of the role of planning bureaus compare figure 5.1-1 below.

The importance of the planning bureaus lies in the information and expertise they provide for government. Besides their publications, planning bureaus take seat in a number of influential governmental policy negotiating structures.⁹⁹

"The Dutch advisory councils and planning bureaus are hybrid fora for research-policy interactions in which information and advice are developed through close collaborations between researchers, policy makers and other societal actors. These bodies have to be close to politics without being too close; they have to depoliticize policy problems without doing away with the normative choices associated with them; and importantly, they have to sustain their authoritative positions and credibility in order to perform these roles. By continuous stakeholder interactions, which are negotiation intensive by nature, these bodies come to a shared understanding of the problem at hand. These interactions enable them to produce useful reports and models that are considered scientifically sound and suited to specific policy needs." 100

⁹⁷ Bekker (2010)

⁹⁸ Bekker (2010)

⁹⁹ Bekker (2010)

¹⁰⁰ Bekker (2010) p. 249

Governance infrastructure for research policy

Most research at universities is still predominantly financed through direct funding by the government. Increasingly this – direct – stream of funding of universities' research capacity is being replaced by another – indirect – stream of funding from governmental agencies such as the Netherlands Organization for Scientific Research NWO, giving NWO a dominant position in research policy. In health and healthcare the Netherlands Organization for Health Research and Development ZonMw is the governmental funding agency for research. ZonMw is independent from NWO but strongly linked to. This is illustrated by NWO and ZonMw sharing a common address in The Hague. NWO and ZonMw support programs of research that respond to public needs as defined by government. More information on ZonMw can be found in the organizational profile below. For a graphic illustration of the role of NWO and ZonMw as research commissioners compare figure 5.1-1 below.

Netherlands
Organization for
Scientific Research
NWO and its offspring
for health research –
ZonMw – play key role
in NL's research policy
as research
commissioners

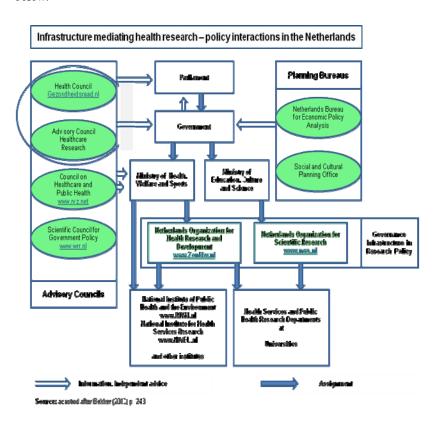


Figure 5.1-1: Infrastructure mediating the interaction between health research and policy in the Netherlands

¹⁰¹ Bekker (2010)

¹⁰² Bekker (2010)

Research evaluation

stakeholders jointly developed widely used tool for evaluating research sensitive to context

The main challenge in evaluating research programs is finding good indicators of the social value and impact of research. The governmental funding agencies NWO and ZonMw, together with the Royal Netherlands Academy of Arts and Sciences KNAW and the Ministry of Education and Science, have developed social indicators and a specific methodology for 'evaluating research in context': the so-called 'sci-Quest' method. 103 It aims to both assess the quality of research and to offer a formative 'learning perspective'. The audited body is asked to perform a self-evaluation based on its mission statement and both a self-rated performance analysis and a SWOT¹⁰⁴ analysis. These then are juxtaposed with stakeholder and (outsider) expert views of the body's mission statement and performance. The analyses aim to reveal changes in social needs, target audiences as well as produce methodological innovations. The sci-Quest method is now increasingly being adopted in reviews of science and social science departments. 105 The Netherlands Institute of Health Services Research for example makes its 'sci-Quest' self evaluation available to the general public. 106

NL have culture of transparency in evaluation

5.1.2 Scientific Council for Government Policy WRR

WRR

... has remit of broad, long term societal perspective

... conducts original research for its reports

... puts focus on emerging societal dilemmas

... thinks in alternatives

... conceptualizes offmainstream The Scientific Council for Government Policy - Wetenschappelijke Raad voor het Regeringsbeleid - WRR aims to advise the government about future developments of great public interest. 107 WRR covers all sciences and all policy areas. WRR examines social developments in a broader perspective and gives advice on long-term multi-sectoral developments. The task of WRR is to harvest existing evidence and to provide expert judgment on it. Conduction primary research for its reports, often in cooperation with universities, is also within WRR's remit.

WRR has a more general agenda and a broader scope than all advisory councils. Independent of the currently prevailing societal or political climate, it is the duty of WRR to put exactly those topics on the political agenda it deems necessary. From WRR's foundation in 1972 the vision was not to focus on what everybody agrees upon anyway, but instead to address emerging dilemmas, propose alternative options for action and research new issues. With other words, the remit is not to follow mainstream thinking but to reflect in alternative ways. WRR's remit is to be a countervailing power to short term oriented day-to-day politics. Government and the prime minister generally understand this role and see it in a positive light. On the other hand the role of WRR is not to be in essential conflict with government. Making a difference in the long run with government as a partner is the goal of WRR.

¹⁰³ KNAW Royal Netherlands Academy of Arts and Sciences (2010)

 $^{^{104}}$ derived from the business management literature SWOT stands for Strengths - Weaknesses - Opportunities – Threats

¹⁰⁵ Bekker (2010) p. 246

¹⁰⁶ NIVEL (2010)

 $^{^{107}}$ www.wrr.nl

Table 5.1-1: Fact sheet WRR

WRR

Scientific Council for Government Policy

Wetenschappelijke Raad voor het Regeringsbeleid

Location

The Hague, NL

Telephone interview partner

Senior expert

Legal status

- Independent council of researchers
- Employees are civil servants

Founded

1972

Council Members

Chairperson (full time) plus currently 7 members (3-4 days a week)

Employees

35 full time equivalents

- 25 scientific
- 10 supportive

Annual budget

fully financed by Dutch government

approximate figures

Source: telephone interview, www.wrr.nl

Legal status

WRR occupies a special position within the system of advisory bodies in the Netherlands. This position is regulated by an Act of Parliament that guarantees the complete independence of WRR. This strong remit cannot be overruled. The chair is in an independent position and enjoys a prominent standing in Dutch society. *The chair has no reason to be steered by other influences.*

complete independence established in act of parliament

History

WRR was established in 1972 by government and institutionalized in its present legal form by an act of parliament in 1976.

Funding

WRR is exclusively funded by the government, it reports via the prime minister directly to the government.

Selection of council members

Initially a selection committee of independent experts is appointed to ensure that an open scan for members is undertaken. In addition to academic expertise the following factors are taken into account:

- mastery a variety of academic disciplines
- a broad social orientation
- ability to make independent judgements

independent judgement and broad social orientation as necessary qualification for council members

WRR council members are appointed by the queen for a maximum of five years. The appointment follows a proposal by the prime minister, after consultation with the cabinet. Council members may be reappointed once. Basic trust between advisor (WRR) and advised (NL government) is necessary and in place. Chairs functioning well tend to be re-appointed.

council membership enjoys high reputation in scientific community and general public Council membership is considered an honorable position. Selected candidates tend to accept and the university the nominated candidate works for applauds the appointment as it brings prestige also to the institution. Advisory councils in the Netherlands in general hold a strong authority in peer groups and among the general public.

Organization

WRR is a working council, members write reports themselves, supported by secretariat

> quality of scientific secretariat is key for quality of reports

> council members responsible for their topics and advisory boards

WRR publishes 3-4 indepth advisory reports per year ...

... a few touch upon HSPHR issues

WRR's modus operandi is that of a working council. WRR's council members actively conduct research and participate in writing the reports. In this working method WRR differs from many other advisory bodies whose members do not actively participate in writing the report but make decisions on research performed by the academic staff, on the basis of their generally acquired expertise: compare Health Council of the Netherlands GR below, which is working as a sitting council. The WRR chair works full time for WRR. The presently seven additional council members work between 3 and 4 days per week for WRR. They are responsible for their respective advisory boards which are formed ad-hoc for specific topics. In their function as leader of a topic focused team they are responsible for the team's research—which leads to an advisory report. The reports are jointly written by WRR's council members and by WRR's permanent staff.

Every two weeks WRR meets for half a day, going over draft reports and deciding on the next steps of the working program.

Research products

WRR on average produces 3-4 advisory reports per year. All reports are published on WRR's webpage. Original primary research – like for example a survey – is conducted for the reports, often in cooperation with universities. Examples of past (public) health (care) related WRR reports are:¹⁰⁸

- Public health care: priorities and a sound financial basis for health care in the 21st century
- Uncertain Safety. This advisory report advocates a paradigm shift towards general uncertainty acceptance.

In the case of the Dutch health care system, for example, futures studies were done during the implementation of the policy. Different actors were invited to discuss several possible futures. ¹⁰⁹

¹⁰⁸ www.wrr.nl

 $^{^{109}\,\}mathrm{www.wrr.nl}$

Setting the research agenda

WRR is appointed for a period of five years. At the start of a council period, WRR produces independently, after consultation with the prime minister, a work program. The program can be modified during the council period. Subjects can be added if new ideas or insights emerge. In practice WRR evaluates its work program halfway through its term, and makes changes where necessary. The government can also ask WRR for advice on a particular subject; normally such requests are for research on overarching policy fields that concern several departments. WRR employs the following criteria for choosing subjects for its reports:¹¹⁰

WRR sets its own research agenda after consultation with the prime minister

- The subject should be of importance to long-term government policy,
- The subject should concern a current or future socially relevant problem,
- The subject should be challenging and should be suitable for academic research,
- The subject should be within the sphere of government policy, or enter that sphere in the future,
- The subject should be directed at the future,
- The subject should concern several sectors of government policy, it should be possible to approach it in different ways, and it should allow for suggestions for taking action.

Interaction with stakeholders

WRR makes sure it is informed about the questions arising in ministries, in politics and in society. Collaboration with politicians and policy-makers has intensified over the last couple of years. WRR council members and its permanent staff are active in their respective fields of expertise and have a good idea of what is going on in the areas concerned.

Every council member runs one or more advisory projects. Every individual council member has a strong role within her or his portfolio of projects including direct contact with parliament, ministers or the prime minister.

As mentioned above, WRR has the most general agenda and the broadest scope compared to field-specific advisory councils. WRR has a good overview in many fields – not least through WRR's regular topic specific interactions with a number of advisory councils. Twice a year the Dutch advisory councils and strategic advisory councils exchange their working programs in the draft phase in a meeting chaired by WRR. In this process synergies are to be discovered and double work is to be avoided. It is WRR's role to safeguard coherence in a cooperative manner following a non-directive approach. The idea of formally installing WRR in a hierarchy above the advisory councils was abandoned. WRR was not to turn into a bureaucratic coordinator, rather WRR and the advisory councils should work as a subject matter oriented team, focused on content.

multi level stakeholder interaction with topic specific direct council member access to parliament, prime minister and ministers

WRR coordinates activities of other Dutch advisory councils in a cooperative, nonhierarchical manner

 $^{^{110}\,\}mathrm{www.wrr.nl}$

WRR has a number of advisory members:111

- Netherlands Bureau for Economic Policy Analysis, which provides independent economic analyses relevant to policy making in the Netherlands;
- Netherlands Institute for Social Research, which analyses expected developments in the social and cultural field in the Netherlands;
- Netherlands Environmental Assessment Agency, whose tasks include recommendations and research on the development of public health and the system of health care, the effects of nutrition and other consumer products on health, and environmental and nature issues;
- Statistics Netherlands with the core task of collecting, processing and publishing of statistics for practice, policy and science.

The advisory members meet with WRR on a regular basis, among other things to coordinate activities and to comment on WRR's ongoing research.

Cooperation with the academic field

Apart from the full time chair of WRR all council members work part time as university professors. Some of WRR's permanent staff, too, are working part time at a university, collaborating in ongoing research.

International cooperation

WRR is working towards intensifying international cooperation among strategic policy making institutions and think tanks on a European level.

Communication of results to stakeholders

Until recently, WRR mainly produced reports containing research results and policy recommendations. More and more other ways are being used for disseminating knowledge and contributing to debate in society:¹¹²

- Organization of series of debates discussions take place on current events between senior policy-makers and academic specialists;
- ♣ Internal conferences leading specialists from the Netherlands and abroad are frequently invited to exchange ideas with WRR and its staff, relevant policy-makers are also involved;
- Conferences, workshops and public for aare organized regularly to foster debate and disseminate the knowledge acquired by WRR during the production of an advisory report;
- * WRR-lectures well-known Dutch or international speakers are invited to share their view on current issues from a policy and science perspective.

Implementation of research

WRR focuses on long term impact. If it is a good report, it can also start having an impact after five or more years. Advice is not unsuccessful if it is not immediately implemented. WRR invests in specifically assigned staff working on the clarity and readability of the language used in its advisory reports. Reports should be technically correct, not technically written.

council members are part time university professors, also some of WRR's academic staff

spectrum of dissemination activities to communicate research results gains prominence at WRR

WRR employs staff specifically to enhance clarity and readability of reports

¹¹¹ www.wrr.nl

 $^{^{112}}$ www.wrr.nl

Evaluation of research impact

Every five years, at the end of each term of office, WRR is evaluated by an independent commission. The make-up of this commission is proposed by WRR and the commission is appointed by the prime minister. The evaluation focuses on WRR's products in terms of topic choice and output quality. The reviewers form a judgment if WRR recommendations have been useful in the shorter or longer term. In this sense an aim WRR reports are evaluated against is *if WRR reports made a difference*. The evaluation team talks to stakeholders and citizen groups and makes recommendations for the future work of WRR.

periodic evaluation of WRR by independent commission

5.1.3 Health Council of the Netherlands GR incoporating the Advisory Council on Health Research RGO

The Health Council of the Netherlands – Gezondheidsraad – GR is "to advise the government and Parliament on the current level of knowledge with respect to public health issues and health (services) research ..." (Section 22, Health Act). The task of GR is to harvest existing evidence and to provide expert judgment on it. As opposed to WRR presented above, conducting primary research is not within GR's remit.

GR incorporates the Advisory Council on Health Research - Raad voor Gezondheidsonderzoek - RGO. RGO's remit is to influence the agenda setting for health research in the Netherlands in a forward looking manner. RGO is to advise government on priorities in health research, in healthcare research and on the technological developments in this sector, as well as on the associated infrastructure. RGO was merged with GR in 2009 (integrated, not taken over). The two bodies had cooperated closely before. The motivation for the merger was to create a continuum from existing knowledge, covered by GR, to knowledge that still needs to be developed, covered by RGO. RGO retains a separate board within GR.

GR's remit is to synthesize existing knowledge in public health and health (services) research, not to conduct original research

RGO's remit is reflection on agenda setting for health research in NL

Table 5.1-2: Fact sheet GR incorporating RGO

GR

Health Council of the Netherlands - Gezondheidsraad

incorporating

RGO

Advisory Council on Health Research – *Raad voor Gezondheidsonderzoek*

Location

The Hague, NL

Telephone interview partner

Senior expert

Legal status

- Independent scientific advisory body
- Employees are civil servants

Founded

history dates back to 1902

Council Members

President (4 days per week), two Vice Presidents (1-3 days per week), 200 voluntary members

Employees

45 full time equivalents

- 30 scientific
- 15 supportive

Annual budget

fully financed by Dutch government

approximate figures

Source: telephone interview, Health Council of the Netherlands (2010a), www.gezondheidsraad.nl

Legal status

GR is an independent scientific advisory body.

GR's independence from government enshrined in law and highly esteemed "The independence of the Health Council of the Netherlands – which is required by law – is a great asset to our public health system. Time and time again this independence must be demonstrated in practice and be able to stand the test of criticism." 113

History

GR's history dates back to 1902.

Funding

GR is entirely funded by government and works predominately with five government ministries:

- # Health, Welfare and Sport
- Social Affairs and Employment
- ♣ Infrastructure and the Environment

 $^{^{113}}$ Statement of GR's president, quoted from www.gezondheidsraad.nl

- Economic Affairs, Agriculture and Innovation
- ☼ Education, Culture and Science

Organization

GR's modus operandi is as a sitting council (where members do not perform the actual task of writing the reports themselves as opposed to a working council like WRR, compare above). GR has a professional secretariat – consisting of scientific and support staff – doing the writing. This secretariat plays an important role throughout the advisory process and does most of the work of actually writing the report. The permanent secretariat staff prepares the action plan for the reports, advises on the composition of the committees, carries out literature surveys, and prepares draft recommendations for the committees. ¹¹⁴ The strong staff of the secretariat is considered the motor of the advisory system.

GR does not meet on a plenary basis, but instead operates in independent, multidisciplinary committees and standing committees. GR currently has 196 members, 47 of them are women. Members become active, if they are invited to form report producing topic specific ad-hoc committees and/ or standing committees. The role of standing committees is further touched upon in the section on quality assurance below. The advantage herein is that working with the best experts in the field is made possible by drawing on a relatively large pool of experts. For each report GR assesses the current scientific knowledge and consults leading experts from the Netherlands and abroad – often by means of a specially appointed ad-hoc committee. GR's members sitting on ad-hoc or on standing committees and external experts receive no remuneration but a modest attendance fee. Of GR's members, only the president (4 days per week) and the two vice presidents (1-3 days a week) are employees of GR.

If someone has essential expertise but through her or his own research is so close to the advisory topic that she or he should not participate in the conclusions and recommendations sections of a report, she or he may be appointed as an adviser. Advisers may be invited to participate in certain parts of the committee's deliberation process. A single consultation may also suffice when extremely specific expertise on a part of the advisory report is concerned.

Research products

GR covers optimum healthcare, prevention, healthy nutrition, environmental health, healthy working conditions, innovation and knowledge infrastructure. The Advisory Council on Health Research RGO covers health(care) research. 116 GR does not conduct primary research but synthesizes available knowledge. Sometimes small additional surveys or the like are undertaken.

Advisory reports describe the existing knowledge base and point out where knowledge is lacking. Uncertainties in the examined field and areas relevant for consideration are pointed out to ultimately formulate conclusions and recommendations. All advisory reports are made public. For decisions in which political or social factors play a major role GR presents various sce-

GR council members guide and supervise reports actively written by GR's scientific staff

quality of scientific secretariat is key for quality of reports

GR works through topic specific ad-hoc committees drawn from expert pool of 196 council members

if required, outside advisors and single consultations with experts support ad-hoc committees

GR's reports

- ... synthesize existing knowledge on specific topics
- ... make areas of uncertainty explicit
- ... present possible alternative scenarios
- ... give recommendations

¹¹⁴ www.gezondheidsraad.nl

¹¹⁵ www.gezondheidsraad.nl

¹¹⁶ www.gezondheidsraad.nl

every year 30-40 advisory reports are produced narios with their advantages and disadvantages, sometimes with one scenario indicated as GR's preference. Policymakers can subsequently address their responsibilities in decision making with a solid knowledge base. 117 Every year approximately 30 to 40 advisory reports are produced by GR. A report typically takes 10 to 15 months to prepare.

Monitoring or horizon scanning reports are less comprehensive than advisory reports. Advisory letters deal with quick answers to upcoming questions, entail more expert judgment and are less based on evidence.

