Dialogue meeting on the ALF evaluations

Swedish Research Council

National Board of Health and Welfare

Agenda

10:00   **1. Introduction**
         Jan Nilsson, vice chair for the board of the Swedish Research Council

10:20   **2. Swedish Research Council – evaluation of the quality of the clinical research**
         Hugh McKenna, chair of the expert panel
         Lisbeth Tranebjaerg, chair of the expert panel
         Stig Arild Slørdahl, chair of the expert panel

12:30   *Lunch*

13:30   **3. National Board of Health and Welfare - evaluation of the university health care**
         Anders Bengtsson, National Board of Health and Welfare
         Helena von Knorring, project manager, National Board of Health and Welfare

14:15   **4. Introduction to discussions**

14:30   **5. Group discussions (coffee will be served)**

15:30   **6. Summary of the discussions**

16:00   **7. The meeting ends**

The evaluation process

- Three independent panels

- Three categories:
  - inferior quality
  - good–high quality
  - very high quality

Utvärdering av den kliniska forskningens kvalitet vid de landsting som omfattas av ALF-avtalet

Vetenskapsrådet

2018

The evaluation results

Swedish clinical research is of high quality.

Some improvement areas:
- Quality registers and biobanks are valuable assets, but could be utilised better.

- The prerequisites for access to infrastructures are generally good.

- Certain research areas, where several regions are successful, could increase the quality further by collaborations.

- The prerequisites for time for research and career paths are generally good but varies much.

- There is little international exchange of researchers.

The panels propositions

- Strengthen the collaboration between basic and clinical research.

- Increase the participation by primary care in research.

- Increase national collaboration.

- Involve patient organisations to a larger extent.

- Targeted information campaigns aimed at the general public.

- Increase collaboration between different professions.

The quality of the scientific output– ALF PANEL 1

Project team:

- Malin Eklund
- Karin Tegerstedt
- Sten Söderberg
- Andreas Augustsson
- Gustav Petersson
- Carole Desmoulins
- Peter Lundin
- Emma Bergström

ALF Panel 1 Members

Name	Affiliation	Country	Main area of expertise
Hugh McKenna (chair)	Ulster University	N. Ireland (UK)	Health Sciences/Research assessment
Per Bakke	University of Bergen	Norway	Respiratory System
Alexandra Durr	Institut du Cerveau et de la Moelle épinière	France	Neurosciences
Keith AA Fox	University of Edinburgh	Scotland (UK)	Cardiac & Cardiovascular Systems
Jan Frystyk	Odense University Hospital	Denmark	Endocrinology & Metabolism
Robin Grant	University of Edinburgh	Scotland (UK)	Neurosciences
Per Ole Iversen	University of Oslo	Norway	Hematology
Christine Katlama	Hôpital La Pitié Salpêtrière	France	Infectious Diseases
Paulus Kirchhof	University of Birmingham	England (UK)	Cardiac & Cardiovascular Systems
Tina Lavender	University of Manchester	England (UK)	Obstetrics & Gynecology
Marjatta Leirisalo-Repo	Helsinki University Hospital	Finland	Rheumatology
Valerie Lund	University College London	England (UK)	Otorhinolaryngology
Brigitte Malgrange	University of Liège	Belgium	Neurosciences
Helle Prætorius	Aarhus University	Denmark	Urology & Nephrology
Jon Rhodes	University of Liverpool	England (UK)	Gastroenterology & Hepatology
Susan Smith	Royal College of Surgeons in Ireland	Ireland	Health Care Sciences
Peter Tyrer	Imperial College London	England (UK)	Psychiatry
Cornelis van de Velde	Leiden University Medical Center	The Netherlands	Oncology
Hannele Yki-Järvinen	University of Helsinki	Finland	Endocrinology & Metabolism

ALF PANEL 1- Assessment Criteria

❑ **Bibliometric analysis:** The overarching quality and extent of the scientific output

❑ **Peer review:** Scientific profile in terms of clinical relevance and quality

ALF PANEL 1- Assessment Criteria

The overarching quality and extent of the scientific output

- ❑ Bibliometric analyses of publications from 2012 to 2015 within Health Sciences, Web of Science database:
    - Overall volume of publications (in total and in relation to ALF-funding).
    - Citation impact (in total and in relation to ALF-funding).
    - Average citation rate.
    - Share of highly cited publications.

