



Vetenskapsrådet

# REPORT FROM THE SIMSAM MID-TERM EVALUATION

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**15–16th of November, 2011**

REPORT FROM THE SIMSAM MID-TERM EVALUATION

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# PREFACE

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The Swedish Research Council is a governmental agency with the responsibility to support basic research of the highest scientific quality in all academic disciplines. It is also part of the Council's remit to evaluate research and assess its academic quality and success.

In order to support the development of research using Swedish registers, the Swedish Research Council took the initiative in 2008 to strongly expand direct support for research which use microdata for investigations into matters to do with society and health. The initiative was named SIMSAM – Swedish Initiative for Research on Microdata in the Social and Medical Sciences.

The purpose of the Research Council's initiative was to stimulate a new generation of researchers and research leaders within disciplines which can make the best use of the data in Swedish registers.

According to the call for application for the SIMSAM framework grants and the graduate school, assessment was to be carried out in the middle and at the end of the five year contractual period. An international half-time evaluation of SIMSAM was therefore conducted in November 2011. This evaluation report constitutes an independent statement from the international expert panel, whose recommendations will serve as a basis for further discussion on the development of SIMSAM.

The Swedish Research Council would like to express its sincere gratitude to the members of the expert panel for devoting their time and expertise to this important task.

The Swedish Research Council would also like to thank the SIMSAM groups for providing information to the panel.

Stockholm 2012-11-30

Juni Palmgren  
*Secretary General*  
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# SVENSK SAMMANFATTNING

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År 2008 utlyste Vetenskapsrådet rambidrag samt medel för en forskarskola (båda för fem år) inom ramen för SIMSAM-initiativet (SIMSAM = Swedish Initiative for research on Microdata in the Social And Medical sciences). Detta initiativ syftade till att stimulera en ny generation forskare och forskningsledare inom discipliner som på bästa sätt skulle kunna dra nytta av data som finns i olika svenska register. Förhoppningen var att initiativet skulle leda till 1) en förbättrad kunskap om hur registerforskningen är organiserad i Sverige och internationellt samt 2) en förbättrad och utvidgad användning av registerdata i forskning. Totalt beviljades sex forskningsprojekt och en forskarskola.

En panel bestående av internationellt erkända experter inom områden som faller under SIMSAM:s ansvar hade till uppgift att halvtidsutvärdera SIMSAM och sammanträdde under två dagar i november 2011.

Enligt panelens halvtidsutvärdering har SIMSAM-initiativet på ett framgångsrikt sätt gynnat registerbaserad forskning i Sverige. Exempelvis har studier som inte hade uppstått utan detta initiativ initierats och ett flertal andra redan påbörjade studier har kunnat avslutas. Forskningsaktiviteterna i de olika noderna har visat sig vara dynamiska med starka resultat. Synergieffekter och interaktioner mellan de i initiativet involverade forskargrupperna samt mellan dessa forskargrupper och ett flertal forskningsinfrastrukturer är ytterligare ett positivt resultat av initiativet (inte minst förberedandet av en övergripande SIMSAM-infra-ansökan). Men, panelen betonar samtidigt att det finns potential att göra betydligt mer när det gäller att stärka registerbaserad forskning utanför de specifika SIMSAM-noderna. Enligt panelen bör Vetenskapsrådet vara tydligare när det gäller dess engagemang i SIMSAM på lång sikt; dels beträffande framtida forskningsanslag men också vad man förväntar sig av samverkan mellan noderna.

## Rekommendationer

- 1 Vetenskapsrådet bör meddela på vilket sätt SIMSAM-initiativet kommer att utvecklas efter den nuvarande finansieringsperioden, det vill säga inom två års tid. För att möjliggöra långtidseffekter av initiativet krävs att åtminstone koordinatornoden, den potentiella infrastrukturen samt forskarskolan finansieras över en längre period.
- 2 Den koordinerande nodens roll behöver definieras och struktureras på ett tydligare sätt, särskilt när det gäller mandat och ansvar för forskningsledaren på denna nod. Därutöver behövs en tydligare definierad roll för koordinatorn.
- 3 Ett oberoende rådgivande organ för hela SIMSAM-initiativet bör etableras för att marknadsföra svensk registerbaserad forskning på såväl nationell som internationell basis.
- 4 Det är mycket angeläget att en hemsida för hela SIMSAM-initiativet etableras. Hemsidan skulle kunna bli en viktig kommunikationskanal för att kommunicera ut information om registerbaserad forskning men också för berörda forskare att dela med sig av verktyg och resultat. Vissa noders existerande hemsidor behöver förbättras med hänsyn till SIMSAM-initiativets synlighet.
- 5 Workshops, presentationer och andra medel för att nå ut med kunskap om SIMSAM-initiativet behöver intensifieras och annonseras.
- 6 Ett större utbud av forskarutbildningskurser bör erbjudas via SIMSAMs forskarskola.
- 7 Olika typer av problem (metodologiska, organisatoriska, juridiska, etiska o.s.v.) som uppstår under bedrivandet av denna typ av forskning, inklusive lyckade och misslyckade sätt att hantera dessa problem, bör dokumenteras och föras fram till beslutsfattare.
- 8 Initiativ bör tas för att utveckla strukturer för forskare att dela olika produkter, t.ex. syntax för dataanalyser, mjukvaror, datadokumentation, datamodellering o.s.v. Sådana produkter bör delas såväl inom och mellan noder som med andra forskare.