Setting the research agenda

GR draws up annual work programs after consultation with government

parliament can submit requests for advice

GR may initiate a report to fulfill its alerting function about future trends

80% of reports answer questions from government or parliament, 20% answer GR's own questions

> observer from the ministry initiating a report has seat on adhoc committee to facilitate communication and

access to required data

close personal linkage to universities

Research is undertaken from a societal perspective, public issues relevant for government are prioritized. Question that GR addresses in reports need to conform to several criteria: It needs to be possible for the issue to be addressed scientifically, it needs to be policy relevant, a complex multi disciplinary approach has to be warranted and the issue should not have been covered in comparable form before.

Each year, GR draws up a work program containing an overview of the issues that will form the subjects of advice for the coming calendar year. The annual work program is formulated after conferring with various departments and consulting with groups within GR. Parliament can also submit a request for advice. As mentioned above, GR also plays an "alerting" role at times. It can publish reports on its own initiative. It usually does this in order to raise attention for developments or trends that are thought to be relevant to government policy. Unsolicited advice has a "signaling" function and is produced in cooperation with Dutch experts and international networks. The minister of health, welfare and sport adopts the final work program. 119

Of GR's advice 80 % is solicited by government, 20 % is unsolicited advice. Initially unsolicited advice occasionally also gets promoted to solicited advice by a government ministry.

Interaction with stakeholders

As a rule, an official observer who is an expert in the particular area is added to the topic specific ad-hoc committee from the side of the ministry that is requesting the advice. This has the advantage that all relevant government information needed for an effective advisory process is immediately accessible. This kind of official observer has no input into the advisory report. 120

Cooperation with the academic field

Council members are drawn from academia. Also GR's president and two vice-presidents continue working part time at their respective universities. Some members of GR's permanent staff (secretariat) work part time at a university, too, fostering collaboration in research.

¹¹⁷ www.gezondheidsraad.nl

¹¹⁸ Health Council of the Netherlands (2010a)

¹¹⁹ For the working program 2011 compare Health Council of the Netherlands (2010a)

¹²⁰ www.gezondheidsraad.nl

International cooperation

GR publishes an international newsletter in English twice a year to keep interested parties abroad updated on GR's activities. GR's advisory reports generally include an English executive summary. Insofar as finances permit, a full English translation is published. 121 The English summaries of the advisory reports are compiled in annual executive summaries. GR and the Belgian Health Council set up the European Science Advice Network for Health EuSANH in 2006, for which the support of the European Commission was secured.122

dissemination of reports or summaries in English

GR is cofounder of EU network of health policy advising bodies

Quality assurance of research

Advisory reports are usually drafted by ad-hoc committees appointed by GR's president. Multidisciplinary approaches guarantee that the advisory multi disciplinary approach

report contains a broad and balanced assessment. In addition to biomedical aspects, epidemiological, ethical and health-economics angles of approach are also contributed by the various members of an ad-hoc committee. Expertise that may be underexposed in the scientific literature is also involved in the advisory process, for example the experiences of patients and practical knowledge.123

perspectives underrepresented in published literature integrated into reports

Possible conflicts of interests are dealt with transparently. For participation in a GR committee the general requirement applies that one may neither have – nor represent – a direct interest in a certain outcome of the advice. Candidate participants in GR committees fill in a form on which they declare any possibly relevant interests. The president of GR then evaluates whether these interests are reconcilable with appointment as member of a committee. During the appointment meeting, the "interest forms" are discussed, so that all committee members are made aware of any interests. Also advisors fill out a declaration of interests form. The forms are also available for examination by third parties. 124

conflicts of interests dealt with transparently

GR's standing committees play an important role in safeguarding the quality of the council's work. A key characteristic of these permanent committees is that they maintain an overview of a broad field. The main tasks of a standing committee are twofold: on the one hand reviewing draft advisory reports, on the other monitoring issues and developments within their appointed field. There are standing committees in the fields of medicine, genetics, health and environment, health ethics and health law, infection and immunity, public health, nutrition and in the field of radiation and health. 125

GR's standing committees peer review reports produced by adhoc committees

In the concluding phase of the production of an advisory report one or more standing committees review the draft advisory reports for correctness and give feedback to the ad-hoc committees. 126

Evaluation

In 2008 an international team of evaluators evaluated GR and concluded that its quality and independence were of the highest level. 127

external evaluation of

¹²¹ Health Council of the Netherlands (2010a)

¹²² www.eusanh.eu

¹²³ www.gezondheidsraad.nl

¹²⁴ Health Council of the Netherlands (2010a)

¹²⁵ Health Council of the Netherlands (2010a)

¹²⁶ www.gezondheidsraad.nl

¹²⁷ www.gezondheidsraad.nl

Dissemination of research

GR assigns specific staff to work on readability of reports

Government response to GR reports published on its homepage GR strives for transparency towards the public. The readability of its reports for interested audiences including stakeholder groups and society at large is a priority for GR. GR has specifically assigned staff working on language clarity.

There is a formal procedure to be followed once GR delivered a report. GR formally delivers its reports to the responsible minister in government. The Dutch parliament receives the report, too. The minister is personally responsible for the implementation of the report's findings and advice. She or he subsequently has to state her or his position on the report to the Dutch parliament and qualify it. This response is also published on GR's webpage.

At the end of this institutional presentation are recent questions the Dutch MoH posed to the Advisory Council for Health Research RGO in the field of HSPHR that were answered in the format of a report:

- 2008: Healthy services research. The future of health services research in The Netherlands¹²⁸; for details on this report compare the end of the chapter on the Netherlands below.
- 2009: Paying upfront. The problem of matching European subsidies for health research¹²⁹

RGO advises MoH to go through with its plans of establishing a fund intended to match European Union research subsidies for Dutch health (services) research institutions. Taking a wider perspective, RGO in addition proposes to create a subsidy scheme to reimburse the costs patients' organization incur when preparing and writing subsidy applications for submission to European Union programs. Finally RGO points to a recent development: "The matching of non-cost-covering research subsidies, regardless of the party that provides them, is increasingly causing problems in the health research domain.¹³⁰

2010: Value for our money. Deciding on public investments in health research.¹³¹

This advisory report deals with the so far little explored terrain of *early* health technology assessments in biomedical research covering the stages from basic research, proof of principle, product development to phase 1&2 clinical trials.

"I believe that support for the Council's work rests to a significant extent on our ability to respond appropriately to ongoing developments in science, politics and the wider community." (GR President). 132

¹²⁸ Advisory Council on Health Research (2008)

¹²⁹ Advisory Council on Health Research (2009)

¹³⁰ Advisory Council on Health Research (2009) p. 15

¹³¹ Health Council of the Netherlands (2010b)

¹³² Health Council of the Netherlands (2010a)

RGO's assessment of HSPHR in the Netherlands

At the end of this section on advisory councils, RGO's latest advice to the government on health research in the Netherlands – published in 2008 – is presented. 133

After the previous advice to the Dutch government on health services research by RGO from 1994 "a lot has changed for the better" 134. The level of funding for health services research in the Netherlands is deemed adequate by RGO. Most of the funds come from contract funding. Their share has kept increasing so that today "the ability of the field to perform 'risky, innovative research' is under pressure. This situation may endanger the stability of the research field, threaten capacity building and decrease responsiveness of the field."135 Therefore RGO recommends "funding that is sufficiently flexible to afford scope both for addressing ad hoc issues and for developing stable, continuous lines of research."136 RGO goes on to suggest a concrete funding model: Direct funding should be allocated in proportion to the ability of the research group in question to attract contract funding. Money for "free health services research" would come as a bonus to grant money attracted competitively.¹³⁷ For continued high quality capacity building the creation of PhD fellowships enabling junior researchers to enhance theoretical and/ or methodological aspects of their research is advocated. 138 RGO finds that there is still too little interaction between researchers and decision makers in the Netherlands: "Crucial systematic and mandatory interaction between researchers and knowledge-users at every stage in the knowledge cycle is still rare, which results in suboptimal use of knowledge." ¹³⁹ The proposed remedy is the creation of platforms for systematic interaction: 140

- Development of a knowledge agenda through an interactive exploration between research and central government, care providers, insurers, patients, municipal authorities etc..
- Joint drawing up of implementation plans for health services research projects in advance between researchers and knowledge-users.
- Joint review of the implementation achievements afterwards.
- Making evaluation involving both researchers and practitioners a formal component of every transition in policy and health care practice with fixed time points for assessment from the outset.
- Creation of workplaces for researchers within relevant knowledgeuser organizations like healthcare facilities, insurers and municipalities.

Finally RGO proposes both researchers and knowledge-users to introduce each other to their respective environment, process dynamics and system RGO publishes advice on health research in 2008

- ... level of funding adequate
- ... increased contract funding may endanger innovative research
- ... bonus grant for free research suggested
- ... creation of PhD fellowships for capacity building suggested
- ... interaction researchers and decision makers still lacking

remedy: creation of platforms for systematic interaction

¹³³ Advisory Council on Health Research (2008)

¹³⁴ Advisory Council on Health Research (2008) p. 16

¹³⁵ Advisory Council on Health Research (2008) p. 16

¹³⁶ Advisory Council on Health Research (2008) p. 17

¹³⁷ Advisory Council on Health Research (2008)

¹³⁸ Advisory Council on Health Research (2008)

¹³⁹ Advisory Council on Health Research (2008) p. 17

¹⁴⁰ Advisory Council on Health Research (2008)

demands. Through open communication and learning about the other side mutual respect is to be promoted.¹⁴¹

5.1.4 Netherlands Organization for Health Research and Development ZonMw

ZonMw established to bundle funding for health research

HSPHR only a small part of ZonMw's commissioned research

ZonMw as intermediary between research, policy and practice

Transfer of existing and new knowledge as priority

Before 2001 the Health Research and Development Council - Zorg Onderzoek Nederland – Zon (part of the Ministry of Health, Welfare and Sport) oversaw the ministry's health research budget. The ministry for Education, Culture and Science funded research - including mainly basic health research - through the Netherlands Organization for Scientific Research -Nederlandse Organisatie voor Wetenschappelijk Onderzoek - NWO. To bundle funds for health research NWO's medical sciences arm the Council for Medical and Health Research *Medische Wetenschappen* Mw was merged with the Ministry of Health's Zon to form the Netherlands Organization for Health Research and Development - Zorg Onderzoek Nederland en Medische Wetenschappen - ZonMw. ZonMw is responsible for commissioning the whole spectrum of health research in the Netherlands: from fundamental biomedical research to clinical, organization of care and implementation research. It also funds pilot projects. As is true worldwide, biomedical and clinical research is predominant in the field of health research also in the Netherlands. HSPHR in the definition used for this report accounts only for a relatively small part of ZonMw commissioned research.

ZonMw is not simply a health research funding and commissioning institution. Nor does ZonMw undertake research itself. Rather ZonMw fulfills the role of an intermediary between research, policy and practice. The central aim of ZonMw is not only to generate research-based innovations but also to implement these innovations in health and social care. To this end, ZonMw has invested considerably in creating expertise on implementation and in guiding research groups towards working on the impact and implementation of their results.

"In our view, two things are needed to improve health and healthcare in the Netherlands: knowledge, and actual use of knowledge. For us the transfer and use of knowledge and experience is at least as important as the development of new knowledge." ¹⁴³

¹⁴¹ Advisory Council on Health Research (2008)

¹⁴² Bekker (2010)

 $^{^{143}}$ www.zonmw.nl

ZonMw focuses on speeding up the translation of research findings into improvements in practice. ZonMw's strategy therefore takes inspiration from the "innovation cycle" 144 , see figure 5.1-2 below.

ZonMw focus: translation of research findings into action

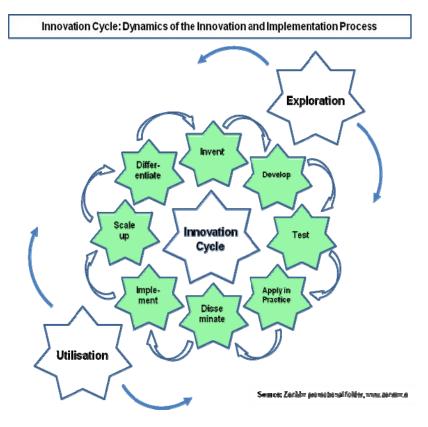


Figure 5.1-2: Innovation Cycle: Dynamics of the Innovation and Implementation Process

 $^{^{144}}$ ZonMw corporate brochure in English, www.zonmw.nl $\,$

Table 5.1-3: Fact sheet ZonMw

ZonMw

Netherlands Organization for Health Research and Development Zorg Onderzoek Nederland en Medische Wetenschappen

Location

The Hague, NL

Telephone interview partner

Senior expert

Legal status

 Independent, at arm's length distance from Ministry of Health, Welfare and Sport (governed by law on ZonMw) Employees are civil servants

Founded

2001

Employees

250

- 150 full time equivalents
- 5-10% of staff work on knowledge transfer and implementation

Annual budget

 \upliame 180 Mio. (mainly for commissioning health research, in part also for ZonMw activities and overhead)

• 10% for knowledge transfer and implementation

Main commissioners

- Netherlands Organization for Scientific Research NWO
- Ministry of Health, Welfare and Sport

approximate figures

Source: telephone interview, www.zonmw.nl

Legal status

The law on ZonMw inscribes ZonMw's independent status at arm's length distance from the Ministry of Health, Welfare and Sport. ZonMw's employees are civil servants.

More on ZonMw's history

already ZonMw's predecessor established transparent processes for commissioning research In 1997 the Health Research and Development Council – *ZorgOnderzoek Nederland* – Zon was established within the Ministry of Health, Welfare and Sport MoH. It was Zon's mission to put a transparent system for commissioning health research in place: explicit criteria, peer referees, periodical application procedures.

Before the commissioning of research had not been coordinated and personal contacts of health researchers to civil servants in the MoH were important for getting funding.

Also the Ministry of Education, Culture and Science funded mainly fundamental health research through the medical sciences arm of the Netherlands Organization of Scientific Research NWO. It is the most prominent financier of science in the Netherlands. Its task is to facilitate excellence in Dutch

scientific research through national competition.¹⁴⁵ To bundle health research in the Netherlands Zon and NWO's Council for Medical and Health Research Mw were integrated to form a new organization, ZonMw, in 2001.

Funding

ZonMw's annual budget for commissioning research and for its own activities and overhead is & 180 Mio.; 10% of the budget is invested in knowledge transfer and implementation aspects of commissioned research projects. The main commissioners are the Netherlands Organization for Scientific Research and the Ministry of Health, Welfare and Sport. Other avenues to extra commissions are via parliament asking questions about certain areas. A large new commission, meaning extra funding, was recently initiated this way in the area of long term care. ZonMw now coordinates a national quality assurance program in long term care.

10% of budget invested in implementation

Most new programs are commissioned with extra money. No money to fund new programs is taken from existing programs.

Setting the commissioning agenda for research programs

Government ministries – above all MoH – the Netherlands Organization for Scientific Research NWO and other organizations commission ZonMw to find solutions to certain problems or to boost work in particular areas. Together with experts from the field, ZonMw analyses the status quo in the particular area and the problems that exist there. Priorities are identified and it is determined in which direction it would be best to look for solutions.

government gives direction, ZonMw and experts from the field add precision

We then incorporate our findings into a program – a plan of action that sets out the direction for developments in scientific research and health care. The program gives scientific and health care institutions the opportunity to conduct research or to develop, test and implement innovations on a project basis.¹⁴⁶

Although ZonMw has some 'open' programs through which innovative research is funded, most of its programs are thematic and formulated in close cooperation with MoH.

most funding programs determined by government ...

We would like to have more non-earmarked money. MoH is reluctant to give more free money. MoH wants the authority to steer. Some adjustment of commissions happens every year. If a very interesting research proposal comes up that does not fit into an existing program, ZonMw enters into discussions and tries to convince the MoH to adjust. This takes energy, though. On the other hand it is good to be aligned with policy and to be of service and help to MoH.

...little non-earmarked funding available

There are approximately 80 ongoing programs in various program lines managed by ZonMw at any given point in time. A few of them deal with HSPHR. The in-house coordination of 80 research programs at a time is a challenge to ZonMw. There are two conflicting aims: MoH wants recognizable care research programs, ZonMw wants to bring together related fields. Towards this aim ZonMw created a structure of four thematic clusters: fundamental research, preventive care, curative care and long term care.

¹⁴⁵ www.nwo.nl

¹⁴⁶ www.zonmw.nl

If MoH for example commissions a program for elderly patients this is sorted to the "long term care" cluster quite straightforwardly. If a new program is commissioned for a disease management program, ZonMw has to be creative to organize the new program into its cluster structure.

MoH programs are commissioned for 4 years.

funding horizon of four years perceived as too short term oriented The four year program cycle is too short. The problem is that politics and research have different time frames. Research needs stability. Politics have a shorter time frame. After four years it is necessary to invest a lot of energy to get a new program running. Both researchers and ZonMw spend a lot of time and effort to continue with a new program. This is a wasteful process. In times of economic uncertainties like today, characterized by cut backs, there always is the possibility that a program in a certain area will – after its four year cycle expired – not exist for some time and it would be restarted only later. Maybe a line of research is also terminated altogether.

trade-off between incorporating ministry needs and flexibility in funding framework The advisory council on health research RGO also suggested to provide less strict frameworks in the programming of health services research by ZonMw: "Strict frameworks within a program hamper flexible funding of health services research that exceeds specific themes and prevents researchers to quickly address new questions from policy and practice." ¹⁴⁷

Interaction with stakeholders

focus on Dutch stakeholders as well as on international peers Policy makers and practitioners participate in ZonMw's Program committees and research groups in order to improve the links between research and policy. For ZonMw it is important to be close to knowing the needs of MoH. Internationally ZonMw looks for best practice examples abroad. It introduced e.g. quality management tools from the USA. Now it publishes results from its own quality management programs in the Netherlands: This time others profit from us. It is a give and take. 149

far reaching "listening exercise"

More recently MoH asked ZonMw to investigate priorities for research by questioning all relevant stakeholders: professionals and patients and their organizations, health care providers and insurers and the organizations involved in benefit package decisions. This resulted in the development of eight priority themes for programs.

Two examples of fostering the interaction with ZonMw stakeholders are presented below:

(1) Academic Collaborative Centers Public Health

In order to strengthen the public health system, MoH concluded that a strong knowledge infrastructure on public health was a prerequisite, linking practitioners, policy makers, researchers and the education sector. This gave rise to the two stage "Academic Collaborative Centers Public Health" program, aiming at bringing the worlds of academics and health care practice closer together, and thus fostering evidence-based working. An Academic Collaborative Centre for Public Health is a long-term partnership between one or

¹⁴⁷ Advisory Council on Health Research (2008) p. 16

¹⁴⁸ Bekker (2010)

¹⁴⁹ See also "Examples for successes in implementation from the last years" below.

more community health services (municipal public health departments) and a university. The main purpose of the academic collaborative centre is to improve knowledge transfer between practitioners, policymakers, researchers and the education sector.¹⁵⁰

(2) Network Grants

The network grants program is designed to encourage the formation of networks of scientists, and of scientists and practitioners, working in the field of health research and development. One option available is the provision of partial funding for meetings of scientists in the Netherlands, lasting one or more days.¹⁵¹

Evaluation

Evaluation for government associated bodies involving outside experts is mandatory every five years. The results of the present evaluation cycle are published in December of 2010.

The results show that ZonMw has been well established in the Netherlands. ZonMw is associated with transparent procedures and is trusted both in the research and policy making communities. The health sector perceives ZonMw as a distinct entity from MoH, which is regarded as a success at ZonMw.

government mandated external evaluation every five years ...