- ❑ Additional statistics on collaboration and subject profiles were also included as contextual background information.

- ❑ Assessed by the 18 panel members and discussed at the panel meeting.

ALF PANEL 1- Assessment Criteria

Scientific profile in terms of clinical relevance and quality.

❑ Peer review of submitted publications on two assessment criteria:

- Scientific quality (including novelty)
- Clinical relevance.

Scientific quality (including novelty)

The following guiding questions were considered by the reviewers:

- ❑ Do/will the findings significantly advance our understanding of the field?
- ❑ Does the publication challenge current understanding, opinion, or practice in its field?
- ❑ Does the study design meet the standards of the highest scientific quality?
- ❑ Are potential problems and alternative strategies identified and presented?
- ❑ Are there relevant scientific collaborations?
- ❑ Are data analyses well performed?
- ❑ Does the publication include use of novel technologies/ methodologies, or innovative application of existing methodologies/ technologies in new areas?

Clinical Relevance of the Publications

The following guiding questions will be considered by the reviewers:

❑ How significant is the contribution of this publication to the knowledge base in the area into which it may be classified?

❑ What are the potential impacts from research in this area?

❑ What is the reach and significance of these potential impacts?

- **Reach** may in this context be defined as the <u>spread or breadth of influence</u> on the relevant constituencies; for instance, how frequently the research results have made an impact on relevant stakeholders. An example is how many or how frequently patients would benefit from a new treatment.

- **Significance** may in this context be defined as <u>the intensity of the influence</u>; for instance, how important the impact has been to the concerned stakeholders. An example is how many quality-adjusted life years an individual patient would gain from a new treatment.

ALF PANEL 1 – Number of Submitted Publications

ALF region	County Council	University	Share of ALF funding for clinical research 2015	Number of publications
Stockholm	Stockholm's County Council	Karolinska Institutet	27%	97
Västra Götaland	Region Västra Götaland	University of Gothenburg	21%	74
Skåne	Region Skåne	Lund University	20%	70
Uppsala	Region Uppsala	Uppsala University	12%	42
Västerbotten	Västerbotten County Council	Umeå University	11%	38
Östergötland	Region Östergötland	Linköping University	8%	29
Örebro	Region Örebro	Örebro University	2%	10

- Corresponds to 1% of the total scientific output within health sciences.

- Number of publications proportional to share of ALF-funding.

- The selection of publications for submission were made by each region.

ALF PANEL 1- Assessment

Scientific profile in terms of clinical relevance and quality

❑ The peer review of the 360 publications was performed by the 18 panel members and 31 external reviewers. 3 reviewers for each publication.

❑ Publications where assessed using the Swedish Research Council's 7-graded scale, ranging from poor to outstanding.

❑ All assessments, including comments were compiled and distributed to the panel members before the meeting.

❑ All panel members had access to all 360 publications.

ALF PANEL 1 – Panel Meeting
24th to 26th January 2018

- ❑ Presentation and discussion around the bibliometrical statistics followed by a common assessment of each region;

- ❑ Discussion and common assessment of the publications for each region regarding clinical relevance and scientific quality, using a 7-graded scale;

- ❑ Overarching assessment for each region on all criteria and placement of each region into one of three categories: Inferior quality, Good-high quality and Very high quality;

- ❑ Writing of the report in 7 groups followed by discussion and agreement with the complete panel.

- ❑ The final report was compiled by the panel chair with support from the ALF-team. The final report was approved by all panel members.

ALF PANEL 1 – Results from the Assessment

❑ The panel was in full agreement on the final results.

❑ Overall, clinical research in Sweden is of high quality and relevance.

❑ Swedish areas of strength such as Swedish registry databases could be used more efficiently. These databases have international relevance in addressing questions of global relevance (e.g. elderly and co-morbid populations).

❑ Several multicenter studies of high quality and relevance.

❑ The panel suggested strengthening the links and co-operation between basic research and clinical research.

❑ The panel suggested increasing national and international collaborations.

ALF PANEL 1 – Assessment Process: Panel Reflections.

❑ More information on the research environment of each region such as number of researchers, number of clinical researchers, which topics, other funding sources etc.

❑ Need more granularity in the categorisation of regions. Three categories are too few.

❑ More information on how the regions selected their publications.