- 9 När det gäller metadata och annan datadokumentation bör gemensamma insatser med tillhandahållare av datainfrastrukturer, såsom SND (Svensk Nationell Datatjänst), initieras.
- 10 SIMSAM-noderna, i form av ett nätverk, kan och bör inte på egen hand möta kraven på en nationell infrastruktur för registerbaserad forskning. Det är av största vikt att arbetet med etablerandet av en hållbar infrastruktur för registerbaserad forskning implementeras i nära samarbete med Sveriges hela forskningsfält inom registerbaserad forskning. Vidare bör infrastrukturen integreras med internationellt relevanta infrastrukturer vilket skulle möjliggöra att svensk registerbaserad forskning får ett internationellt genomslag.

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# EXECUTIVE SUMMARY

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Overall, the SIMSAM initiative has led to the successful promotion of register-based research in Sweden. The specific grants have supported the completion of several studies, as well as the initiation of new ones that would not have emerged without SIMSAM. In general, the research activities of the SIMSAM nodes are dynamic and their output is strong. The initiative is also adding new synergies and interactions between the research groups involved and between them and several research infrastructures/authorities. Of note are the research cooperative projects initiated by the nodes, and also their cooperation regarding the enhancement of infrastructure – e.g. by preparing the comprehensive SIMSAM-INFRA application. However, with regards to cooperation and promoting register-based research at the national level, much more can be done. In order to guarantee further development of cooperative and national efforts, the Research Council needs to be clearer about its long-term commitments to SIMSAM with regards to future grant allocations and what is expected from the cooperation between the nodes.

## Recommendations

- 1 The Research Council should signal how the SIMSAM initiative will be developed after the end of the current funding period, that is, in two years' time. To have any long-term impact, at least the coordinating node, potential infrastructure, and the research school would require a longer funding period.
- 2 The role of the coordinating node needs to be more clearly defined and structured. In particular, the mandate and responsibilities of the PI for the coordinating node need to be specified. A better defined role for the coordinator is also needed.
- 3 An independent advisory board for the whole SIMSAM initiative should be established in order to promote Swedish register-based research on both a national and international basis.
- 4 There is an urgent need for establishing a web site of the whole SIMSAM initiative. This could be an essential communication channel for activities promoting register-based research and for sharing tools and results. Also, the web sites of some of the nodes warrant improvements, particularly regarding the visibility of the SIMSAM initiative.
- 5 Outreach activities, e.g. in the form of workshops and presentations, should be further intensified and advertised.
- 6 A richer program of graduate courses should be offered through the SIMSAM Graduate School.
- 7 Different types of problems (methodological, organizational, legal, ethical, etc.) in pursuing this type of research, including successful and unsuccessful ways of handling them, should be documented and brought to the attention of policy makers.
- 8 Initiatives should be taken to develop structures for sharing different products, such as syntax for data cleaning and data analysis, software and work flows for data management, data documentation, data modeling and analysis, etc. Such products should be shared within the nodes, between the nodes, and with other researchers.
- 9 Collaborative efforts with data infrastructure providers such as SND on metadata and other data documentation need to be initiated.
- 10 Obviously, the SIMSAM nodes, as a network, cannot and should not singlehandedly meet the needs for a national data infrastructure for register-based research. It is of utmost importance that an extended effort towards establishing sustainable infrastructure for register-based research is implemented in close collaboration with the full span of the Swedish register-based research community. Also, this infrastructure should be integrated within relevant international infrastructures – enabling full international impact of Swedish register-based research.



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# BACKGROUND

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During recent years, a number of reports within and external to the Swedish Research Council have pointed out that Swedish registers, which cover the whole population, are an underused goldmine for research. In an even more internationalized data- and research environment, Swedish registers may well increase their importance as a valuable source of new knowledge well beyond Sweden's borders. From a Swedish point of view, it is important to make use of the possibilities for better national and international exploitation of the data found in Swedish registers.