Evaluation of ZonMw impact on practice

Finding evidence for ZonMw's impact on practice is a difficult issue. This is also reflected in the results of this cycle's mandatory evaluation. Independent of this formal five yearly evaluation, ZonMw evaluated its impact on practice in a report on its implementation activities. The results are also positive.

Dissemination of knowledge

Presently ZonMw's homepage is mainly used by researchers and prospective grant applicants. They look at the projects and program data base to learn about upcoming calls for research proposals and formalities of the application process. In addition ZonMw is in the process of building a data bank with research results. Target audience for this compilation of best practice examples emanating from ZonMw funded research are people busy with implementation in the field. This new service of bringing results together and making them accessible to practitioners is part of a one-stop-shop project. Health care providers would then get implementation specific best practice examples with updated research results and access to the relevant implementation theories: transformation guidelines from ZonMw. In the long run ZonMw aims to add new cost effectiveness results to this data base. This, though, will take a long time to implement. In the future ZonMw's web presence will include interactive elements, fostering discussion, enabling network building and connecting program leaders with other researchers.

one-stop-shop project for dissemination of research results ... including implementation guidelines

ZonMw website to be upgraded to interactive platform

 $^{^{150}\,}http://www.zonmw.nl/en/Programs/all-Programs/academic-collaborative-centres-public-health/$

¹⁵¹ http://www.zonmw.nl/en/Programs/all-Programs/network-grants/

Implementation of research

applications to ZonMw need to incorporate implementation strategy Each of the four ZonMw program clusters employs an implementation team of two to three people. These four teams are coordinated by ZonMw's central implementation team.

Research proposals to ZonMw must be accompanied by implementation plans, which towards the end of research projects have to be further specified.¹⁵²

ZonMw offers implementation assistance

Implementation is a standard procedure, an automatic add on to ZonMw funded research. In the last year of the research program ZonMw's implementation experts ask what is relevant for implementation and what the researchers need from ZonMw in order to implement it.

10% of all funding in all projects is earmarked for implementation Every research program has a separate implementation budget of 10% of total funding. Program individual implementation activities as well as communication of program results, cost for publications and for conferences are covered by this funding share. ZonMw recently started to specifically fund open access publishing of research results.

The importance of implementation was recognized when ZonMw was started. Implementation has grown with ZonMw. The initial reaction of a researcher on a program committee would have been always to spend more money on research itself. Researchers always want to do more research. Now a 10% implementation budget has become normal.

ZonMw also funds specific programs in the implementation of best practice, such as the national collaborative approaches in acute care (the so-called 'Better Faster' program).¹⁵³

Examples for successes in implementation

ZonMw changes practice of quality programs ...

... and influences priority setting in government spending cuts The two following examples highlight successful ZonMw initiatives in the area of implementation of research during the last years. In the first example best practice quality programs from international experience were chosen for implementation in the Netherlands. In the second example, where implementation is defined more broadly as influencing political decision making, ZonMw's input will directly influence the allocation of funds in the next health care budget:

(1) MoH funded ten national quality programs with a total funding volume of € 100 Mio., with 100% of funds going to implementation: e.g. long term care, patient safety.

We looked for best practice. What should we use as models for quality initiatives in certain areas?

ZonMw is the coordinator of these programs. ZonMw does not do the work itself but commissions third parties to undertake it, e.g.

- Project management contracted out to manage breakthrough series (US inspired quality programs)
- Investment in training of doctors and nurses to change processes in care giving, making them safer for patients

¹⁵² Bekker (2010) p. 242

¹⁵³ Bekker (2010) p. 242

(2) In 2011 MoH intends to cut the health care budget by 10-20%. The approximately 100 hospitals in the Netherlands are supposed to save € 500 Mio. over the period of one year. Against this backdrop of cutbacks, ZonMw was approached to determine which programs should be introduced to save money on the way. ZonMw came up with a catalogue of 100 projects. Each one would result in both an improvement of quality of care and a saving in costs.

These programs should be implemented independent from the current cost saving drive because they improve quality. Now this intrinsic quality motivation is joined by the extrinsic pressure of urgently having to save money. And as a result, the chance for implementation arises. ZonMw came up with its catalogue based on research results from pilot projects. A heated, ongoing, debate started, if these findings would translate into system wide benefits if introduced on a large scale. Critics doubt that.

Looking to the future

Data on effectiveness of all ZonMw programs will have to be collected in the future. Cost-effectiveness studies are an important tool for government to cut costs. The new right wing coalition government plans to cut funding for ZonMw by between 10-15%. There are no details out yet, there is a degree of uncertainty in the air.

ZonMw costeffectiveness studies
becoming important
government tool to cut
costs

Playing god for one day: what would you change?

The 4 year program cycle is a problem. You need to question your existence every day! After a 4 year program has ended MoH should not stop the program. A lot of energy, brainpower and stress invested is wasted in the process of working out a new program after 4 years. Everyone is running after the next program. A funding commitment is necessary for the long haul.

There is a need for MoH to understand the long term investment in quality improvement. There is the need for continuous investment for teaching people quality improvement skills. One example is a project to inform staff about new processes to prevent falls in the elderly, new technologies available, new insights from research. Often new initiatives are advertised and funded in the framework of a 4 year program. After the end of the program funding is not renewed. Some other activity takes center stage. The reaction of practitioners in the field is that they get confused and frustrated. They feel left alone by government.

wish for generally longer funding commitments for programs

wish for continuous government investment in quality improvement initiatives

5.1.5 Netherlands Institute of Health Services Research NIVEL

NIVEL's has both scientific and societal mission with an international focus The Netherlands Institute for Health Services Research – Nederlands institute voor onderzoek van de gezondheidszorg – NIVEL is the national institute for health services research in the Netherlands. Its domain is applied and applicable health services research. NIVEL has a dual mission: scientific and societal. Increasingly, NIVEL has an international orientation.¹⁵⁴

The following figure 5.1-3 illustrates NIVEL's six interrelated work domains: care processes, health and illness, patient experiences and evaluations, health care professionals and organizations, outcomes, governance.

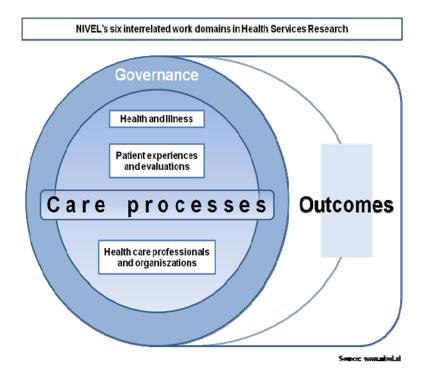


Figure 5.1-3: NIVEL's six interrelated work domains in HSR

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¹⁵⁴ www.nivel.nl

Table 5.1-4: Fact sheet NIVEL

NIVEL

Netherlands Institute of Health Services Research Nederlands instituut voor onderzoek van de gezondheidszorg

Location

Rotterdam, NL

Telephone interview partner

Senior expert

Legal status

- Private, not for profit foundation
- Employees have private employment contracts

Founded

1965

Employees

173, thereof 108 researchers

- Post doctoral: 50%
- Part-time university professors: 9

Annual budget

€ 14 Mio.

• Approx. 25% freely disposable

Funders

- Ministry of Health, Welfare and Sport
 - o € 6 Mio. direct funding in the framework of a four year covenant (2008 2011)
- Ministry of Education, Culture and Science
- Rest: project grants (competition or direct) from e.g. ZonMw

Staff flows

- Between NIVEL and universities
- From NIVEL to government and administration

approximate figures

Source: telephone interview, NIVEL (2010), www.nivel.nl

Legal status

NIVEL is a not for profit, private foundation. NIVEL's staff works under private employment contracts.

History

NIVEL was originally established as the scientific institute of the Dutch College of General Practitioners. NIVEL's domain has expanded gradually from general practice to primary care, secondary care and hospital care. NIVEL started from primary care research focus

Nowadays, NIVEL's research covers the entire field of 'somatic' health care.¹⁵⁵ The strong tradition of primary care research remains important.

Funding

NIVEL's annual budget is € 14 Mio.. NIVEL is funded via three main channels:

- The Ministry of Health, Welfare and Sport MoH directly funds
 € 6 Mio. within the framework of a four year covenant (2008 –
 2011). Negotiations for a renewed framework agreement (2012 –
 2017) are under way. The direct funding share from MoH falls into
 4 categories:
 - National databases, National panels largest share
 - NIVEL Center of Knowledge Exchange
 - development of new tools for knowledge exchange
 e.g. between MoH, municipalities and local
 actors
 - NIVEL homepage: often updated, high maintenance
 - Strategic orientation e.g. for quality topics, for free research and for matching funding for EU projects
 - ☼ Specific short term questions − time intensive
- 2. The Ministry of Education, Culture and Science funds NIVEL with € 1.5 Mio. through an extra grant for more fundamental research.

half of NIVEL's funding through tenders, many of them competitive

3. For the rest (about half) of its funding NIVEL relies on project grants awarded either competitively or directly. The wide range of commissioners includes for example ZonMw, central, local or regional government, health insurers, health service providers and their organizations, or private entities.

Project grants

acquiring grants is transaction cost intensive As opposed funding by bulk grants, in order to win funding from specific project grants, research proposals have to be submitted. This is time consuming:

- ⇔ To actually write up a research proposal takes about one week.
- * Before that, time-intensive consultations and talks on the subject between NIVEL researchers and potential funding organizations like MoH or the umbrella organization of Dutch hospitals take place.
- Networking is important but takes time away from actually doing research.

Some project grants ask for answers that come from yet undeveloped areas of research. *Developing new areas of research takes effort and energy.* These

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¹⁵⁵ www.nivel.nl

are two recent examples of new areas of research NIVEL developed for project grants:

- Due to a change in national health policy in the Netherlands, new research needs to be developed to analyze the impact of this policy reform and to make instruments available, which are newly required after the reform.
- The market turn in the Dutch health care system¹⁵⁶ has led to new commissioned research about indicators for transparency of quality (such as the Consumer Quality Index developed by NIVEL).

Setting the research agenda

NIVEL's research agenda is set in a round of consultations with directors at MoH, organizations of healthcare providers, patient organizations etc..

- The research agenda for the parts that are funded by the subsidy of the MoH is set in direct talks between NIVEL and contacts at the MoH. The research agenda for the rest of NIVEL's research is set in both more formal and informal meetings.
- However, much of priority setting actually takes place through NIVEL decisions to react to formal calls for research proposals or to react to requests to send in a proposal by organizations in health care that want to commission a research project.

setting of research agenda formally and informally with government ...

... and through filing proposals for commissioned research

Interaction with stakeholders

- Most interaction is on management and team leader level. However, many research projects have a stakeholder committee that advises the project teams. In meetings of these committees the (junior) researchers who actually conduct the research also participate.
- Researchers who leave NIVEL often find a job in government and health services administration, in this way adding to NIVEL's network.
- We are constantly working with other groups and institutes and building new relations. This is both important for the support and legitimacy of NIVEL in the outside world, and for the scientific output of NIVEL.

focus on intensive stakeholder interaction

Cooperation with the academic field

- Research schools: NIVEL participates in two research schools accredited by KNAW, the Royal Netherlands Academy of Arts and Sciences:
 - ** Netherlands School of Primary Care Research¹⁵⁷, with the universities in Maastricht, Amsterdam (VU) and Nijmegen
 - * Research Institute for Psychology & Health¹⁵⁸, with the universities in Utrecht, Leiden and Tilburg

This is important for the links of NIVEL with academia and for NIVEL's PhD students (courses and contacts with other PhD students).

NIVEL participates in research schools

¹⁵⁶ e.g. Westert (2009)

¹⁵⁷ www.researchschoolcare.nl

¹⁵⁸ http://pandh.fss.uu.nl

- ZonMw established to bundle funding for health research
- Part time professorships of NIVEL staff at a university: currently 9
- Occasional internships of junior NIVEL researchers of about 3 months in another research institute or abroad (occasional, no structural funding program exists for this exchange)

Research Data

- NIVEL national data bases
 - NIVEL researchers use the data for their research
 - many researchers outside NIVEL get access to the data
- NIVEL only does research when it is allowed to publish the results. On proprietary data NIVEL does not undertake research.
 - Some organizations, such as insurance organizations, tend to define research information as strategic information that they don't want to share

Research quality

- S ISO 9001 certification NIVEL Quality Handbook
 - The Quality Handbook describes many procedures and thus contains a lot of information about how to proceed in concrete situations.
- Mandatory peer review at all stages of research
 - The core of our quality system is mandatory peer review of all research proposals, reports, articles etc.
- Mandatory participation in review meetings
 - Individual researchers have to participate in the review meetings.

 Apart from the recommendations they get when their own research is reviewed, they learn a lot from the review of products of their fellow researchers.
- "Standard Evaluation for Public Research Organizations" also known as "sciQuest"159 every five years. The Standard Evaluation Protocol grants the freedom for every evaluated organization to set its own terms of reference.
 - This evaluation tool captures all relevant aspects of NIVEL's activities. NIVEL participates on a voluntary basis (although it is mandatory for participation in the research schools).
 - NIVEL evaluation of period 2004 2009 just completed
 - The transparency of the process is underscored by NIVEL's decision to share the detailed results with the general public by posting them on NIVEL's homepage: compare self evaluation of 2004 –

¹⁵⁹ Standard Evaluation Protocol 2009 -2015 – Protocol for Research Assessment in the Netherlands by Royal Netherlands Academy of Arts and Sciences KNAW, The Netherlands Organization for Scientific Research NWO, Association of Universities in the Netherlands VSNU, see www.knaw.nl/publicaties/pdf/20091052.pdf

2009 review160 and report of external review committee for the period of 1997 – 2003161

- Activities towards interlinking different lines of research within NIVEL.
 - Information exchange within department meetings and staff meetings.
 - In the management team we also look at whether research by others within the institute is used in writing research proposals.
- Quality of Information and Communication Technology
 - That is quite well up to date. ICT is an important precondition for the quality of research.

Implementation of research

NIVEL tries to combine its focus on producing peer group relevant research with its focus on societal impact in all of its research:

- If we do applied policy oriented research, we still try to publish about it in international peer reviewed journals.
- If we do research with funding from e.g. the research council (NWO), we still try to give it societal impact.
- Innovative ways of dissemination of knowledge to different target groups
 - NIVEL feeds back information to participants in research on their own data in comparison to data of other participants (health care providers/ organizations).
 - Dynamic publishing on websites participants are able to upload information and retrieve processed information.

Evaluation of research impact

In the view of NIVEL, the overall aim of health services research is to strengthen the evidence base of health policy. Accordingly, the evaluation of health services research should not be restricted to scientific quality as such but also assess the contribution of the research and the researchers to this policy oriented aim. ¹⁶² At present NIVEL collects narratives of its research impact – that are not included in the scientific literature – as part of NIVEL's effort to evaluate its research impact, and publishes them in the Dutch versions of the annual reports. ¹⁶³

NIVEL involved in development of instruments for measuring research impact in practice

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¹⁶⁰ NIVEL (2010), available for download together with other results at www.nivel.eu/selfevaluation

¹⁶¹ External Review Committee (2005) available at www.nivel.nl

¹⁶² Bensing (2003) p. 605, this publication is part of the outcome of work done at NIVEL on societal impact on health research

¹⁶³ for examples in English compare NIVEL (2010)

Human resources policy

- Career development at NIVEL
- NIVEL's human resources policy is "up or out". 164 Researchers at NIVEL start on temporary contracts. To get a tenured position they have to finish a PhD, to publish in international peer reviewed journals, to be able to attract research money, to have a network in research and policy, and, finally, at the point of decision of tenure, the economic position of the institute has to be good. All in all these requirements are quite demanding and many researchers leave NIVEL after some years of research.
- Staff flows to and from other institutions
 - Between NIVEL and universities
 - From NIVEL to government and administration

Playing god for one day: what would you change?

securing funding as recurring issue for NIVEL management

competitive human

resource policy at NIVEL

From 2008-2011 we have a funding covenant with MoH. However, we now are in the midst of negotiating a new covenant for the next six years (2012-2017). Due to the economic situation of the country this will not be easy. So, funding is at present NIVEL's main problem. One nice way of funding would be to have a fixed percentage of the health insurance premiums/ contributions earmarked for NIVEL - one euro for each inhabitant. 165

National Institute for Public Health and the 5.1.6 **Environment RIVM**

The National Institute for Public Health and the Environment -Rijksinstituut voor Volksgezondheid en Milieu - RIVM is a centre of expertise in the fields of health, nutrition and environmental protection. The results of RIVM's research, monitoring, modeling and risk assessment are used to underpin policy on public health, food, safety and the environment.166

¹⁶⁴ NIVEL (2010)

¹⁶⁵ On March 1st 2010 the Netherlands counted 16,587,551 inhabitants. Source: Wikipedia.

¹⁶⁶ www.rivm.nl

Table 5.1-5: Fact sheet RIVM

RIVM

National Institute for Public Health and the Environment *Rijksinstituut voor Volksgezondheid en Milieu*

Location

Bilthoven, NL

Telephone interview partner

Senior expert Public Health and Health Services Division

Legal status

- Ministry Agency under the Ministry of Health, Welfare and Sport
- Employees are civil servants

Founded

1909

Employees

RIVM (4 divisions)

- 1.625
 - 1.200 full time equivalents
 - Academic degree: 47%
 - Post doctoral: 27%
 - Part-time university professors: 19 persons RIVM-wide

focus of the telephone interview:

Public Health and Services Division within RIVM

- 200 full time equivalents
 - 25% laboratory/ white coat (counterfeit drugs, viruses, diseases)
 - 25% directing, transferring knowledge to stakeholders
 - 50% conducting new or integrating existing research
 - o 50% researchers
 - 50% production of services (e.g. screening of newborns)

Annual budget

€ 200 Mio.

• Approx. 20% freely disposable

Commissioners only government bodies

- Ministry of Health, Welfare and Sport
- Ministry of Housing, Spatial Planning and the Environment

RIVM cooperates with private entities as partners (not as commissioners)

Staff flows

- Predominately between RIVM and universities
- Only very limited exchange between RIVM and policy making and administrative bodies

approximate figures

Source: telephone interview, RIVM Annual Report 2008 at www.rivm.nl

Legal status

RIVM is a so called "Ministry Agency" under the Ministry of Health, Welfare and Sport. RIVM's employees are civil servants.

RIVM's independent status

RIVM Act guarantees independence from government

4 weeks exclusive access to research results The RIVM Act of 1996 stipulates that commissioning bodies will not have any influence on the organization and on the outcome of RIVM's activities. In addition, RIVM may report on research results independently of commissioning bodies. In practice this means that if the commissioned products are delivered to the commissioner (e.g. a research report to the Ministry of Health), the commissioner has four weeks exclusive access, then the results are published online.

RIVM funding

Up until 2004 RIVM was a directorate in the Ministry of Health:

The Director General used to come at the beginning of the year: Here is the money, we can spend it! Money was the starting point.