❑ Guidance on how to assess author contribution. Ask regions to describe their contribution.

❑ Separation of the three panels did not give the panel an overview and see the regions's submission 'in the round'.

❑ Peer-review vs bibliometric analysis – bibliometric analysis cannot assess clinical relevance, it misses out on some specialities, small regions give uncertain bibliometric analysis due to small sample size.

Dialogue meeting with the ALF regions- Panel 2

May 16th 2018

Chair Lisbeth Tranebjærg

tranebjaerg@sund.ku.dk

Members of Panel 2

name	Affiliation	Country
Lisbeth Tranebjærg (chair)	University and Univ Hosp, Copenhagen	Denmark
Henning Beck Nielsen	Odense Univ Hosp and University South Denmark	Denmark
Elizabeth Bergsten Nordström	The Swedish Breast Cancer association	Sweden
Anders Blanck	The Swedish Association of the Pharmaceutical Industry (LIF)	Sweden
Kåre Birger Hagen	Diakonhjemmet Hospital Oslo and univ Oslo	Norway
Charlotte Hall	Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU)	Sweden
Anne Sales	Univ of Michigan and VA Ann Arbor Health Care System	USA
Ian Viney	Medical Research Council (MRC)	UK

Aims of the evaluation

- ALF region = County council + University
- Criteria for and allocation of ALF funding under scrutiny and change
- Main aim: Continously to develop clinical research in a positive direction in the ALF regions

Job description for Panel 2

- To evaluate the clinical significance and societal impact of the clinical research

Assessment: process and criteria

- How does the ALF region work to implement research results into clinical practice?
- What is the clinical significance and the societal impact of the research performed in the ALF region?
- Criteria:
- 1.Research competence (some overlap with panel 3)
- 2.Collaboration
- 3.Implementation of research results into clinical practice
- 4.Impact beyond academia of the clinical research

1.Research competence

- High presence of research trained professionals in clinical practice
- Substantial and continuous supply of research trained professionals to society

2.Collaboration

- Collaboration between medical expertise and non-academic stakeholders
- Multidiscliplinary collaboration
- Appropiate strategy and clearly defined target groups for knowledge dissemination

3.Implementation of research results into clinical practice

- Appropiate practices and strategies for keeping own clinical practice in line with best evidence in the relevant field
- Appropiate practices and strategies for the evaluation of efforts to keep own clinical practice in line with best evidence
- Appropiate practices and strategies for the utilisation of findings from the evaluation above

4.Impact beyond academia- (1-3 impact case studies)

- The reach and significance of the impact. The spread or breath of influence, i.e how frequently research results have made impact on relevant stakeholders, and the intensity of the influence, i.e how important the impact has been to the relevant stakeholders

- Underpinning research: to which extent research in the ALF region has made substantial and distinct contribution to the impact described (1-10 publications)

- Key processes and factors: the extent to which the processes and strategies of the ALF region has contributed to the impact-contributing factors? Time as a key factor from research to impact

Impact beyond academia

- Local, regional, national, international benefits to
- Economy,society, public policy and services,health, environment, or quality of life…….individuals, organizations,communities
- Two kinds of impact:
- **Clinical significance** (patient care, recommendations of guidelines, phasing out redundant methods etc)
- And/or
- **Societal impact** (national guidelines, dissemination of knowledge to patient groups, spin off companies, regional growth)
- Self chosen impact case studies(1-3) by each ALF region in the self-evaluation

Process and premises

- Self-evaluation, including impact case studies, and SWOT analysis
- Statistics (dissertations,% in county council with PhD, % in Univ hosp with PhD, number with dual affiliations)
- Data on clinical impact through references to i.e. guidelines
- Hearings with 5-6 persons in management positions- general and specific questions were given in advance

Ways of showing   good implementation of clinical research regarding societal impact

- Clear, systematic procedures to adjust clinical practice by use of available registers

- Good collaboration: University, University Hospital and county council

- (impression at hearings gave highly variable impressions)

- Involvement of patient organisations, spreading information material, focus days etc

- Collaboration across regions

- Inter-professional learning clearly facilitates smooth collaboration between different health professionals

- The above-mentioned points could serve as recommendations!!