Within each subject area there are relatively few researchers and groups who have sufficient access to, and knowledge of, relevant data and modern statistical tools so as to fully exploit this unique resource for pioneering research work. Potential synergies between research groups, opportunities for interdisciplinary exchange, and settings for inviting distinguished international researchers to share in Swedish data and participate in Swedish research are often not exploited to a sufficient extent.

In order to support the development of research using Swedish registers, the Swedish Research Council took the initiative in 2008 to substantially expand direct support for investigations concerning society and health that used microdata. The initiative was named SIMSAM – Swedish Initiative for Research on Microdata in the Social and Medical Sciences.

## The SIMSAM initiative

The purpose of the Research Council's initiative was to stimulate a new generation of researchers and research leaders within disciplines which could make the best use of the data available in Swedish registers.

A number of research groups were to receive support with the aim to produce world-class research within all disciplines where the data on population-based registers are an important information source. The initiative was expected to lead to:

- The expansion of knowledge on how research with registers is organized inside Sweden and internationally.
- The improved and expanded use of registers in research.

In 2008, the Swedish Research Council advertised the launch of framework grants and of a grant for a graduate school within the SIMSAM initiative. A total of SEK 25 million per year for five years were allocated for framework grants. A further SEK 2.3 million per year, for five years, for a graduate school was advertised at the same time as the framework grants, with the aim of linking together the research groups being awarded framework grants. Funds for the graduate school were applied for separately. Support from the SIMSAM initiative was considered strategic, and could only be applied for by university Vice-Chancellors, not by individual researchers or research groups.

In December, based on a total of 22 applications, the Committee for Research Infrastructures at the Swedish Research Council granted funds to six research projects and one graduate school (SIMSAM Graduate School in Register-based Research, SINGS) to a total of somewhat more than 135 million SEK for five years (Appendix 1). Of these, one is located at Umeå University, one at Lund University, and four in Stockholm, at two different universities; Stockholm University and Karolinska Institutet (KI).

## Review Procedure

According to the call for application for the SIMSAM framework grants and the graduate school, assessment was to be carried out in the middle and at the end of the five year contractual period (2009-2013). This is the report of the international half-time evaluation of SIMSAM, conducted in November 2011.

The evaluation was conducted by a panel (Appendix 2) consisting of internationally recognized experts with broad expertise in the various activities that fall under the responsibility of SIMSAM.

The panel convened in Stockholm from the 15th to the 16th of November in order to carry out the mid-term evaluation of SIMSAM. The panel based the evaluation on material provided by the Research Council and handed in by the SIMSAM network, the web pages of the different nodes, and a hearing with researchers from all the SIMSAM nodes. The panel also contacted the SIMSAM coordinator Anna Holmström during the evaluation meeting for some follow-up questions regarding the role of the coordinator within the SIMSAM network.

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## STATEMENTS BY THE PANEL

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The panel notes that the SIMSAM project is successful in the sense that it has contributed significantly to the volume of register-based research in Sweden, while also adding synergies and interactions between research groups. In general, the SIMSAM nodes are very active and dynamic and their research output is strong. However, the panel notes that there is a potential to do much more in order to strengthen register-based research outside the SIMSAM nodes, including awareness of the SIMSAM initiative. The SIMSAM nodes themselves have already identified areas in need of development. In particular they have recognized that there are several problems that cannot be handled within the nodes alone, or even in collaboration between them. These problem areas require another and extended type of infrastructure to strengthen register-based research in Sweden. The nodes have, therefore, joined forces and made a comprehensive application for a SIMSAM infrastructure (SIMSAM INFRA) in a call for large infrastructures launched in 2011 by the Swedish Research Council. If granted, the infrastructure applied for would be an important addition to the current initiative.

The SIMSAM initiative is currently promoting successful interactions between medical and social sciences. This, however, should be fostered in the long term too.

Many activities have been initiated; however, these activities are not always made visible under the SIMSAM umbrella – which means that the potential impact of the initiative as a whole is not fully exploited.

The panel finds that the SIMSAM nodes have so far not fully taken up the assignments and challenges envisaged by the Research Council SIMSAM call for applications – possible these were not included in the contracts with the Scientific Council. This can, to a certain degree, be attributed to the process for selecting and initiating the projects at the Research Council and the lack of clear instructions provided, especially during the first year. However, the panel strongly believes that a more coherent collaborative effort, as described in the original call, would be very beneficial for Swedish register-based research and urges the SIMSAM nodes to continue to move in this direction. This will require a longer-term commitment from both the participating nodes and from the Research Council.