RIVM culture changed as a result of gaining arm's length distance from government This changed in 2004:

Now RIVM is a ministry agency. Now the starting point is not a fixed budget but questions in certain fields of knowledge. RIVM now needs to transform these questions into an offer with a price tag and find a commissioning partner for the package. Only then money flows. The process is business like, entailing planning and control. The model is also more customer oriented. This change meant that RIVM now burns its own money but is on the other hand freer to do with its own money what it wants. Some researchers at RIVM used to like the easiness and certainty of incoming funds pre 2004. They worked at RIVM because research money was easy to get. Now they are no longer working at the "University of Bilthoven". Now customer wishes matter. The RIVM program changed from knowledge research to putting knowledge into practice.

This change in the institutional setting was influenced by the general market reform orientation 168 in the Netherlands at the time:

RIVM operates in a more "customer oriented way" these days It was driven by the spirit of competitiveness and by ideology. Since RIVM does not compete with anybody it does not act in a market. I would call it being more business-like, more customer-oriented.

The private basis of the Dutch healthcare system, and the recent introduction of increased competition between insurers and providers in the 2006 Health Insurance Act¹⁶⁹, has led the government to develop supervisory and accountability arrangements and instruments. The government is now in the

¹⁶⁷ RIVM history, www.rivm.nl

¹⁶⁸ e.g. Westert (2009)

¹⁶⁹ Westert (2009)

process of closely monitoring the effects of the market-oriented reforms. For this the government needs research evidence. ¹⁷⁰

An example of RIVM's changing role is the establishment of the Centre for Population-Screening in 2006:

RIVM coordinates all national population screening programs and acts as the divider of money to private care givers. Today RIVM disseminates a larger budget to third parties (including private care providers) than RIVM's own annual budget (ca. \in Mio. 300 vs. \in Mio. 200)

RIVM acquired additional role as distributor of budgets to third parties

Funding share without earmark and the research function

About 20% of RIVM funding is without earmark. To maintain a high quality research function it should not be less than that, it is on the edge. Part of the 80% earmarked funding goes to supporting the research function, too.

20% of funding is nonearmarked

Agenda setting, interaction RIVM researchers with decision makers

Staff from the level of project leader upwards (approx. 200) interact directly with decision makers. The expectation is that they spend at least one day of the month in The Hague.¹⁷¹ The management takes this obligation very seriously and monitors RIVM's senior researchers' interaction with decision makers.

interaction of senior staff with stakeholders as RIVM priority

This is an investment that has long term benefits. It takes time to understand research questions. It takes time to be able to re-phrase research questions. If the necessary time and interaction with decision makers and research commissioners is not invested up front there will be no success in implementation. Some researchers prefer to have vague questions on the outset of a project. They believe vague questions leave them more freedom to do what they want in their research. This is not RIVM's policy.

investment in jointly formulating research question as prerequisite for successful research

In terms of agenda setting and stakeholder interaction 80 % happens informally and 20% in formal settings like committee meetings.

Special RIVM office at Ministry of Health, The Hague - bridge function

Since 1995 RIVM has been running an office with a staff of six at the Ministry of Health in The Hague. The aim is to be near to the decision makers, to translate policy questions into a researchable project format. The office assures proximity to decision makers not only at the Ministry of Health but also to other important stakeholders: *The Hague is the place where policy related things happen in the Netherlands.*

RIVM liaison office of six staff in Dutch ministry of health

Staffers working at the RIVM liaison office in The Hague need to be both excellent researchers and have a feeling for policy making. RIVM talent scouts constantly amongst its staff for individuals with these very scarce bridge function skills.

bridge function skill sought after

Whenever a new minister of health takes office, a senior member of RIVM's staff is put at the new minister's disposal for six months at RIVM's office in the Ministry of Health. This senior RIVM expert answers the newly incoming minister's questions she or he wants to have knowledge on. This RIVM

new health minister gets RIVM adviser for 6 months

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¹⁷⁰ Bekker (2010)

¹⁷¹ The capital of the Netherlands is Amsterdam, The Hague is the seat of government.

expert explains to the incoming minister how things work in the field of health and health care according to the new minister's need.

Politicians only want knowledge if it supports their position. 90% of decisions are being taken without knowledge/ evidence consideration: "There is nothing a government hates more than to be well-informed; for it makes the process of arriving at decisions much more complicated and difficult." 172

political decision making influenced by many factors outside of research

Knowledge is only one <u>small</u> factor in the process of policy making. Many other influences play a role in democratic systems. But this does not mean that knowledge production and research is a futile undertaking. Evidence can make a difference.

knowledge may be applied only after many years Knowledge can be important, also over time. Therefore knowledge production "for the shelf" makes sense, too. The market for it might come only ten years down the road.

bridge function to raise likelihood of capturing possibilities arising from rare windows of opportunity The planning of the bridge function is essential. You have to have your processes rolled out <u>very</u> well to capture the rare windows of opportunity and to deliver the appropriate knowledge in the appropriate format to the appropriate audience at just the appropriate time. It is a great skill to know when to bring research results up in the policy arena.

The context of policy decisions is often unknown to the researcher. This often leads to arrogant and patronizing judgments about politicians. The sophisticated skills needed to answer parliamentary questions, to mobilize support, to make oneself heard in political discussions etc. are often not understood by researchers.

MoH internships for RIVM high potentials

Six months internships for RIVM's high-potential junior researchers are available at the Ministry of Health liaison office. Spending one to two days per week in The Hague and the rest of the week at RIVM in Bilthoven allows these young researchers to gain an understanding of the system and to establish professional networks.

RIVM's international office - bridge function

RIVM also invests in international bridge function

In some way analogous to the RIVM liaison office at the Ministry of Health, six staff members work at RIVM's international office with a bridge function towards the European Commission (Director General DG for Health & Consumer Protection, DG Environment, DG Research), towards the World Health Organization WHO and towards other international organizations. RIVM's international office also coordinates RIVM's participation in international networks like the European Public Health Association EUPHA.

John Maynard Keynes, The Times (March 11, 1937); Collected Writings, vol. 21, p. 409

Drivers for RIVM's international activities:

One driver is that public health problems like infectious diseases have no borders. Another driver is RIVM's policy of giving and taking. Also, we don't know everything by ourselves. The motivation is <u>not</u> financial. The financial flows from the EU are too little too late. Only salary costs are covered in EU projects, not the overhead. Approximately 20% of RIVM's budget can be spent freely; RIVM may decide to use some of this money for international activities. Up until now the government has been open towards these international activities. Most of the time the government found them to be important and made funds available. The new government might view this differently.

driver for RIVM's international activities not financial ...

... RIVM has to offer something to the world

... RIVM aspires to play in the "world league"

Cooperation in education and training

- Netherlands School of Public and Occupational Health¹⁷³
- ☼ Netherlands Institute for Health Sciences NIHES¹⁷⁴

Formal arrangements with universities

- Part time professorships at each university in the Netherlands
 - RIVM staff works 1-2 days a week at the university
 - University pays part of the salary
 - Approx. 20 person RIVM-wide
- Senior lecturers at universities
 - 2.5 days of teaching a year per university
 - Approx. 100 persons RIVM-wide (50% of project leaders do it to a different degree at one or more or many universities)
- ⇔ 50:50 shared researchers
 - Half the time at university, half the time at RIVM
 - RIVM pays entire salary
 - Approx. 40

RIVM gains knowledge from universities!

Research quality assurance

- RIVM has a so called "Audit Committee on the Quality of Research" consisting entirely of external members. This committee initiates both internal and external audits of the academic standards of RIVM's research. Those audits are known to researchers in advance.
- RIVM is ISO 9001 certified. In this context unannounced audits by external experts take place.

Technological infrastructure

The technological infrastructure is considered important for RIVM's work.

- The laboratories are up to standard.
- The information and communication technology ICT could be better.

¹⁷³ www.nspoh.nl

¹⁷⁴ See also the following organizational profile of NIHES below.

Evaluation of research impact

RIVM research impact periodically evaluated

The evaluation of research impact is part of the audit process in accordance with the Standard Evaluation for Public Research Organizations. 175

The scheme is capturing important aspects reasonably well.

job applicants already having a network attractive for RIVM

What RIVM looks for in potential employees?

What they know! What network they have!

Candidates offering only skills, without a network are not attractive for RIVM.

Standing of natural sciences vs. social sciences

- In three of the four RIVM divisions the distribution of educational background is 90 percent "science" to 10 percent "arts"
- There it is mildly true that the natural sciences look down on the social sciences.
- In RIVM's Public Health and Health Services division it is more balanced at around 60 percent "science" to 40 percent "arts"
- Here there is full recognition of the extra social sciences bring. Social sciences are fully recognized. It is the field of work that makes the difference here, not the ratio.

Staff flows to and from other institutions

only limited staff exchange between RIVM and governmental bodies

Staff mobility is predominately between RIVM and universities. There is only very limited exchange between RIVM and policy making and administrative bodies.

RIVM looking into the future

RIVM expects a shift from a research institute to a knowledge center. 176

RIVM on the way to becoming a "knowledge center" We will bring together results from many sources. We will not do all the work by ourselves anymore. There will be outsourcing of repetitive work, like all measurements needed for research. The analysis will remain inhouse.

Appendix 8.2 describes RIVM's Public Health Status and Forecast Report as an example of the difficulties involved in finding the right balance between stakeholder involvement and the resulting relevance for decision makers on the one hand and independence of research on the other hand

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¹⁷⁵ Standard Evaluation Protocol 2009 -2015 – Protocol for Research Assessment in the Netherlands by Royal Netherlands Academy of Arts and Sciences KNAW, The Netherlands Organization for Scientific Research NWO, Association of Universities in the Netherlands VSNU, also called 'sci-Quest' http://www.knaw.nl/publicaties/pdf/20091052.pdf

¹⁷⁶ RIVM history, www.rivm.nl

5.1.7 Netherlands Institute for Health Sciences NIHES

The Netherlands Institute for Health Sciences NIHES is presented as an example for an institution building capacity in the field of health sciences research. NIHES was not chosen for its size and overall health system relevance but rather as an example for the successful cooperation between different institutions in establishing NIHES and as an example for a successful link between academic science and scientifically qualified practice.

NIHES builds capacity in quantitative health and health services research

NIHES aims to contribute to the identification of determinants of health and disease, to find factors contributing to the efficiency of health services and to further develop methods for the acquisition and interpretation of medical data. NIHES does so by offering research training at graduate and postgraduate level in quantitative medicine and health sciences. NIHES aims to prepare students for a career as researchers, executives or advisors in clinical medicine, drug research, public health and health policy development. NIHES has a quantitative research orientation and puts its focus on competence in epidemiology and biostatistics.

NIHES aspires to play in the "world league"

Table 5.1-6: Fact sheet NIHES

N	П	H	4	F۲

Netherlands Institute for Health Sciences

Location

Rotterdam, NL

Telephone interview partner

Senior expert

Status

• Alliance between universities and research institutes

Founded

1992

Graduates annually

- 100 masters of science (graduate, post graduate)
- 50 doctor of science diplomas (i.e. additional year of research training preparing for PhD)

approximate figures

Source: telephone interview, www.nihes.nl

NIHES is an alliance between the following universities and research institutes who collaborate and share knowledge in quantitative medical and health research:

University Medical Center Rotterdam/ Erasmus University Rotterdam (Departments of Epidemiology; Biostatistics; Public Health; Medical Psychology and Psychotherapy; Child and Adolescent PsyNIHES is a cooperation between universities, making it in itself an example of the added value of networking

¹⁷⁷ www.nihes.nl

- chiatry; Health Policy and Management; Medical Informatics; General Practice)
- Academic Medical Center Amsterdam/ University of Amsterdam (Departments of Clinical Epidemiology and Biostatistics; Social Medicine; Medical Informatics)
- Netherlands Cancer Institute (Department of Cancer Epidemiology)
- National Institute for Public Health and the Environment RIVM (Centre for Prevention and Health Services Research; Public Health Forecasting)

NIHES offers graduate and post graduate students the following programs:

- Research Master's Program (100 graduates per year)
 - Research training for bachelor graduates
 - Research training for master graduates and health professionals
 - Research masters for medical students
- Doctor of Science Diploma (50 graduates per year)
 - Additional year of research training after master's degree to acquire more research experience or increase chances of qualifying for a PhD research project involving actual research in the field

NIHES as networking platform for alumni

In addition to capacity building NIHES is a forum for establishing networks. Many people doing research at institutions in the field (including at the above presented Netherlands Institute for Health Services Research NIVEL and at the National Institute for Public Health and the Environment RIVM) and decision makers in government departments have NIHES degrees.

NIHES focuses on attracting international students

NIHES also attracts international students and is actively cooperating with academic institutions abroad.

5.2 Denmark

5.2.1 Danish Agency for Science, Technology and Innovation

The Danish Agency for Science, Technology and Innovation – Forsknings-og Innovationsstyrelsen¹⁷⁸ is an agency under the Danish Ministry of Science, Technology and Innovation. It performs tasks relating to research and innovation policy. It supervises the scientific research councils which allocate funds for independent research, for strategic research and for innovation. These scientific research councils also advise the political system.

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 $^{^{178}}$ www.fi.dk

Half the funding goes to "independent research", where only the quality of research is a deciding factor. This stream often funds basic research. The other half of funding goes to "strategic research" on politically decided themes. The minimum grant size for strategic research is 10 Mio. Danish Kroner (or 1.3 Mio. EUR) and may also be used to fund infrastructure. There is a two round competitive application process entailing international peer review in place.

health services research funded under "strategic research" targeted at institutional applicants

Clinical research, health services research and public health research is addressed via the strategic research's Program Commission for Individuals, Disease and Society. The Program Commission has eight members. Six of them are more clinically inclined, one member is from academic general practice with health services research leanings, one member is an anthropologist and health economist. Clinical research has an overweight and health services research fields like health economics have to fight for their roles in committees and in funding. Health services research as a field is bad at promoting itself and at presenting the possible benefits of its research.

non-clinical researchers underrepresented on program commission

health services research bad at self promotion

5.2.2 University of Southern Denmark Research Unit of Health Economics

The Research Unit of Health Economics at the University of Southern Denmark in Odense conducts research and provides research-based teaching in health economics and related subjects. The research unit has a tradition of research-based interaction with authorities and the business community.¹⁷⁹ It contributes to society by undertaking also applied and policy relevant research.¹⁸⁰ Approximately 20 employees, mainly researchers and PhD students work in the research unit.¹⁸¹

The Research Unit of Health Economics is the leading health economics department in Denmark. One of the Unit's strengths is its formal relationship with both the social science and the medical faculties. This organizational framework was established in 1991. ¹⁸²

bringing together social science and medicine

60% of staff's salaries are "earned" through government money for teaching. Some of this teaching is undertaken to get additional revenue to maintain or expand PhD student numbers. Roughly a quarter of funding is attracted from third parties. Drawing up a research proposal to apply for third party funding can be intellectually stimulating. It entails developing a new area of research. What can be tiresome is the day to day running of projects that are externally funded. Also "spending money" takes a lot of energy. EU and other public bodies require periodic status reports, very specific accounting and monitoring, which can be demotivating for researchers.

funding predominately through teaching

In Denmark's 2007 healthcare reform the five regions became responsible for the delivery of health care and also for health services research.

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¹⁷⁹ www.sdu.dk/Om SDU/Institutter_centre/c_ist_sundoek?sc_lang=en

¹⁸⁰ Report of the external evaluators, December 2008, available at

 $http://static.sdu.dk/mediafiles//Files/Om_SDU/Centre/c_ist_sundoke/Forsiden/ExternReport.pdf$

¹⁸¹ www.sdu.dk/Om SDU/Institutter centre/c ist sundoek?sc lang=en

¹⁸² Report of the external evaluators, December 2008

¹⁸³ Report of the external evaluators, December 2008

non-earmarked research funding has become scarce

Non-earmarked or free grants to research organizations are no longer available. Funding for research capacity is difficult. Health technology assessment, for example, used to have money for capacity building. This money ran out and today is no longer available. No one decided to reestablish that money. Central government took no explicit decision. Neither did regional government. A blame game is going on between the levels of government now.

time frames of researchers and policy makers often clash

A paradox is often encountered: When there is demand for a specific project, there is no free research capacity. When on the other hand researchers have time, there is no funding available. The windows of opportunity often do not coincide.

little staff exchanges with outside of academia

Staff exchanges between federal ministries, regions and hospital administrations work smoothly. Staff flows in and out of universities and research institutions also work well. There is little exchange between academia and administration, though. Career steps at university are rigid. Work experience gained e.g. at a hospital does not count in academia. Competition at universities is fierce. Academics need to focus on publishing and teaching in order to advance. More exchange between administration and academia would, though, be very beneficial to the whole system.

very little contact with research stakeholders

research stakeholders

Danish health services

research community

without tradition of

Since there is only very little informal contact with decision makers and no formal contact between university and ministries at all, academic research is not relevant for practice. It does not address real problems of the health care system. Research only benefits academic colleagues. Health services research in Denmark is not good at formally or informally listening to stakeholders. Often it is the coverage of health care issues in the press that gives researchers an idea of what line of research might be relevant. Our profession should be asking itself more often if our research really benefits society. We should be more self-critical, we should be better at addressing key problems for society and ask ourselves if we could do other types of studies to address these. If we addressed relevant areas, more funding would be made available. In general a more analytical approach to decision making in the health care sector is necessary in Denmark.

listening to stakeholders

As part of a self-evaluation process of the Research Unit for Health Economics the external evaluators raised the following issues:¹⁸⁴

external evaluation of research unit

- The present size is probably at a minimum level, and increasing the faculty would give greater long term stability.
- The opportunities for funding from specific research funds for economics and medicine respectively are limited.
- The financial challenge lies in the need to break the dependence of research funding on teaching activity.
- There is a need for more specific funding for basic research projects and for PhD students.

 $^{^{184}}$ Report of the external evaluators, December 2008

5.2.3 Ministry of Health

The expert interview with the Danish Federal Ministry of Interior and Health – *Indenrigs- og Sundhedsministeriet*¹⁸⁵ focused mainly on looking back on the history of the institutionalization of health technology assessment and Denmark and on the lessons to be drawn from it.

A few innovative and active researchers dedicated to health services research and individuals on an administrative level of government who were open to new developments became aware of the perspectives of health technology assessment. At the time new institutions for health technology assessment had been established in the UK and Sweden. In 1996 a committee reported on the possibilities of health technology assessment. Via the above mentioned open administrators the findings were relayed to the political level and generous separate funding for health technology assessment resulted. In 1998 the Danish Institute of Health Technology Assessment was established. It was later merged with the Danish Center for Health Evaluation. *The Institute initially had a very large budget of 50 Mio. Danish Kroner* (or 6.5 Mio. EUR) *allocated.*

window of opportunity gave health technology assessment considerable budget in late 1990ies

Since health technology assessment was new to the Danish community, it had to counter skepticism by the local clinical research environment and felt it needed to establish itself as highly scientific. Health technology assessment had to be defended in every lecture against a clinical audience claiming that it was "not really research". As a consequence the implicit target audience of early health technology assessments was clinicians. Initially the attitude was to choose the topic for a report yourself and to set the deadline yourself. The Institute of Health Technology Assessment and Health Evaluation's internal capacity to produce such report was limited. The Institute was in addition free to use its budget for commissioning research externally. This would have required, though, to find out what kind of health technology assessements were asked for. In spite of the fact that there was a systematic process for selecting topics for commissioning health technology assessments in place at the time, the Institute was not good at finding relevant topics. In addition the highest scientific standards applied to internally produced reports were applied also to commissioned research. To accept an imperfect product was not done. The very best was the enemy of the good. Reports were long in the making - two to three years - and comprised a volume of 300 - 400 pages each. The resulting reports were "too many, too expensive, too elaborate, too slow".