Evaluation of the quality of clinical research in the ALF regions-panel 2

ALF region	Very high quality	Good-high quality	Inferior quality
Stockholm		x	
Västra Götaland		x	
Skåne	x		
Uppsala		x	
Västerbotten		x	
Östergötland		x	
Örebro			x

Evaluation results

General reflections- and good examples-1

- Clinical research is of wide variety in Sweden

- Life Science research, development and translation has high priority in Sweden

- All regions have strengths and weaknesses

- Clustering of research trained individuals in uneven sized ALF regions is a challenge.

- Some parts of Sweden not part of any ALF region

General reflections and good examples-2

- Health technology assessments and phasing out redundant methods is noteworthy

- Examples of well functioning collaboration betwen primary health care and University hospital

- The utilization of national database data and quality registers are highly variable (annual report versus extensive regular use)

- Distinct career pathways for medical and non-medical professionals are excellent in some regions

- Highly variable degree of systematic processes in evaluating being in line with best evidence continously

- Examples of diseases reported from more than one region: prostate cancer, thrombectomy, antocoagulation therapy), indicating across regions collaboration

General reflections and good examples-3

- Selection criteria for reporting impact case studies varied form top areas to showing diversity within a ALF region
- Examples of impact cases with international influence, like medical abortion, vaccines for preventing HPV associated cancers
- Strong focus of attracting and retaining young clinical researchers
- Pioneer example of interdiscliplinary learning (IPL), spreading nationally and to all of Nordic countries
- County based program aiming at improving health care for selected diseases, involving patient representatives (Breast cancer, Type 2 diabetes ++)
- Examples of strong collaboration with industry (historical factors regarding technical industry)

Recommendations for future focus areas

- The grading in three categories is very rough

- More sharing of knowledge and collaboration across the regions
- More use of Quality registers in a country wide systematic way and combine with biobanks
- The way ALF money was applied varied from open application process to topdirected allocation
- ALF funding could be used to let young post-docs become independent researchers (panel 3)
- Keep in focus longer term impact
- Pre-requisites for clinical research impact: incentive, research capacity, career development, and collaboration (small versus larger ALF regions)
- The uneven size of the ALF regions- What does that imply?
- Somehow include all health regions of Sweden in ALF funded clinical research
- Prioritized ALF money dedicated to inter regional collaborative projects/research activities? (oncology, diabetology, cardiovascular diseases)
- Need for joint national strategies and discussions between the regions.

The process and the premises

- Case studies (3 impact and 3 clinical implementation) were few and could be reviewed and assessed in greater details (external referees?)
- Publication by the government of succesful cases of clinical implementation?
- Face to face interviews extremely important (self evaluation good briefing)
- Expertise needs both to be international and with Scandinavian background
- Feed back to the panels if the government got what they wanted??
- Regions should to a much higher degree work together efficiently

The process

- A lot of work for all parties implied
- Excellent steering/support/preparation from the VR staff
- Evaluating societal impact is a very difficult task!! (quantitative/qualitative)

Finally

- For all involved it has been a first time learning process-important to keep in mind!!

- All panel members learned a lot about Sweden and how the health care system is organized and works.

- Overall you are doing great!!

-                   Thanks   ☺
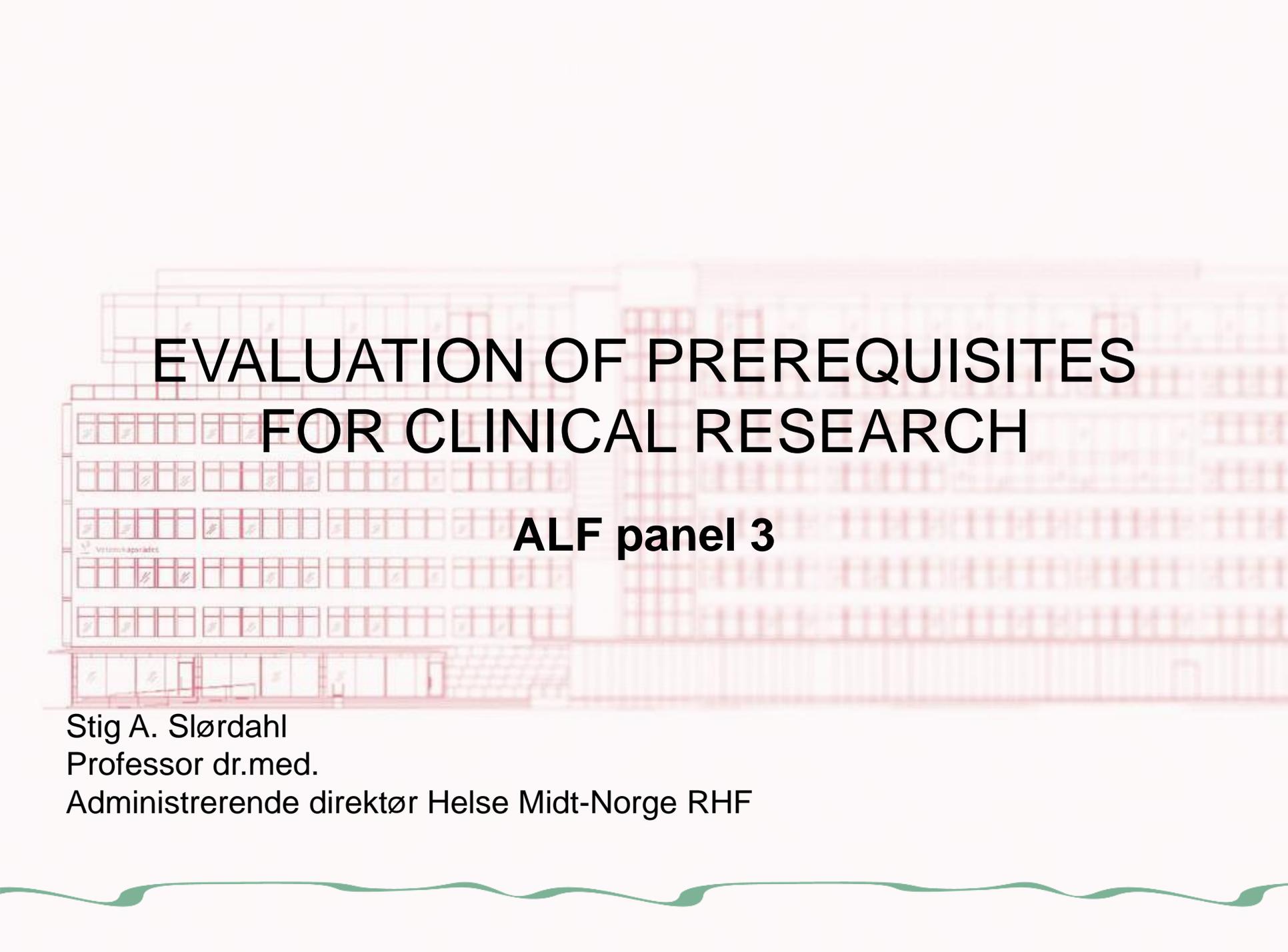
EVALUATION OF PREREQUISITES FOR CLINICAL RESEARCH

ALF panel 3

Stig A. Slørdahl
Professor dr.med.
Administrerende direktør Helse Midt-Norge RHF

It is always good to be back in Sweden

En väl parkerad cykel ger en inre tillfredsställelse och är den grund varpå samhället vilar.

Best research-Best Hospital

#1	Harvard University — Boston, MA
#2	Johns Hopkins University — Baltimore, MD
#3 Tie	New York University (Langone) — New York, NY
#3 Tie	Stanford University — Stanford, CA
#5	University of California—San Francisco — San Francisco, CA
#6 Tie	Mayo Clinic School of Medicine — Rochester, MN
#6 Tie	University of Pennsylvania (Perelman) — Philadelphia, PA
#8 Tie	University of California—Los Angeles (Geffen) — Los Angeles, CA
#8 Tie	Washington University in St. Louis — St. Louis, MO

RANK	NAME
1	Mayo Clinic, Rochester, Minnesota
2	Cleveland Clinic
3	Johns Hopkins Hospital, Baltimore
4	Massachusetts General Hospital, Boston
5	UCSF Medical Center, San Francisco
6	University of Michigan Hospitals and Health Centers, Ann Arbor
7	Ronald Reagan UCLA Medical Center, Los Angeles
8	New York-Presbyterian Hospital, New York
9	Stanford Health Care-Stanford Hospital, Stanford, California
10	Hospitals of the University of Pennsylvania-Penn Presbyterian, Philadelphia