HTA focused more on establishing itself vis a vis clinical scientists rather than listening to needs of policy makers

HTA reports produced were ...

"... too many"

"... too expensive"

"... too elaborate"

"... too slow"

Establishing scientific credibility among the wider clinical peer group was perceived as more important than policy responsiveness. Health technology assessments were sought as decision making input by government. In the view of politicians' the reports produced came too late. And when the reports arrived – after decisions had already been taken – they were seen as interfering with decisions taken. Politicians did not perceive these health technology assessments or health services research reports as helpful but rather as criticizing policy decisions after they had been taken. Health technology reports without a recipient asking for it are just annoying for policy makers. People responsible for health technology assessment and health evaluation were reluctant to meet government requirements. They adapted too late to political wishes of producing "faster, smaller, more". The image

establishing scientific credibility for HTA was initially more important than to engage with users of research ...

... harming trust from policy makers

¹⁸⁵ www.im.dk

of health technology assessment and health evaluation was tarnished among Danish politicians and decision makers. An image, once established, is difficult to change.

HTA in Denmark as an opportunity missed

Over the last ten years central government's investment in health technology assessment and health services research grew smaller. When government money became scarcer and government funded institutions lacked money, funds were reallocated from health technology assessment and health services research to general health care planning. As mentioned above the health technology institute eventually found it difficult to spend its entire budget. Today the Danish Center for Health Technology Assessment had in the meantime become a part of the National Board of Health. The money not spent was taken away and given to other activities in the National Board of Health. Also government money for health services research is no longer located with one institution but scattered. Larger hospitals have their own health technology assessment and health services research staff or work closely with universities.

future for HTA reports

"... quick and <u>not</u> so dirty"

Due to the change in the economic background, less funding is available to spend on health services, or at least there is no extra money to pay for growing needs. The discussion about prioritization of health services has become more open as a result. It used not to be discussed at all in Denmark. This poses a new opportunity for health services research, as there is a need to decide where to invest. The health services research community should be able to respond to government wishes on certain topics "quick and not so dirty" by giving not very thorough and not too scientific advice within 15 to 30 days, sometimes perhaps in the form of just a whisper into a decision maker's ear.

today HTA is scientifically established research cooperation with clinicians

government more HTAliterate Today the scientific reputation of health services research and health technology assessments has been well established in Denmark. There is widespread understanding of and openness towards health technology assessment. Clinical research partners with health technology assessment to attract interest for the research among decision makers, to make implementation of results a focus and to combine clinical research with health economics. Administrators in government have become better educated in public health and health services research and are getting better at linking clinical research, health technology assessment and implementation.

Ministries in Denmark usually staff internally. Out of the 20-25 management position at the Danish Ministry of Health one person has been recruited from outside.

In terms of the staffing needs for internal capacity building at the Ministry of Health it is possible to find people who are able to read health technology assessments and who know to ask the right questions. These are primarily required in the Ministry of Health's staff. On the other hand it is still difficult to find people with more profound understandings of health economics, epidemiology and systematic literature reviews.

5.2.4 Institute for Health Services Research DSI

The Danish Institute for Health Services Research – Dansk Sundhedsinstitut – DSI aims to provide an improved knowledge base for the work and decisions of the Danish health authorities at local, regional and national levels. The institute pursues this objective by collecting, examining and disseminating information, conducting research and providing theoretical and practical consultancy. The main areas of work include hospitals, primary health care, community health services and the pharmaceutical sector. ¹⁸⁶

DSI owned by Danish regions

Table 5.2-1: Fact sheet DSI

DSI

Danish Institute for Health Services Research

Dansk Sundhedsinstitut

Location

Copenhagen, DK

Telephone interview partner

Senior expert

Legal status

- Independent non-profit research organization set up by the Danish State, Danish Regions and Local Governments
- Staff works on private employment contracts

Founded

1975

Employees

50

- 40 researchers (including 5 PhD candidates)
 - Multidisciplinary team including
 - o Physicians, nurses, sociologists, economists, political scientists, lawyers, health informatics, statistics
 - 1/3 economists
 - 1/3 organizational research
 - 1/3 public health

Annual budget

€ 5 Mio.

- About half as block grant from Danish regions
- About half from research grants and consulting activities
- Rest financed through post-graduate training, courses, conferences, seminars, workshops

Staff flows

• In multifold directions

approximate figures

Source: telephone interview, www.dsi.dk

186 www.dsi.dk

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Legal status

DSI is an independent non-profit research organization set up by the Danish State, Danish Regions and Local Governments. DSI's staff works on private employment contracts.

History

DSI has long tradition in the field

DSI was founded in 1975.

Funding

half the funding comes from commissions

The annual budget of € 5 Mio. is funded in equal parts by a block grant from Danish regions and by research grants plus consulting activities. Research commissioners are the Danish government, regional and local health authorities. The remainder is financed through post-graduate training, courses, conferences, seminars and workshops.

Setting the research agenda

DSI both undertakes its own research and works for commissioners. Two factors influence the priority setting of DSI's own research:

(1) What expertise does DSI want at the institute? Which PhD students does DHI want to encourage, e.g. medical anthropologists or economists?

setting of research agenda mainly informally (2) Board of directors from municipalities, hospitals, primary care: An example of a research question recently prioritized by DSI's board resulted from recent health sector reform in Denmark. The regional level became responsible for the delivering of care in Denmark. In the field of acute medical care the question arose how to best set up a regional admission system.

Research agenda setting works mainly via informal communications. *Denmark is a small country.* For DSI's "general practice research", for example, the program coordinator responsible entertains a widespread personal network in the field. Informal discussions of the program coordinator with members of the personal network would result in topic suggestions to the head of DSI, who would take it to the board for approval.

Cooperation with the academic field

At any given time five PhD candidates work at DSI. Their salaries are paid in part by DSI. DSI tries to have academic networks. On a formal level DSI makes resources available for attending scientific conferences.

Internal review process

strong role for director in research agenda setting ... In all its projects DSI applies a working process with a built-in internal quality assurance (internal review), carried out by one of DSI's researchers who is not part of the project group, typically the responsible research director. Projects published internationally or in DSI publications also pass through an external review before publication. External reviews are also used in other projects according to prior agreement. ¹⁸⁷ One third to half of DSI's work is reviewed externally by two individuals. In this formal peer review process there is no personal interaction between the DSI researcher and

... and in review process

¹⁸⁷ www.dsi.dk

the external reviewers. DSI researchers receive the external reviews in writing and need to qualify their reaction to them. All documents formally coming out of DSI are read by the director, who provides feed-back to the author(s) before publication.

Research data

Data on HTA related questions has become scarce over the last five to six years.

Impact of DSI on innovation in health services research in Denmark

- In Denmark DSI functions as an incubator for research areas in the making: HTA activities were housed at DSI until the agenda was taken to the National Board of Health in 1998.
- DSI developed prototype diagnosis related groups DRGs for hospital remuneration in Denmark. The MoH later took over the work in the field
- ⇔ DSI worked on patient safety. In 2001 DSI's patient safety expert group became an institute of its own: Danish Society for Patient Safety. Denmark eventually passed two patient safety acts (2003, 2009) and became the first country to introduce nationwide mandatory reporting of adverse events.

DSI also fulfills a capacity building role in the Danish HSPHR system. It develops functions and trains qualified staff.

From DSI's laboratory also failures resulted, e.g. in the areas of hospital management and local-regional communication, where research was discontinued. Failure is accepted by the funding bodies with a certain error tolerance for DSI as a generally successful incubator organization.

Failures are not explicitly talked about in Denmark. But if the management of DSI delivered only failures it would be replaced.

Human resources policy

DSI has a special place in the Danish health services research community by bringing together researchers from various backgrounds and with interest in both applied and academic research. Some DSI researchers have 4-5 years of work experience in the Ministry of the Interior and Health or in other administrative organizations. Traditionally health services researchers in Denmark tend to have a background in more clinically oriented work. DSI also employs researcher coming from private industry.

To have worked for say two years at DSI is a potential career step towards holding a top position in administration.

50% of DSI's researchers were formerly students at DSI. Some go on to write a PhD while working at DSI.

DSI has long standing incubator function for field of Danish health services research ...

... and capacity building role

... with leeway for "creative errors"

DSI of focal point of staff flows within Danish health services research and administration

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 $^{^{188}}$ www.patientsikkerhed.dk

Looking to the future

Up and coming areas for health services research in Denmark are quality assurance and patient safety. There will not be demand for the wider HTA areas of research.

Playing god for one day: what would you change?

I keep asking my friends in clinical research: Why can politicians wait three years for the results of a clinical trial and when they have questions pertaining to health services research they expect to have an answer one year before they asked?

The problem of health services research is that timing is too short to give high quality answers.

5.3 Norway

5.3.1 Research Council of Norway RCN

The Research Council of Norway – *Noregs forskingsråd* – RCN is an advisory body on research strategy issues, a research funding agency and an initiator of meeting places and networks.¹⁸⁹

RCN is a strong council when it comes to formulating Norway's research strategy. Most suggestions will be incorporated by government. Government and government ministries have a strong role of influence in research strategy via funding. They decide on targeted funding schemes and the distribution or research funds. RCN has only very limited capacity to initiate targeted funding schemes of its own.

RCN funding for health services research: 2.5 Mio. EUR

Health research is broadly defined at RCN. Most money goes to biomedical research. Funding for health services research at RCN started approximately 10 years ago. The annual funding amounts to roughly 20 Mio. Norwegian kroner (or 2.5 Mio. EUR). The main funding program in health services research is health economics. Public health research is not a specific funding scheme at RCN. Research is directed at broader diseases.

RCN is also responsible for maintaining open contacts with the Norwegian regional health authorities, who are responsible for hospitals. Independent of RCN, these regional health authorities invest larger amounts of money in health services research.

Periodical evaluation of RCN funded research areas Evaluation of RCN funded research areas takes place at regular intervals of five to ten years. The next evaluation for health services research and public health research is due in the spring of 2011.

¹⁸⁹ www.forskningsradet.no

5.3.2 Institute of Public Health NIPH

The Norwegian Institute of Public Health – Nasjonalt Folkehelseinstituttet – NIPH is a national centre of excellence in the areas of epidemiology, mental health, control of infectious diseases, environmental medicine, forensic toxicology and drug abuse. ¹⁹⁰

Table 5.3-1: Fact sheet NIPH

NIPH

Norwegian Institute of Public Health

Nasjonalt folkehelseinstitutt

Location

Oslo, NOR

Telephone interview partner

Senior expert

Legal status

- Governmental institution placed directly under the Ministry of Health and Care Services
- Employees are civil servants

Founded

1929

Employees

5 divisions

- 1.000
 - 850-900 full time equivalents
 - 1/3 service delivery
 - 1/3 health surveillance
 - 1/3 research
 - o 2/3 epidemiology (approx. 200 full time equivalents)
 - o 1/3 laboratory, white coat, of these half hold academic degree

Annual budget

€ 100 Mio.

- Main funder Ministry of Health and Care Services
- € 20 Mio. (representing 20% of NIPH's overall budget and most of NIPH's research budget) from Research Council of Norway, EU research grants, United States National Institute of Health
 - o this share funds most of NIPH's research activity

Staff flows

- Predominately between NIPH and universities/ hospitals
- Only very limited exchange between NIPH and policy making and administrative bodies

approximate figures

Source: telephone interview, www.fhi.no

190 www.fhi.no

Legal status

NIPH is a governmental institution placed directly under the Ministry of Health and Care Services MoH, its employees are civil servants.

History

NIPH as guardian of trove of population data

NIPH was founded in 1929. In the 1980s health services research was first incorporated at NIPH. In 2004 NIPH was given responsibility for all health-related population registries. ¹⁹¹ Since then NIPH also <u>coordinates</u> all public collection of epidemiological data in Norway.

Funding

most of NIHP's research funded through grants

increasing grant acquisition compensates for stagnating ministry of health funding NIHP annual budget of € 100 Mio. is mainly funded by the Ministry of Health and Care Services MoH. These government funds are intended for surveillance, advice, research infrastructure and (some) for infrastructure of bio-banks. Some € 20 Mio. come in after application or competitive tender from the Research Council of Norway RCN, hospitals, EU research grants, national and international foundations, or the likes of the US National Institute of Health. Most of NIPH's research activity is funded this way. For the last 10 years NIPHS fixed part of the budget from MoH has seen cuts. Through alternative sources of funding NIPH's overall budget still rose. Research funding through RCN is forward looking and long sighted. There is no fear about the continuity and the strategic focus of RCN financed research at NIPH. Activities necessary for fundraising are shared in the management team. That is why fundraising is not perceived as overly burdening the top levels of employees.

Setting the research agenda

NIPH generally has no problem to fund its research, doing research into recently upcoming areas may be a problem Most of the research funding at NIPH comes in after application or is based on competitive grant based. This determines the research agenda. Funding volume for research is not a problem. There is a prioritizing problem, though. If research in an area not covered by RCN's programs needs to be addressed, NIPH would first have to convince RCN to install a new program. This takes time and lobbying efforts. An example would be that research on Alzheimer's disease is not covered by RCN's mental health program. Additional preventive health work and research is sometimes financed by extra earmarked money from MoH.

Competitive research applications

competition for funding improved quality of NIPH research

Writing proposals and making applications before embarking on research was a change of culture for NIPH staff. Overall the competition has improved the quality of research done at NIPH. All in all there are now 400 – 500 research partners inside and outside of Norway.

Interactions with stakeholders

Junior NIPH researchers have no direct personal interaction with MoH. They interact a lot, though, with hospital staff, when projects are funded by hospitals or regional health authorities.

¹⁹¹ Except the Cancer Registry of Norway

The international stage

In 2007 the position of an *international director* was created at NIPH to strengthen NIPH's international commitment and to co-ordinate international efforts. All divisions of NIPH collaborate internationally and NIPH is involved in approximately 80 international research projects. NIPH contributes to international capacity building, participates in networks and carries out advisory functions in various international fora. Representatives from each of NIPH divisions take part in NIPH's *International Committee* to co-ordinate activities, share knowledge and hold cross-professional dialogues.

international director appointed to highlight importance of international networking

Cooperation with the academic field

There is a lot of cooperation in Norway with hospitals and with universities. Also where there is no money involved. Cooperation includes co-funding of research. NIPH is open for exchange among researchers. Also universities are open. Maybe not as open as NIPH.

Staff exchanges with universities

NIPH's best researchers hold part time positions at universities, e.g. 20% professorships. Most of these shared employees are 100% paid for by NIPH.

It is our aim to improve relationships with universities.

NIPH produces 20- 30 PhD candidates per year. (To put this figure into perspective, the University of Oslo annually produces 80-90 in these fields, the other universities in Norway a little less.)

Universities in Norway receive most of their frame budget for education.

Capacity building works in Norway.

Capacity for qualified research is well under way in most areas.

Quality assurance of research

NIPH's main policy is transparency.

NIPH's research infrastructure is open for everyone to use for her or his own research. Using NIPH data entails in a corresponding obligations: *Everyone has to share findings*. There are strict rules on the level of data sharing. If NIPH data is used for research the results of the research have to be entered into the data banks in return, e.g. when performing DNA analysis.

The quality of information and communication technology at NIPH is up to standard in the areas of health services and bio-banks. The health registers are old and need renewal. NIPH developed a strategic plan for the future of its registers. A three year plan was put into place to update the required infrastructure. The struggle for funding relies on MoH alone, which traditionally is not willing to give grants in this field.

Interlinking research lines within NIPH is a major challenge.

This tops our strategic plans every time again.

NIPH produces 20-30 PhD candidates per year

NIPH research infrastructure (data) open for external use

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Research data

NIPH data sought after worldwide for extensive data linkage possibilities with other Norwegian data bases At NIPH there is a focus on research that combines data from health registries and population studies with biological material from bio-banks such as the Mother and Child Cohort Study and the Twin Study Program. NIPH has a unique international position in this area. Like for example Finland, also Norway has a unique identifier to link databases across sectors to one individual. That enables e.g. the integration of income data.

I would say that the potential our national data bases offer are realized. We have very good researchers, no lack of funding and high quality research in this area.

Dissemination of research results

Presently there are not many examples of innovative ways of disseminating research results to different target groups at NIPH.

NIPH is working on it.

Several projects in this direction are ongoing, these are two examples:

- (1) NIPH will give data feed-back to all individuals who provide NIPH with data. Patient organizations find this interesting. One day everything that is stored on a Norwegian citizen will be made available to her/ him individually.
- (2) Improve use of registries: *The day to day updating of registries is not working very well.* In the future it is envisioned e.g. that an event like a death should be entered the same day and not with a possible delay of two years. This improves the quality of the registry.

Evaluation of societal research impact

ongoing work on development of instruments to evaluate societal impact of NIPH research

MoH wants to make it possible to follow the health of the population over time and identify influences and establish causal relationships.

There is the general problem with evaluation to isolate single influences like that of NIPH's work. There is ongoing work to find instruments to come closer to this goal.

Human resources policy

In Norway laying off staff is not easy. Before laying off an employee, the employer has to prove that she/ he has tried to educate the employee and tried to change the employee's behavior. This is true for the public and the private sector alike. Civil servants can also be laid off. So there is not much practical difference. This situation is only a minor problem at NIPH.

But every organization finds it difficult to motivate <u>all</u> staff. This is the same at NIPH as in private industry.

only limited staff exchange between research and administration

There are staff exchanges with universities and hospitals, very few though between research and administration: In the course of my entire career I have only seen a hand full. Most researchers stay at NIPH for the long term: Here they have more time for actually doing research. Recruiting problems for NIPH staff are present in the areas of mathematics, physics and chemistry.

Playing god for one day: what would you change ...

I would make the budgeting system a little more flexible to address newly emerged problems in research.

5.3.3 Norwegian Knowledge Centre for Health Sciences NOKC

The Norwegian Knowledge Centre for Health Sciences – *Nasjonalt kunnskapssenter for helsetjenesten*– NOKC supports the development of quality in the health services by summarizing research, promoting the use of research results, contributing to quality improvement, measuring the quality of health services, and working to improve patient safety.¹⁹²

NOKC houses the Norwegian Patient Safety Campaign and the Norwegian Council for Quality Improvement and Priority Setting in Health Care.

Table 5.3-2: Fact sheet NOKC

NOKC

Norwegian Knowledge Centre for Health Sciences Nasjonalt kunnskapssenter for helsetjenesten

Location

Oslo, NOR

Telephone interview partner

Senior expert

Legal status

- Organized under the Norwegian Directorate of Health
- Scientifically and professionally independent
- Employees are public sector employees

Founded

2004

Employees

- 140
 - 50-60 % have PhDs
 - 1/3 work on health technology assessments, on guidelines and on teaching evidence based medicine

Annual budget

• Funded exclusively by Directorate of Health

Staff flows

- Predominately between NOKC and universities/ clinical practice
- Only very limited exchange between NOKC and policy making and administrative bodies

approximate figures

Source: telephone interview, www.kunnskapssenteret.no

¹⁹² www.kunnskapssenteret.no

Legal status

NOKC is organized under the Norwegian Directorate of Health. NOKC is scientifically and professionally independent.