ALF panel 3

Namn	Organisation	Land
Stig Arild Slørdahl (ordförande)	The Central Norway Regional Health Authority	Norge
Inger Thune	Oslo University	Norge
Rein de Vos	AMC	Nederländerna
Ian Hall	Nottingham University	England
Erik Fosse	Oslo University Hospital and Facility of Medicine och University of Oslo	Norge
Nina Langeland	University of Bergen	Norge
Björn Gustavsson	Norges teknisk naturvitenskapelige universitet	Norge
Marite Rygg	Norges teknisk-naturvitenskapelige universitet	Norge
Marja Riita Taskinen	University of Helsinki	Finland
Jaap Bonjer	VUmc	Nederländerna
Lars Bo Svendsen	Rigshopsitalet,	Danmark
Janna Saarela	FIMM, Institute for Molecular Medicine	Finland

Results from the evaluation of prerequisites for clinical research

	Inferior quality	Godd-high quality	Very high quality
Stockholm		x	
Västra Götaland			x
Skåne			x
Uppsala		x	
Västerbotten			x
Östergötland		x	
Örebro		x	

Prerequisites for clinical research

The following four components regarding prerequisites for clinical research were evaluated:

- Access to research infrastructures
- Time for research
- Next generation researchers
- Career models

The task for the panel

- The evaluation was performed in three steps:
  - Pre-evaluation based on the self-evaluations from the ALF-regions and the results from a survey to PI´s active in clinical research in the ALF-regions. The pre-evaluation was performed individually by each panelmember who used the rubric for the assessment.
  - Site-visits with hearings
    - The panel was divided into three groups that travelled parallelly to the different ALF-regions for hearings during Monday to Wednesday.
    - Hearings where held with overall management for the ALF-region, heads of clinical research units at the hospital, and finally with phd-students and postdocs. After lunch the panel was given a tour at the site.
  - The evaluation continued with panel-discussions on Thursday and Friday in Stockholm, where results were presented from the tre panelgroups. The three groups calibrated their assessments and a joint panel discussion commenced were the final grading was decided. The panel started writing the evaluation report in Stockholm.

RUBRICS

Aspect\Precondition	1. RUBRIC **Access to infrastructure**	2. RUBRIC **Time for research alongside clinical work**	3. RUBRIC **Next generation of clinical researchers**	4. RUBRIC **Career model for clinical researchers**
<u>Aims and objectives:</u> Description of the desired outcome or future target	Not to be assessed	Not to be assessed	Not to be assessed	Not to be assessed
<u>Target group</u>: Those that are affected by the objectives of the precondition	Not to be assessed	Not to be assessed	Not to be assessed	Not to be assessed
<u>Structure</u>: The formal structure for establishing organizational measures enabling the achievement of the objectives.	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)
<u>Process</u>: The processes needed to implement the use of the structure, and the ongoing processes involved to reach the objective.	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)
<u>Results</u>: An assessment of what has been achieved in terms of outputs and outcomes that relates to the aim and objectives.	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)	(Begininning) (Developing) (Accomplished) (Exemplary)

Very high quality

- Rate reasoning for the highest grade "Very high quality":

  The County Council and the University showed evidence for:
    - strong partnership
    - shared strategy for clinical research
    - clinical research being a priority in both organisations
    - robust and strategic approaches for allocating time for research and fostering next generation researchers – career ladder
    - leadership creates confidence and enthusiasm
    - focus on multi-disciplinary research and internationalization
    - clear strategy in establishing and supporting excellent infrastructure

  This was evident at all levels in the awarded organisations.

Reflections and general comment

- The ALF-funding works well in order to secure resources for clinical research in Sweden
- Sweden would benefit from a national strategy for clinical research
- Sweden has extensive health registries, but very uncordinated biobank data.
- Well organized mechanism for allocating time for research and career development, but this varies a lot between the regions
- Need to increase research in primary health care in order to strengthen the whole health care chain
- Very few PI´s go abroad, which seems to be a neglected area in Swedish clinical research
- The panel was however impressed with general level of support for clinical research in Sweden

Conclusions

- Overall impression – money is well spent
- Impressed with the general level of support for clinical research in Sweden

- Potential challenge separate entitities – university hospitals

- Joint strategy important
- Variation between the counties too large
- Increase research in primary health care
- Very few go abroad
- Potential to be even better!!

At the end of the evaluation

Thank you