Towards the end of the 1990ies Norway founded the Norwegian Center for

Health Technology Assessment as a separate agency. At around the same

time a group for health services research was established in the Cochrane

framework at the Norwegian Institute of Public Health championing evidence based medicine, Cochrane reviews and implementation research in Norway. In 2002 the Norwegian Department of Health pushed a reorganization of agencies leading to the establishment of the Norwegian Directorate of Health 193. The Directorate was intended to have more freedom to deal with professional issues and not to be as close to politics as the department of health. The health department's knowledge management unit and the Norwegian Institute of Public Health's health services research group (Cochrane) were merged into the new Directorate of Health. The Norwegian Center for Health Technology Assessment withstood the *strong*

government demand to integrate for two more years. Its strong scientific

board considered the Directorate of Health too close to politics. In 2004

NOKC was founded bringing together the health department's former

knowledge management unit and the Norwegian Institute of Public Health's former health services research group (Cochrane), the Norwegian Center for Health Technology Assessment and another small health services research unit under the Directorate of Health. Initially two separate departments remained at NOKC for Health Technology Assessment and for evidence based medicine/Cochrane. These were later reorganized into a mixed

History

NOKC established in present form after year long organizational reshuffling

> arch ased

health services research and evidence based healthcare capacities bundles at NOKC

Funding

departmental structure.

NOKC does not need to resort to research grants for its funding NOKC is exclusively funded by the Norwegian Directorate of Health. The Directorate of Health gives money every year with a broad mandate in the line of "to conduct health technology assessment and implementation work for health technology assessment". Of NOKC's work 40% is for the Directorate of Health and the department of health. 30% is for hospitals. Some work is done for primary care. Two current projects were initiated by patient organizations. The Directorate of Health is open to funding all of NOKC's work. Also hospitals are important stakeholders for the Directorate of Health.

Setting the research agenda

focus synthesizing of existing knowledge In terms of research NOKC's scope of activities focuses on health technology assessment and systematic reviews. There is not much primary research undertaken.

democratic and inclusive process of agenda setting Suggestions from external parties for topics form the basis of the transparent agenda setting process. Twice a year suggestions can be handed in by anyone via a form on NOKC's website. The latest deadline was the middle of November. 90 suggestions were handed in. A democratic decision making proc-

¹⁹³ The Directorate of Health is a specialist directorate and an administrative body, see www.helsedirektoratet.no

ess starts thereafter. In the beginning of January a one day meeting of patients, hospitals and professional organizations votes the suggestions up or down to about 20. NOKC then sets the agenda. The benefits and drawbacks of this present process are under discussion. Systematic reviews are a time intensive one year process. Will the review ultimately result in guidelines? Will the department of health and its needs be served? Will there be long term benefits from the health technology assessment reports?

Other NOKC-projects are independent of the annual agenda setting process. The guidelines group of the Directorate of Health is supported in its work by NOKC and NOKC undertakes teaching activities. NOKC teaches evidence based medicine guideline making. NOKC teaches the principles of evidence based medicine. NOKC teaches how to undertake systematic reviews. Raising awareness is part of NOKC's mission.

NOKC's Advisory Board councils NOKC's management. The Advisory Board consists of ten to 15 members who serve for two years. NOKC suggest who will serve on the board. Nurses, physicians, people working in the field of ethics, anthropologists, consultants, hospital managers, community health care professionals and community representatives serve on NOKC's Advisory Board. It is getting more interdisciplinary all the time. The board is not a scientific steering committee.

NOKC's advisory board strives on diversity

Interactions with stakeholders

During the research process there is contact with stakeholders at the stage of formulating the research question. Stakeholders give NOKC feed-back on the research protocol. Sometimes they also give input during the research process. Sometimes a draft of a report is sent out to stakeholders.

NOKC holds an annual week long workshop on evidence based healthcare with approximately 100 participants. *It is a 12 year long tradition already. But there is no waiting list to participate.*

NOKC teaches decision makers the principles of evidence based medicine. Decision makers are busy, we struggle to keep their attention. They are basically open to evidence based healthcare. There is a culture shift taking place in Norway with a growing interest in decisions based on evidence based advice. We teach decision makers how to formulate research questions and we make clear what kinds of questions can be answered by health technology assessements. Still, a lot of department of health staff use experts for decision support instead of systematic evidence.

The Norwegian Electronic Health Library¹⁹⁴, which is maintained by NOKC, is the main point of contact with Norwegian health professionals. It contains useful information tailored to their needs.

NOKC currently develops a system to actively involve patients in health technology assessments. Another important field we work on is involving clinicians.

12 year tradition of large annual workshop teaching evidence based healthcare

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¹⁹⁴ www.helsebiblioteket.no (in Norwegian only)

The international stage

EU-funded projects on low and middle income countries are undertaken at NOKC's Unit for Preventive and International Health Care. The Cochrane Group's activities around "Health Systems and Practice", that support low and middle income countries, are based at NOKC.

NOKC houses the international secretariat for the Campbell Collaboration. ¹⁹⁵

Cooperation with the academic field

Between 10 – 20% of NOKC staff hold part time positions at universities. These activities are funded mostly by the Directorate of Health and the department of health. A part is funded by the universities. 20% of NOKC staff is involved in teaching evidence based medicine to different stakeholders.

NOKC teaches the teachers through bringing knowledge about evidence based medicine to college and university teachers. NOKC teaches how to undertake systematic reviews to PhD-students. There is a need for capacity building in Norway.

Quality assurance of research

transparent and stringent quality processes

NOKC's "common methods book" is the basis for all work done at NOKC. Processes are described in detail. The Cochrane handbook is a major influence. It is updated every year. The common methods book also serves as a tool for internal teaching and competence building activities. The GRADE (Grading of Recommendations Assessment, Development and Evaluation) system ¹⁹⁶ has recently been introduced at NOKC.

every report reviewed by two external experts

Every report is reviewed externally by at least two reviewers. As to internal reviewing, five to six different units at NOKC deal with health technology assessments and systematic reviews. Everyone of NOKC's reports is subject to comprehensive internal review by executive managers and unit heads. They meet every other week and discuss final products and give their okay. Every report has been read by all of us.

Dissemination of research results

teaching as important realm of research dissemination

All publications are available through NOKC's website. Workshops and seminars for target groups as well as teaching are part of NOKC's dissemination activities.

NOKC develops new resources. Locally introduced new technologies in hospitals are addressed in the format of "mini-health technology assessements". In these NOKC advises, provides evidence and suggestions. "Hospital evidence based procedures" form part of NOKC-produced guidelines. NOKC developed e-learning resources on using research findings in practice. We have not yet had time to promote this tool enough. Today it is mainly used for preparing participants for courses and for them to review course materials afterwards.

¹⁹⁵ www.campbellcollaboration.org

 $^{^{196}}$ www.gradeworkinggroup.org

Human resources policy

Most of NOKC's staff has an academic background or comes from clinical work. There are nurses and physicians holding MSc or PhD degrees, statisticians, anthropologists, biologists and pharmacists. 50-60% of NOKC's staff holds PhDs. A lot of masters programs exist in Norway. These days more and more nurses and physiotherapists have PhDs. There is not so much work for PhDs at universities. So they are happy to work for example at NOKC.

staff exchange predominately with academia and clinical backgrounds

Among new NOKC-staff a lot of competence building for systematic review is necessary. *PhDs and MDs normally hardly know anything about it.*

There is an annual staff turnover of 10%. Staff tends to stay at NOKC. Researchers move on. (Doing systematic reviews all the time seems to get boring after a while.) Giving NOKC's staff the opportunity to teach and to go out and meet clinicians is a job enrichment strategy to keep them longer.

NOKC's employees are part of the public sector. In Norway there is only a small private sector in health care. NOKC staff has the same contracts as hospital or school employees. They are under the same payment scheme as employees of the Directorate of Health or the department of health. So there is no salary competition for staff. Occasionally NOKC-staff moves to the department of health. *But not often*.

little staff exchange with administration

Playing god for one day: what would you change ...

I see three challenges:

- 1.) We challenge clinicians by reducing their decision autonomy. In this sense there is a lot of power in health technology assessments. Also policy makers have strong opinions about them.
- 2.) Implementation of clinical guidelines is a challenge. We have no formal responsibility for it. The recent Norwegian focus on quality improvement may serve as a case in point here. Contrary to what the department of health seems to believe, putting up indicators is not enough. A lot of work on implementation is needed. In this respect Norway is lacking experience and still fares poorly compared to other countries.
- 3.) Brining evidence based health care thinking to medical schools in Norway is another challenge for the future. Today Norwegian medical students are not being familiarized with the concepts of evidence based medicine at university.

5.4 United Kingdom

5.4.1 Service Delivery and Organisation Programme SDO

The Service Delivery and Organisation Programme SDO is a research and development program at the National Institute for Health Research. In the UK the Medical Research Council sponsors health research up to the introduction of an intervention to the patient population. The National Institute

focus on improving organization and delivery of care

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for Health Research thereafter takes over the responsibility for funding of research and capacity building for research. SDO commissions research evidence that improves practice in relation to the organization and delivery of healthcare. SDO builds research capability and capacity amongst those who manage, organize and deliver services - improving their understanding of the research literature and how to use research evidence.¹⁹⁷

In addition to the personal interview this section draws on information from SDO's annual review $2009/10.^{198}$

Table 5.4-1: Fact sheet SDO

SDO

National Institute for Health Research Service Delivery and Organisation programme

Location

Southampton, UK

Telephone interview partner

Senior expert

Founded

1999

Annual budget

• Commissioned new research projects in the year 2009/10 approx. GBP 10 Mio. or EUR 12 Mio.

approximate figures

Source: telephone interview, www.sdo.nihr.ac.uk

shift towards more applied research in the last 15 years

Research need in the last ten to 15 years has changed. There has been a shift towards more applied research, away from purely biomedical research. In addition to assessing the right health technologies to introduce the mechanisms via which these technologies enter the care path are just as important to be researched. A system for addressing the issues of organization of service delivery, like SDO, is less developed in some countries.

"national listening "exercise"

In 1999, when SDO was founded, and again in 2002 a "national listening exercise" was carried out to enable SDO to understand what issues were most important to those delivering and organizing services and to those receiving them. A wide range of people were consulted during this process including service users, health care professionals, health service managers and researchers.

research for EUR 12 Mio. commissioned annually

In the fiscal year 2009/2010 SDO has commissioned 31 new research projects at a total value of approx. GBP 10 Mio. (or EUR 12 Mio.) on topics like health and social integration, the management of primary care services and the implementation of research in healthcare organizations. SDO funds both commissioned research in priority areas and academic curiosity-led re-

¹⁹⁷ www.sdo.nihr.ac.uk

 $^{^{198}\} Available\ at\ www.sdo.nihr.ac.uk/files/adhoc/annual-review-2010.pdf$

search. For both lines of research a two stage application procedure is in place, inviting only shortlisted applications to submit full research proposals. Some of SDO funded research requires working in partnership between National Health System organizations as research users and researchers. The healthcare organization works in genuine tandem with an academic organization as part of the project team involved in the design and delivery of the research project. All SDO commissioned research is available on the website. In addition to the final report SDO actively encourages project teams to disseminate the findings of their research as widely as possible. Communication vehicles include journal articles, press releases, media interviews, newsletters, conference abstracts or presentations and dissemination events. SDO commissions experts in communication to produce different forms of output. 199 SDO produces summaries of research reports targeted for senior managers and clinicians.

In addition to commissioning research SDO is interested in the interactive exchange of research-based findings. "SDO also convenes research forums on specific topics where decision makers interact with researchers who are experts in the field. For example, symposia on the SDO themes of access to care and continuity of care have been held, and these also serve to bring researchers working in the same topic area together. This allows crossfertilization of ideas and helps in the development of communities of knowledge."200 Under the activity label of "knowledge mobilization" SDO gives high priority to sharing research findings for active discussion between researchers and managers. SDO helps research teams to engage with the National Health System management community. SDO is also engaged in building capacity and capability in the National Health System management community to use research evidence in decision making. The ability to access and use management research in the National Health System is supported by SDO. To this tune "SDO Network" brings researchers and managers together in seminars and conferences. SDO Network organized interactive events, develops local learning sets and acts as a knowledge broker. SDO offers research projects the opportunity to attend Chief Executive Officer Forums to network and share learning with senior managers of the National Health System. SDO funds secondments for academics to spend time working with managers in healthcare organizations and for managers in the National Health System to work alongside researchers on research projects.

The "SDO Management Fellowship Scheme" offers research teams to apply for additional funds to allow a local manager to form an integral part of their research team. Most fellowships run for an equivalent of 12 months full time over the total period of the research project. The fellowships encompass three main objectives:

- 1. To improve the quality and relevance of the respective funded research project through greater managerial involvement.
- 2. To develop capacity in the managerial community for accessing, appraising and using research evidence.

all SDO research available online

tailored research communication formats

SDO engaged in providing forums for exchange of research findings

innovative "knowledge mobilization" program focuses on profound interaction between researchers and administrators

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¹⁹⁹ Allen (2007), p. 128

²⁰⁰ Allen (2007), p. 128, 129

3. To encourage greater engagement, linkage and exchange between the local research producers – usually universities – and the potential local research users within the National Health System.

A formative evaluation of the Management Fellowship Scheme has been commissioned. The results will feed back into future scheme developments.

The "Academic Fellowship Scheme" supports senior to mid-level academics to spend up to 12 months in a partner healthcare organization to undertake relevant health services research and develop the research skills of partner staff.

SDO has three panels contributing to the commissioning process by considering the importance of potential research to the National Health System. Membership of these panels is made up of people with an understanding of National Health System needs and an understanding of healthcare recipient perspectives. The panels include those who use and manage healthcare services.

important standing of reviewing, not only by peers but by wider variety of stakeholders Referees play a vital role in the quality of SDO research. They review research proposals and final reports to ensure that the outputs are useful to the research users. Reviewers are drawn from a variety of backgrounds including health professionals, managers, methodological experts and service users. SDO encourages research suggestions from all sources to ensure projects are important to those who use and manage services. All suggestions received are considered.

In addition to SDO the National Institute for Health Research launched the following initiatives of interest in the field of health services research and public health research:²⁰¹

- Public Health Research program with a predicted annual budget of GBP 10 Mio. (or EUR 12 Mio.) by 2011/12.
- * Health Services Research program will fund large studies of national or international importance into better ways of planning and providing health services with a spending forecast of GBP 5 Mio. (or EUR 6 Mio.) for 2010/11.
- One of 13 Cochrane centres with a Cochrane-associated activity level of GBP 5 Mio. (or EUR 6 Mio.)
- Centre for Reviews and Dissemination based at the University of York annually funded with GBP 2 Mio. (or EUR 2.5 Mio.)
- INVOLVE program supporting public and patient involvement in research

www.nihr.ac.uk/files/Publications/296542 DeliveringHealthResearchReport acc3.pdf

National Institute for Health Research. Delivering Health Research. Progress Report 2008/009, available at

From their reflections of their shaping the work of SDO in earlier years four authors conclude: "Solutions to the question of how to improve the utilization of research may lie more in understanding how research is developed, or how policy agendas are set and policy implemented, than in thinking about how knowledge is transferred from research findings to decision makers. One key element in this task is to ensure the early and sustained interaction of decision makers, research commissioners and researchers." And further: "The case of SDO also illustrates the large amount of resources that need to be deployed if the requisite degree of interaction between decision makers and researchers is to be achieved throughout the research process." 203

getting researchers and decision makers to interact requires resources and patience

The evidence based paradigm has been pushed from North America and the UK, where it has historically been an element of anglo-american governance culture. Also in today's UK there is still scope for more evidence use in managerial and clinical questions.

5.4.2 National Institute for Health and Clinical Excellence NICE

The National Institute for Health and Clinical Excellence NICE provides guidance, sets quality standards and manages a national database to improve people's health and prevent and treat ill health. NICE is the most prolific producer of guidelines in the world.²⁰⁴ NICE produces clinical guidelines, guidelines resulting from health technology assessments and guidelines for public health. NICE guidances are generally reviewed every three to four years to incorporate new evidence. NICE does not have a remit or budget to undertake research. NICE therefore works with the research community to ensure the necessary research is undertaken.

The following section introduces two of NICE's cross cutting units: Implementation and Research and Development.

NICE is major guideline producer ...

... with increasing focus on implementation activities

²⁰² Allen (2007), p. 130

²⁰³ Allen (2007), p. 131

²⁰⁴ www.nice.org.uk

Table 5.4-2: Fact sheet NICE

NICE

National Institute for Health and Clinical Excellence

Location

London and Manchester, UK

Telephone interview partners

Senior experts

Founded

1999

Employees

- 400
 - Implementation Team: 40
 - Research and Development Team: 10

approximate figures

Source: telephone interviews, www.nice.org.uk

NICE Research and Development Team

targeted with highlighting gaps in evidence ...

... and to facilitate their research

The remit of the Research and Development Team cuts across all of NICE. One role is to highlight areas with gaps in evidence. As mentioned above, NICE does not have its own research commissioning budget and therefore no funds to freely set the research agenda. NICE depends on academia submitting research proposals to research funders that cater to NICE's research needs. Together with research funders areas are prioritized. One such funder is the Medical Research Council, which has a traditionally research led attitude according to which the intrinsic quality of research alone should drive funding. Researchers are to be left working objectively and in an uninfluenced way. The Medical Research Council has less and less intervening interaction with researchers. The same is expected of NICE.

Academic health services research is quite developed in the UK. In terms of systematic reviewing skills and health economics graduates, the UK has a strong starting base. Also academics have become more engaged with the needs of organizations using their research. The problem for NICE it how is to make researchers understand NICE's and the National Health System's research needs and how to motivate researchers from various backgrounds to apply for commissioned research that answers NICE's research questions.

Health economics and statistics understand that NICE is interested in their work and are more prepared to answer the Medical Research Council's calls that are inspired by NICE needs.

More innovative NICE research needs are met only with difficulties. Some researchers don't see the relevance of their work for NICE: Qualitative research proposals are less handed in by researchers. Qualitative public health researchers don't see NICE as users of their research. This is true across the board but particularly when it comes to methodological research. Methodological questions regarding the involvement of patients and the public in guideline production happen to be prominent on NICE's agenda, though. Today the methodological question of how we formalize lay evidence is important to NICE. Qualitative evidence around guideline implementation is also important, since the context of an intervention and the environment are relevant and maybe crucial for successful implementation. This drive to highlight qualitative aspects in NICE's work initially came from the NICE boards, committees and panels with lay involvement. The general public and academia is not aware of this aspect of NICE's work, yet. The more qualitative researchers are involved in NICE's committees over time, the better their understanding of NICE's qualitative research needs will get. Overall there is a positive tendency in terms of a growing awareness of "soft aspects" at NICE:

The National Institute for Health Research is another funder of research programs with the National Health System as primary research user. The research agenda for the National Institute of Health Research, the National Health System and NICE changed, supported by the Health White Paper, addressing more service delivery, public health and health technology assessment issues. When it comes to deciding which research the National Institute of Health Research is to fund, NICE is one of the many voices to be considered. More overall funding for NICE-relevant research would be desirable. The bias towards quantitative research with its hierarchy of evidence with randomized controlled clinical trials on the top is still out there. People, though, understand the practical unfeasibility to implement a trial in many settings more and more. There is more pragmatism asking: What evidence do we have available? Multidisciplinary work around NICE gradually changes the climate of research. Researchers from different field are getting used to interaction, which generates more openness towards each other. The interaction on NICE's research panels today focuses less on the different research paradigms of biomedical and public health researchers. It is about whether research addresses the needs of the health service at hand and about the ability of a specific research question to benefit practice.

The Research and Development Team is also charged with making sure that the methodologies used for guideline development in all of NICE's centers are consistent.

2010 saw the introduction of the NICE Fellows and NICE Scholars Program. Ten senior and established employees in the National Health Service such as surgeons, managers or nurses are made "NICE Fellows" for the period of three years. Equally ten juniors beginning their careers in the National Health Service are made "NICE Scholars" for the period of a year. It is a give and take. Their benefit is networking, gaining unique insights into NICE and the learning of specific skills. Every participant is assigned a mentor in NICE. There are quarterly meetings, workshops and learning days with senior keynote speakers. NICE Fellows and Scholars are familiarized with the political background and with the upcoming agenda of developments in the National Health Service. They are being put in touch with the right people on senior levels, to whom access is generally restricted. They also get the chance to share what they do in their administrative or clinical

NICE's "qualitative research interests" not as widely perceived as wished in the scientific community ...

... developing qualitative methods is an example

balance between hard and soft sciences shaping over time

NICE Fellows and NICE Scholars to bring managers and clinicians in touch with research

practice. NICE on the other hand benefits by getting managers and practitioners to understand NICE, thereby promoting NICE in the various organizations in the field. They understand how we make decisions and what NICE's needs are for research and development.

Stakeholder interaction via ...

... NICE Citizen Council

... NICE Partner Council

need for feed-back from and interaction with practice as driver of implementation team

Implementation Team to link NICE to practice and users of guidelines

Because of its cross-cutting function the Research and Development team is also in charge of the NICE Citizen Council and the NICE Partners Council. Established in 2002 the NICE Citizen Council was the UK's first advisory body made up entirely of members of the public. The Citizen Council presents its reports to the board of NICE, who issue a formal response explaining their reaction to the recommendation and how NICE will act on the findings. As a result of inputs from the Citizen Council, messages and processes are adopted all over NICE. The NICE Partners Council's members are drawn from organizations with special interest in NICE's work. Members include patient groups, health professionals, management from the National Health Service, quality organizations and industry and trade unions. The Partner Council provides a forum for the exchange of ideas, concepts and future plans and enables interaction between researchers and decision makers.

NICE Implementation Team

In a series of workshops with stakeholders held six years ago, NICE asked what people expect from it. Previously NICE had produced guidelines and handed them over to the National Health System. At times the National Health System organizations in the field did not know what to do with the new guidelines and how to change their practices according to the new guidelines. The feed-back from practice was that it was important to be guided in going about the implementation of guidelines in every day care. As a result the Implementation Team was set up. The Implementation Team addresses the whole of NICE's "product range": technical appraisals, clinical guidelines, interventional procedures guidelines, public health and quality standards.

Another issue calling for remedy turned out to be that NICE on the other hand was not aware of what was happening in practice. To improve the situation field teams were established four years ago to engage with organizations at the local level. Field teams are based in different parts of the country, talking to local authorities of the National Health System, promoting NICE's work and explaining the support NICE can offer to implement guidance. The aim is to offer practical support to people. Their second goal is to pick up needs in the field. Issues raised in the field are brought back to NICE, e.g.:

** "NICE guidelines are difficult to implement because the cost impact is difficult to assess." As a remedy NICE formed a cost team that produced models where a lot of parameters that may differ locally, like different prevalence rates of a disease, can be adjusted to make cost impact estimates.

Other instruments to bring user perspectives on board are specially set up commissions and panels.

When NICE developed new tools, the Implementation Team undertakes activities to communicate the new developments and to raise awareness about them in the field. For example interactive workshops with users are organ-

ized, where they learn about the details of the new tool and get explanations how to use the new tool.

Implementation needs to be thought of right at the start of developing guidelines. The use of guidelines is determined to a large degree by this exercise. When selecting topics for new guidelines the initial question has to be: Do people need the new guideline? Do people feel it is necessary? If the answer is no, then implementation will be difficult. Also the format in which guidelines are presented to different user groups determines implementation success. We need to keep reflecting, keep asking these questions. The feed-back of field teams is very important.

feed-back to field team important new NICE asset ...

NICE is aligned with national policy and needs to be familiar with other institutions' ongoing activities. The Implementation Team needs to be aware of policy drivers, scanning the horizon of what will happen in the near future. Once a year the Implementation Team formally looks at the organization we engage with. What is going on there? What are upcoming government initiatives?

... making it more responsive to user needs

Following the deterioration of the general economic outlook in the wake of the financial crisis, another aspect of guidelines came to the fore: Some guidelines save money. Today financial savings as a consequence of guideline implementation are a strong argument. An example is the guideline on contraceptive methods. The costing team looked at the financial impact and found that through the reduction in the number of teenage pregnancies fewer hospital abortions would take place, resulting in cost savings for the National Health System. Topic selection for guidelines today is geared at cost savings. The allocation of resources according to cost-effectiveness becomes important in the current economic and political situation. NICE will have to reposition itself. These deliberations have been made all along at NICE but it has not been explicitly said. The benefits of what we do will need to be marketed more openly.

cost aspects of guideline implementation gain prominence

5.5 Some Lessons from Good Practice

Some recurring themes in the experience of the institutions of good practice are listed in table 5.5-1 below.

Table 5.5-1: Some lessons from good practice

Some lessons from good practice in NL, DK, NOR, UK

- Explicit external and internal mechanisms for quality assurance.
- Transparent rules to manage conflicts of interest.
- Periodic external evaluation.
- Publication of entire research output on the internet.
- Exclusive access for research commissioner to research findings only for limited pre-defined time.
- Involving research commissioners, users, stakeholders and the public in the production of research in multiple forms and during the whole research process:
 - o Prioritization of research areas
 - o Formulation of research question
 - o Collaborative research teams
 - o Review of research output
 - o Implementation
 - o Evaluation of impact
- Forums for systemic and individualized research-policy interaction to deepen understanding and to improve practical collaboration.
- Exchange with academia.
- National and international networking to stay on top of developments and to avoid duplication of work.
- Research funding organizations sensitive to policy needs, but as distinct entities at arm's length from political influence.
- Transparent processes for prioritizing and commissioning research.
- Funding for translational research, piloting, implementation, evaluation and evaluation research.
- Funding allowing flexibility to initiate projects that are curiosity driven or react to recent developments quickly.
- Predetermined program lines and fixed research categories may limit research cutting across sectors and hinder linkages.
- Incorporation of incubator function for wider system with proactive early development of research fields.
- Involvement in public debate.
- Development from research institute towards knowledge center.

6 Inspirations for Capacity Building in HSPHR

Combining the recommendations from the literature in chapter 3 and the experience of the Netherlands, Denmark, Norway and the United Kingdom with their organizations of good practice presented in chapter 5, lessons and inspiration for capacity building in HSPHR can be drawn on four levels:

lessons from literature and from examples of good practice ...

- 1. General guidelines for improving the interaction between research and policy.
- 2. The desirable governance culture guiding the policy system relevant for HSPHR.
- 3. The way towards formulating a national HSPHR strategy.
- 4. Organizational blueprints
 - o for a "model HSPHR commissioning organization". Such a research commissioning organization could potentially one day play a role broadly similar to the one being played by ZonMw in the Netherlands or by SDO in the United Kingdom. This blueprint can be found in appendix 8.3.
 - o for a "model HSPHR organization". This could be a "National Institute for Health Services Research and Public Health Research". A blueprint for such an organization can be found in appendix 8.4.

Before turning to the lessons learnt and the inspirations received, some of the caveats about over optimistically embracing evidence aware approaches in the policy system relevant for HSPHR should be recalled.

Limited evidence on the benefits of research use for improving life in society

"Any evidence that increases in research use have indeed made the world a better place is at best partial and contested, and some would say is largely absent." ²⁰⁵

Limitations of research to inform policy making in a meaningful way

"Research will rarely provide definitive answers, especially when the questions are about what works in tackling complex social problems." ²⁰⁶

Limitations of policy evaluation

"Given the astronomical variety of implementation of even one basic program mode, the variety of staffs, clients, organizational contexts, social and political environments, and funding levels, any hope for deriving generalizable findings is romantic." ²⁰⁷

Limited available research knowledge

"The current state of research-based knowledge is insufficient to inform many areas of policy." ²⁰⁸

... with important caveats and limitations:

Does evidence really improve life?

Does research really influence policy?

Can we ever tell if research changed practice?

Is there enough research knowledge in the relevant fields?

²⁰⁵ Nutley (2007), 297

²⁰⁶ Nutley (2003) p. 7

²⁰⁷ Weiss (2000) cited in Nutley (2003)

²⁰⁸ Nutley (2003) p. 5

The potential for tensions between participative and evidence-based approaches towards policy decision making has been noted.²⁰⁹

conflict between independence of research and user orientation as example for delicate trade-offs to be decided upon Given the complexity of the field of learning systems, there are potential tensions and contradictions between various recommendations. An example would be the desirability of collaboration and research co-production between researchers and decision makers on the one hand, and independence of research to fulfill a societal function of critically reflecting on commonly held beliefs on the other hand.

6.1 General Guidelines for Improving the Interaction between Research and Policy

spark needed to motivate capacity building ...

... poor performance in international rankings may spark research development, e.g. PISA in the education sector What could drive a country's interest in evidence based policy and practice? The spread of evidence based discourse via international networks, the use of research to support and legitimize potentially controversial policy developments and the expectation that evidence might inform the way to improve the performance in international rankings may serve as triggers of national action. Decision makers are more likely to use research if they asked for it in the first place, i.e. if this research answers practical questions they face. Timeliness and targeted communication for decision makers is important in this context, too. 211

Aspects to be considered when aiming at improving the supply of research for evidence based policy interactions are:²¹²

- Quality of research synthesis
- Research translation
- Research communication

Promising leverages to use for increasing the demand for research for the same purpose would be:²¹³

- Amended policy processes
 - to increase demand
 - to increase receptivity

"linkage and exchange" as promising concept A set of activities the Canadian Health Services Research Foundation calls 'linkage and exchange' is designed to allow an ongoing relationship to develop between researchers, research funders and potential research users. These activities can be seen as an attempt to create a policy network or further down the road a policy community. An infrastructure conducive to 'linkage and exchange' would consist of people such as knowledge brokers, institutions such as think tanks and processes such as policy forums. Sig-

²⁰⁹ Quinn (2002) cited in Nutley (2003)

²¹⁰ Nutley (2010), p. 139

²¹¹ Allen (2007), p. 123

²¹² Nutley (2007), p. 314

²¹³ Nutley (2007), p. 314

²¹⁴ Allen (2007), p. 124

nificant investment in people, time and resources is required if knowledge brokering is to work well.

Mediation initiatives to improve links between research and policy include:²¹⁵

* Establishment of forums for informal exchange of knowledge.

Establishment "particularly of structures for exchange and debate that are shared spaces – rather than academics being asked into policy debates and having to operate within the policy sphere. This is particularly important if we want to maintain a challenging role for research, one that questions current policy and practice thinking, alongside a more consensual role, whereby research informs and refines current thinking." ²¹⁶

- Employing more staff with a research background in the administration.
- Staff exchanges between research and policy sectors.
- Foundation of intermediary institutions which work with practitioners on the implementation of evidence based interventions.

forums to bring research and policy together ...

... employ more science literate staff in government

- ... staff exchanges
- ... institutions with bridging function

Table 6.1-1: Guiding principles to support the use of research in practice

Guiding principles to support the use of research in practice

Research must be translated

To be used, research needs to be adapted for, or reconstructed within, local practice contexts. Simply providing the findings is not enough. Adaptation can take multiple forms, including tailoring research results to a target group, enabling debate about their implications, 'tinkering' with research in practice, or developing research-based programs or tools.

Ownership is key

Ownership – of the research itself, of research-based programs or tools, or of projects to implement research – is vital to uptake.

The need for enthusiasts

Individual enthusiasts or 'product champions' can help carry the process of getting research used. They are crucial to selling new ideas and practices. Personal contact is most effective here.

Conduct a contextual analysis

Successful initiatives are those that analyze the context for research implementation and target specific barriers to and enablers of change.

Ensure credibility

Research take-up and use is enhanced where there is credible evidence, endorsement from opinion leaders – both expert and peer – and demonstrable high-level commitment to the process.

²¹⁵ Nutley (2010), p. 140

²¹⁶ Nutley (2010), p. 142

Provide leadership

Strong and visible leadership, at both management and project levels, can help provide motivation, authority and organizational integration.

Give adequate support

Ongoing support for those implementing change increases the chance of success. Financial, technical, organizational and emotional support are all important. Dedicated project coordinators have been core to the success of many initiatives.

Develop integration

To assist and sustain research use, activities need to be integrated within existing organizational systems and practices. All key stakeholders need to be involved. Alignment with local and national policy demands also supports research use.

Quelle: Nutley (2007), Box 10.1, p. 312, 312

"Our view is that interactive, social and interpretive models of research use — models that acknowledge and engage with context, models that admit roles for other types of knowledge, and models that see research use as being more than just about individual behavior — are more likely to assist us in intervening to get research used more." ²¹⁷

6.2 Desireable Governance Culture Guiding the Policy System relevant for HSPHR

open dialogue about research evidence may trigger more benefits than obvious at first sight ... A culture of almost playful openness to rational discourse ready to let go of preconceived notions is a worthy aspiration. "Good research should be seen more as a stimulus to respectful dialogue and less often as a trump card to truncate any debate." Ideally the discourse about research evidence between stakeholders would serve as a door opener to different perspectives and the questioning of one's own assumptions. "Instead of simply giving answers to a problem, research can shed further light on the problem itself, and may even call into question what counts as a 'problem' in the first place." Reflecting questions of societal power disparities between stakeholders when it comes to decision making and reflecting questions of access to societal discourse can be encouraged by multi focal research results. "It encourages us to make transparent those interests that are being brought to the table in the process of using research." 220

²¹⁷ Nutley (2007), p. 319

²¹⁸ Nutley (2007), p. 300

²¹⁹ Nutley (2007), p. 301

²²⁰ Nutley (2007), p. 310

Supporting the development of an innovative HSPHR system is not intended to limit the democratically legitimized sphere of policy making. Certain research evidence discourses, though, tend towards establishing an elitist expertocracy of scientists and those in the know. To safeguard against such a development a number of measures are advisable:

- Leadership should be participatory and not aloof, the process of policy making should be "democratized" by ensuring access to relevant information, data sources and available research evidence for all participants rather than "modernized" in a managerialist sense, where decisions influencing society as a whole or local communities are interpreted as optimization problems to be solved by top down management processes like in a private company operating in a market environment.²²¹
- Dedicated HSPHR institutions amongst other aims are established to "digest" existing research evidence, which may facilitate the opening up of evidence informed policy debates.²²²
- "The provision of research evidence via the internet may encourage more open debates which are not confined to those operating in traditional expert domains."

safeguards against expert kingdom:

... democratizing political process

... democratize access to research findings

Table 6.2-1: Desireable properties of a governance culture guiding the policy system relevant for HSPHR

Desireable properties of a governance culture guiding the policy system relevant for HSPHR

Commitment to democratized policy process

Openness to public discourse

- Evidence aware public debate on daily running of affairs
- Widening the circle of participants in this debate

Participatory Leadership

- Visioning the future
- Systems and strategic thinking
- Oriented towards nurturing potentials
- Openness to occasional utopianism for inspiration

Transparency regarding

- Policy processes
- Conflicts of interest
- Information
 - o Requiring the publication of the evidence base for policy decisions
 - Providing open access to information leading to more informed stakeholders and citizens

Accountability

Evaluation

²²¹ Nutley (2003)

²²² Nutley (2003)

²²³ Nutley (2003) p. 11

Trust

- Partnership
 - Co-creation of research by policy makers, research users and researchers
 - Giving researchers and research users a share of the responsibility for policy implementation
- Shared goals

Learning culture

- Learning system
- Organizational learning
- Learning by doing
- Tolerance for mistakes

Provision of occasional spaces for <u>de</u>celeration for slowed down reflection processes in an otherwise time constrained environment

Responsiveness to context and humility

6.3 The Way Towards Formulating a National HSPHR Strategy

Strengthening Public Health Research in Europe *SPHERE's*²²⁴ recommendations for a European strategy for public health research highlight key demands that are equally relevant in the somewhat wider realm of a HSPHR strategy: ²²⁵

- ☼ It should be based on equity and accountability.
- It should be sufficiently stable to consider middle and long-duration policy and scientific approaches.
- It should be flexible enough to integrate new concerns, stakeholders and methodologies.
- Control and management of research requires improved coordination between researchers, funding agencies and society.

TO-DO list in addition to setting research priorities:

In its strategy for HSPHR, a country, both in need of developing research capacity and in need of institutionalizing good practice arrangements in the field of HSPHR, must in addition to formulating priorities for HSPHR address the following:

- Target academic capacity building for high quality researchers, addressing the entire diversity of skills necessary for HSPHR in a balanced way.
- Target HSPHR institutional capacity building by creating workplaces for researchers within relevant knowledge-user organizations like

²²⁴ www.ucl.ac.uk/public-health/sphere/spherehome.htm

²²⁵ Conceição (2009)

government at all levels, public health and healthcare facilities, insurers etc..

- Address the need to establish a sustainable national data infrastructure for HSPHR.
- ☼ Facilitate the establishment of good practice organizations for commissioning and conducting research, again balancing the distribution of research funds across the entire spectrum sub-fields of HSPHR.
- Address wider issues of a desirable governance culture for the overarching health and health care system, of which research constitutes only one rather small part.

The process of developing a HSPHR knowledge agenda through an interactive exploration between the research community, central and local government, care providers, insurers, patients etc. is per se a unique opportunity for systems learning. It introduces both researchers and knowledge-users to their respective environments, process dynamics and system demands, thus offering a forum to build mutual respect and trust.²²⁶

include widest possible array of stakeholders in process of formulating knowledge agenda

Stakeholders in the development of a HSPHR strategy need to understand the long term nature of capacity building. Quick successes cannot be expected, first positive effects of long term capacity activities in HSPHR will materialize only after a decade or so. Stakeholders need to begin by implementing first steps while all the time keeping the long term strategic goals in mind: Starting small, but thinking big.

HSPHR strategy development will take time and commitment for the long haul

The final page of this report closes with a both optimistic and emancipatory thought voiced on the final page of a standard work on using evidence: "Constructive debate and dialogue drawing on research offers the best chance for a collective enhancement of knowledge and practice in public services."²²⁷

open discourse per se has chance to improve quality of public services

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²²⁶ Compare Advisory Council on Health Research (2008)

²²⁷ Nutley (2007), p. 320

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8 Appendices

8.1 Semi structured expert interview guide used, example for Netherlands Institute of Health Services Research – NIVEL

Rules of expert interview:

- No citing of name of expert interviewed, no mention of position in organization
- Report will be published at the end of Jan. 2011, available on www to general public

Abbreviation used

(Ext. Review Comm. 2005) refers to information taken from the report of the external review committee on NIVEL in March 2005, available on the NIVEL homepage.

Identifying Research Priorities

- 1.) There are important data bases on the Dutch healthcare system operated at NIVEL: Is potential for research based on NIVEL data systems realized?
- 2.) On what levels does interaction between NIVEL researcher and political decision maker/ administrative implementer take place? Only on top management and team leader level or for everyone?
- 3.) Is formal stakeholder interaction (board meetings, annual stakeholder consultations, ...) more important for research agenda setting at NIVEL or are informal (and also less transparent) processes (personal contacts, ...) decisive?

Building Research Capacity

- 4.) (Ext. Review Comm. 2005): 30% scientific activity, 70% societal application of research Is this still true?
- 5.) Long term career development for NIVEL staff?
- 6.) Staff flows (exchanges) between academia, other research centres, government, health care administration, private industry and NIVEL? Possibly also internationally?
- 7.) Role of NIHES Netherlands Institute for Health Sciences (Erasmus University Rotterdam, University of Amsterdam, Netherlands Cancer Institute, RIVM) for building capacity at NIVEL?
- 8.) NIVEL participation in Netherlands School of Primary Care Research and Research Institute for Psychology & Health: rational and benefits?
- 9.) Health services research: standing of social science vs. natural (clinical) science reputation, weight in policy deliberations in The Netherlands?

Research Funding

- 10.) (Ext. Review Comm. 2005): growing market orientation in NL healthcare system Has this resulted in growing "grant market orientation" of NIVEL? If so, what are the repercussions?
- 11.) (Ext. Review Comm. 2005 quotes report from 2001): 50% of free funding is necessary to maintain the scientific function

Do you share this view? What is the current percentage of genuinely "free funding" at NIVEL?

Quality of Research

- 12.) When is the next round of "Standard Evaluation for Public Research Organizations" (Dutch Universities, KNAW, NWO) due for NIVEL?
- 13.) Do you considered this tool to capture (most, all, many, ...) relevant aspects of NIVEL activity?
- 14.) What is the benefit of ISO 9001 certification for individual NIVEL researcher in her or his every day work?
- 15.) Activities towards interlinking different lines of research within NIVEL?
- 16.) Quality of NIVEL information and communication technology facilities and relevance for quality of research?
- 17.) Importance of NIVEL library resources for quality of NIVEL research? Attraction of external researchers to NIVEL library (resources)?

Implementation - Impact of Research/ Evidence Informed Policy

18.) (Ext. Review Comm. 2005): Innovative ways in which NIVEL tries to disseminate its knowledge to policy makers and the general public

What would be examples of such innovative ways of dissemination of knowledge to different target groups?

19.) (Ext. Review Comm. 2005): Impressed by work done on societal impact on health research (within KNAW)

This sort of work sounds very interesting. Where can it be accessed?

20.) Has any evaluation on NIVEL's contribution to evidence informed policy making in The Netherlands been undertaken?

Questions beyond ...

21.) (Ext. Review Comm. 2005): structural changes for NIVEL

Are structural changes necessary? Desired? Imminent?

22.) (Ext. Review Comm. 2005): European Institute of Public Health Plans? Activities in that direction? Appreciation by NIVEL funders for this aspect of NIVEL's work?

23.) (Ext. Review Comm. 2005): financing structure as NIVEL's biggest problem

What do you regard as NIVEL's "biggest problem"? What would you change "if you could play god for one day?

- 24.) There are voices saying that The Netherlands are very successful not only in establishing prominent research institutions but also in facilitating "virtual communities" between universities, those institutions and the field of implementation. Is this the case? How important is this creation of national communities with a critical mass (as opposed to many small parallel worlds)?
- 25.) Is Dutch governance culture across the board more transparent and "evidence aware discussion prone" than that of other countries?
- 26.) Scope and limits of evidence aware/ evidence informed/ evidence based policy making?
- 27.) "Chicken or Egg Question" how to go about capacity building for health services research: Is it supply or demand driven? Is major financial investment in universities and research institutions first or societal demand for answers to "health services research questions"?
- 28.) Is there an important question in the area I have not addressed?
- 29.) Being interested in the above questions, is there a person coming to your mind you might suggest me to contact either in The Netherlands or internationally?

8.2 Bringing RIVM research and policy closer together: an example for the delicate trade-off between policy relevance and independence of research

The Netherland Institute of Public Health and the Environment RIVM has taken some fundamental steps over the years to bring research and policy together and to make its reports influential in informing public health policy. This has been a process of learning and adaptation. In this appendix taken mostly verbatim from Bekker (2010) pages 247 and 248, the production process of RIVM's four-yearly *Public Health Status and Forecasts* PHSF report is presented.²²⁸ Readers are invited to form their own opinions on how well RIVM managed to balance these essentially conflicting goals here.

"The first PHSF report, published in 1993, was hardly useful to policy makers. However, as a first attempt to produce unambiguous figures it was quite successful. The figures contained in the report were not contested by policy makers or (public health) researchers, who had been involved at the start of the project. 50 public health experts (including researchers) and representatives from the ministry of health MoH participated in the discussion of the 'definition report' that contained the main outline of the policy information to be provided.

Later versions of the report (and the accompanying websites) increasingly sought to become more useable for policy actors, while at the same time keeping distance from policy to remain authoritative. RIVM used several strategies and tools to deal with this need for closeness and distance, both at the level of policy makers and at the level of participating researchers. A division was made between political and scientific concerns by organizing different kinds of input at different times during the process of writing the PHSF reports. This was done to avoid long and unfruitful discussions about the value of evidence at the wrong moment. For this, RIVM created two policy advisory boards and one research advisory board, which discuss the policy relevance of the issues arising from research data and the general themes in the reports.

Another strategy was to place so-called 'liaison people' within MoH: project leaders from RIVM were placed inside MoH in a separate unit. The policy contacts built by this unit enabled coordinated agenda-setting at different levels within the ministry and agreement between policy makers and RIVM on the issues to be investigated. The timing of the publication of RIVM reports was also changed to fit with the policy cycle of the MoH, enabling the reports to provide input at the right time in the policy process.

Coordination is not only needed with policy makers. RIVM is dependent on data delivered by research departments all over the country, and it has to create a relationship of trust with these departments. One of the accomplishments (and constant challenges) for RIVM is to establish authority for its reports in the research field. To develop trust for researchers involved in the production of the RIVM reports and trust in the models and methods that are used, RIVM uses generally accepted methods to assess research data. For example, systematic literature reviews are generally based on the guidelines used by the Cochrane Collaboration, where softer or 'grey' data are separated from hard data. Standardized compounded health indicators have also been developed by RIVM. Furthermore, the translation and interpretation of the data for the Dutch situation takes place in project groups that focus on specific health-related issues, such as care

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²²⁸ PHSF is based on a number of continuously updated websites. Websites of interest for the PHSF report and the biannual Dutch Health Care Performance report are:

⁽¹⁾ Dutch National Atlas of Public Health (www.zorgatlas.nl)

⁽²⁾ National Public Health Compass (www.nationaalkompas.nl)

⁽³⁾ Cost of Illness (www.kostenyanziekten.nl)

⁽⁴⁾ Dutch Health Care Performance website (www.healthcareperformance.nl)

⁽⁵⁾ coordination of the EUPHIX website (www.euphix.org)

⁽⁶⁾ consumer choice-supporting 'Choose Better' website (www.kiesbeter.nl), comparing providers and purchasers on performance

for older people in larger cities. These groups consist of experts from many different research institutes in the field and the composition of these groups changes according to the focus of the respective project. These external experts collaborate with the RIVM project leaders to sort out the available data and discuss why specific data and related health issues are most relevant and why. This set-up of project groups and the research advisory board provides RIVM with an extensive network of data sources and experts upon which the centre can draw for support."²²⁹

Typically, more than 100 experts participate in the writing of the reports. Studies on PHSF reports show the usefulness of the forecasts for policy makers. "PHSF reports enable backstage negotiations between researchers and policy actors in defining public health issues. The PHSF team has built a successful infrastructure for producing reports that mobilizes research support and authority in a front stage division of labor, while backstage, informal coordination takes place by negotiating the value of particular evidence for policy. PHSF reports have the status of 'credible knowledge' and they contribute to the policy process by depoliticizing public health issues and discussions on the value of evidence. In this way the reports function as a consensus-building platform for both policy makers and researchers and are a kind of 'evidence machine'".²³⁰

"The example of the Public Health Status and Forecast reports further affirms the importance of understanding knowledge and evidence as an outcome of negotiation processes." ²³¹

²²⁹ Bekker (2010) p. 247, 248

²³⁰ Bekker (2010) p. 249

²³¹ Bekker (2010) p. 249

8.3 Blueprint for a Model Research Commissioning Institution

Mission

- Intermediary between research, policy and practice
- Fostering of research based innovation
- Focus on Implementation
- Transparence in all processes
- Collaborative approach

Legal status

- At arm's length from government, stakeholders in the health system and other research funders
- Transparent credible process for selecting members of board, advisory committees and external evaluation committees

Funding

- Long sighted future oriented funding strategy
- Long term funding arrangements to guarantee stability of research field
 - Funding for addressing ad-hoc issues (responsiveness)
 - Funding for developing stable, continuous lines of research
- Distinct share of funding for free research to safeguard
 - Long term innovative potential through curiosity driven "blue skies" research,
 - Talking truth to power through research critically reflecting on current policies and exploring alternatives to widely held conceptions of which health services to provide and how to deliver them
- Distinct share of funding earmarked for implementation of commissioned research
- Creation of PhD fellowships enabling junior researchers to enhance theoretical and/ or methodological aspects of their research

Setting the research commissioning agenda

- Transparent structured process
- Proactive communication with research commissioners and research users to scout research needs in policy and practice
- Equal level of commissioning priority to
 - Research synthesizing and drawing conclusions about state of knowledge in a particular area, "incorporating a broad range of research into reviews of complex issues, interventions and outcomes" 232
 - Translational research, addressing the transfer of existing knowledge in to practice and studying its use in practice
 - Research developing new knowledge

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²³² Nutley (2004)p. 8

Commissioning of research

- * Transparent system
 - Explicit criteria
 - Peer referees
 - Periodical application procedures

Interaction with stakeholders

- Creation of platforms for systematic interaction between policy makers, users of research and researchers
- See Fostering of fora to establish networks in HSPHR
- ☼ Establishment of processes for
 - Mediating research insights to policy makers
 - Mediating policy or social demands to researchers
 - Making researchers and research users partners in the conduct of commissioned research
- Training of staff to assist research commissioners to formulate clear, researchable and implementation oriented questions to guide research to be commissioned
- User friendly and informative homepage in both local language and in English, tailored to specific needs of researchers, research commissioners and research users

Quality assurance of research commissioning

- Transparent process for addressing conflicts of interest
- Periodical external and self evaluation of commissioning process
 - Publication of evaluation results on the website
- ⇔ Openness to new audit methodologies
- Sometimes Fostering of open learning culture through review and evaluation

Data used for commissioned research

- Data transparency and data sharing rules for all commissioned research
- No funding of research on proprietary data

Implementation of research

- Attention to implementation considerations from the onset of research commissioning and throughout the whole process of conducting research
- Joint drawing up of implementation plans for HSPHR projects in advance between researchers and research commissioners
- Joint review of implementation achievements afterwards
- Evaluation of research impact

Human resources policy

- Building capacity amongst staff
- ⇔ Focus on long-term career development
- Encouragement of staff flows to and from other institutions in the health system

8.4 Blueprint for a Model Research Organization

Mission

- Concise scope
- Clear audience
- Focus on important issues
- Transparency in all processes
- Collaborative approach
- In the long run after initial capacity building phase: striving for research excellence on international level

Legal status

- Statutory independence from government or other stakeholders in the health system
- Transparent credible process for selecting members of board, advisory committees and external evaluation committees

Funding

- ♣ Long term funding arrangements
- Sufficient share of non-earmarked or free funding to
 - Undertake curiosity driven "blue skies" and innovative research
 - Undertake research that critically reflects on current policies and explores alternatives to widely supported models of delivering health services
 - To enable model research organization to fulfill long term oriented incubator function for concepts and research methods sustaining the viability of the health services and public health system served as opposed to the risk free taking over of established research fields with already established demand

Setting the research agenda

- Transparent, structured process involving stakeholders
- Proactive and at the same time user receptive agenda setting initiatives

Interaction with stakeholders

- Development of strategies and tools to deal with balance of conflicting needs for both closeness to stakeholders (service orientation, implementation orientation) and distance (independence) in research process
- Prioritizing interaction with stakeholders along the whole process of HSPHR
 - Decision makers
 - Research project stakeholders
 - General public
- (Co)Creation of multiple for a for interaction with an emphasis on participation in processes
 - Mediating research insights for policy makers
 - Mediating policy or social demands for researchers
- ★ Active networking
- Training and co-locating of staff to assist research commissioners in formulating clear, researchable and implementation oriented questions

- Making research commissioners and research users partners in creating evidence
- Institutionalizing of staff exchanges
 - With widest possible array of stakeholders
 - Formalized or informal
 - Long term or ad-hoc
- user friendly, informative and up to date homepage in local language and English
 - To fill culture of transparency with life vis-à-vis the public
 - To increase model organization's visibility and presence
 - To disseminate research findings

Cooperation with the academic field

- Supporting continuing training of staff at Master's and PhD levels, when necessary also abroad
- # Institutionalizing collaboration in ongoing research
- Institutionalizing of staff exchanges
 - Part time professorships
 - Shared researchers
 - Senior lecturers
 - Internships
 - Participation of university students on undergraduate and graduate level in model organization's ongoing research

Cooperation with "sibling research organizations" or academic HSPHR centers nationally

- Collaborative approach of "giving and taking"
- ☼ Information sharing
- Exchange of working programs
- Joint submission of research proposals

International cooperation

- Collaborative approach of "giving and taking"
- Conceptualization of HSPHR issues as reaching across national borders interlinking research and policy development on supranational levels (bilateral, EU, ...)
- Participation in international networks, e.g.
 - EuroHealthNet²³³
 - European Public Health Association²³⁴
 - European Network for Health Technology Assessment²³⁵
 - International Network of Agencies for Health Technology Assessment²³⁶
- Model organization as partner in joint submission of research proposals funded by the EU

²³³ EuroHealthNet is a not-for-profit network of regional and national agencies responsible and accountable for health promotion, public health and disease prevention in Europe, see www.eurohealthnet.eu

²³⁴ www.eupha.org

²³⁵ www.eunethta.net

²³⁶ www.inahta.org

Quality assurance of research

- Use of good research methods
- Transparent processes for production of research involving peer review, evaluation and possibly certification
 - Establishment of open learning culture through review and evaluation
 - Periodical external evaluation and internal self evaluation of research
 - Publication of evaluation results on the website
- Transparent process for addressing conflicts of interest
- ⇔ Openness to new audit methodologies
- Interlinking of lines of research in-house
- Investment in required technical infrastructure

Research data

- Transparency in sharing data used for research
- No research on proprietary data
- Access to routine data available in the health (care) system from central and regional governments and other stakeholders (health insurance, operators of hospitals, pharmacies, etc.)
- stablishment of data banks in specialized areas (registries, panel data, ...) for in house research and external researchers

Dissemination

- All research results accessible to the general public
 - Either at once when completed
 - Or after very brief period of exclusive commissioner access to research
- - Focus on readability of reports
 - Brief and concise summaries in local language and English
 - Clarification of policy and practice implications of research
 - Clear recommendations
- Tailoring of dissemination to the target audience
- Use of combination of dissemination methods
- Participation in societal debates in the mass media

Implementation of research

- Attention to implementation considerations from the very onset of the research process, even if lacking explicit drive by commissioners
- Evaluation of research impact

Human resources policy

- Building capacity amongst staff
- ♣ Focus on long-term career development
- Forming of multi-disciplinary teams bringing together natural and social sciences
- Encouragement of staff flows to and from other institutions in the health system

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²³⁷ For exemplary reporting compare e.g. Health Council of the Netherland GR, www.gezondheidsraad.nl

8.5 Initially screened institutions of interest not included in report

Institution	Weblink	Additional information
Australian Institute of Health and Welfare	www.aihw.gov.au	
Danish Centre for Health Technology Assessment	www.sst.dk/English/DACEHTA	
Institut for Folkesundhed	www.folkesundhed.au.dk	Aarhus University
National Institute of Public Health	www.niph.dk	University of Southern Denmark
Arbeits- und Koordinierungsstelle	www.akg.uni-bremen.de	University of Bremen
Gesundheitsversorgungsforschun		
Clearingstelle Versorgungsforschung Nordrhein- Westfalen	www.gc.nrw.de/index.php?id=82	Healthcare Campus North Rhine- Westphalia
Deutsches Institut für Medizinische	www.dimdi.de	German Institute of Medical
Dokumentation und Information		Documentation and Information
Deutsches Netzwerk Versorgungsforschung	www.netzwerk-	
	versorgungsforschung.de	
Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen	www.iqwig.de	Institute for Quality and Efficiency in Health Care
Robert Koch Institut	www.rki.de	
Zentrum für Versorgungsforschung Köln	www.zvfk.de	University of Cologne
Finnish National Institute for Health and Welfare	www.thl.fi	
Haute Autorité de santé	www.has-sante.fr	French National Authority for Health
Association of Universities in the Netherlands	www.vsnu.nl	
Netherlands Institute for Social Research	www.scp.nl	
Netherlands School of Public & Occupational Health	www.nspoh.nl	
Rathenau Instituut	www.rathenau.nl	Rathenau Institute
Raad voor de Volksgezondheid en Zorg	www.rvz.net	Council for Public Health and Health Care
Scientific centre for the transformation of the	www.tilburguniversity.edu/research/	Tilburg University
nature and quality of care and welfare	institutes-and-research-	,
	groups/tranzo	
Catalan Agency for Health Information,	www.gencat.cat/salut/depsan/units/a	
Assessment and Quality	atrm/html/en/Du8/index.html	
Swedish National Institute of Public Health	www.fhi.se	
Department of Health	www.dh.gov.uk/en/Aboutus/Researc	
Research and Development	handdevelopment	
National Institute of Health Research	www.nihr.ac.uk	
Health Services Research programme	www.hsr.nihr.ac.uk	National Institute for Health
		Research
Institute for Improvement and Innovation	www.institute.nhs.uk	National Health System
Science Council	www.sciencecouncil.org	
Conference on the Science of Dissemination and	http://conferences.thehillgroup.com/	National Institute of Health
Implementation	obssr/Dl2011/abstracts.html	Tradising institute of fredicti
Knowledge Transfer/Implementation Program	www.ahrq.gov/news/ktint.htm	Agency for Healthcare Research and Quality
		· /

Institution	Weblink	Additional information
Canada Research Chair in Knowledge Transfer and Exchange	http://fhs.mcmaster.ca/ceb/faculty_ member_lavis.htm	McMaster University
Evidence Network	www.kcl.ac.uk/schools/sspp/interdisciplinary/evidence/	provided by the Centre for Evidence & Policy at King's College London
Research Unit for Research Utilisation	www.ruru.ac.uk	Universities of Edinburgh and St Andrews
AcademyHealth	www.academyhealth.org	
Center for Health Decision Science	www.chds.hsph.harvard.edu	Harvard School of Public Health
European Science Advisory Network for Health	www.eusanh.eu	
New Opportunities for Research Funding Co- operation in Europe	www.norface.org	partnership between European research councils