The panel notes that there is currently no strong national research infrastructure for register-based research. The research groups in SIMSAM are essential for defining such needs and for contributing to the development of a national research infrastructure for register research. However, a national infrastructure should be managed and operated in a sustainable setting, independent of a research project involving certain distinct groups. Here, an essential role in connecting the research infrastructure with the research can be taken by a group of “national application experts” – managed by the infrastructure but working very closely with the research community in the register field.

Moreover, the panel suggests that a (Nordic/international) senior advisory board should be set up for the SIMSAM initiative, providing independent advice to the steering group that we later on in the text suggest be organized.

### Collaboration between nodes

Formal and informal collaborations between the nodes have had a slow start and a coordinator for this effort is in place only since May 2011. This may be a consequence of the slight disagreement between the Research Council and the nodes concerning the overall aim and goals of the SIMSAM initiative. The call text states: *“In order to clearly signal the vigor and long range of the initiative, the Research Council wishes to collect all these research groups together under a common initiative”* and *“Grants are not intended as reinforcement or a continuation of support for existing research using registers.”* However, the expectations with regards to collaborations and the required achievements for renewal were not strongly reflected in the SIMSAM evaluation criteria for the applications and, as far as the panel understands, not at all reflected in the resulting grant agreements.

The panel thus believes that the program was not set up in an optimal way by the Research Council. Even with more appropriate evaluation criteria and a more directed grant agreement, a program of this complexity would probably also have needed an active project officer, e.g. at the Research Council, in the initial phase. One reason for that strong collaboration was not initiated can be that the program is different from initiatives usually launched by the Research Council and does not directly fall within the area of a single scientific council or committee. For instance, today, the program is administrated by the Council for Research Infrastructures within the Research Council– even though it is mainly a research program and not a research infrastructure.

Opportunities for collaboration between nodes have been partly hampered by the delayed setting up of the national coordination group. Also, a 50% Full Time Equivalent coordinator was appointed only this year, and started working in this capacity only this fall. The coordination group meets quarterly and includes all the six SIMSAM PIs, the SINGS Director, and representatives from the Swedish National Data Service (SND) and the Database Infra-Structure Committee (DISC) of the Swedish Research Council. So far, main achievements of the group have been the organization of the first SIMSAM annual meeting (see below) and the joint research infrastructure application to the Swedish Research Council (SIMSAM INFRA application, submitted 2011) mentioned above.

Independently of the coordination group, some of the nodes appear to more fully have exploited their shared SIMSAM umbrella<sup>1</sup>. Furthermore, the SIMSAM Graduate School in Register-Based Research (SINGS) acts as a link for junior staff in particular, as they participate in the graduate courses. It is unfortunate, however, that specific knowledge and expertise regarding data extraction and data management, e.g. regarding computer codes, is not systematically shared.

The panel strongly believes that the type of initiative (coordinated effort with strong national and outward-looking focus, strong interaction with research infrastructure) described in the original call would be very beneficial for Swedish register-based research and urges the participating nodes to continue on the path that they have recently entered, revisiting the original call and focusing more on these aspects of the initiative. The SIMSAM initiative would be significantly strengthened if the participating nodes would form a more structured consortium.

The panel suggests that the coordination group be developed into a steering group with a clear mandate, governed by a Terms of Reference-document describing the work, responsibility, and mandate of this body. Possible, the PI of the coordinating node could be the chair of the steering group, and given mandate to handle operational questions between meetings. Also, the role of the coordinating node should be clarified - it would further strengthen the initiative if the PI of the coordinating node could speak on behalf of the national consortium when contacting research infrastructure providers and international research collaborators.

Moreover, a written description regarding the tasks and mandate for the coordinator is urgently required. The steering group should develop activity plans with goals to be achieved with set time limits and with responsible persons in charge. This includes a communication plan and identifying and reaching out to target groups who are involved in or will benefit from Swedish registries/registry research. The steering group probably needs to meet more often in order to steer and monitor consortia-wide activities. Also, it is important that the research activities at the nodes are firmly anchored within the local research environments.

A potential problem with the call, that is, with awarding grants only to younger researchers, as in this case, is that the groups spend unnecessary energy and time “re-inventing the wheel”, not fully exploiting the competence and experience of senior researchers. Developing clearer ways of sharing and using input and expertise from senior colleagues would be an advantage.

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<sup>1</sup> For example, SUNDEM and SUNSTRAT, possibly because they also share maintenance of two databases, jointly organize courses (“Crash courses on data handling”) and also seem to interact in their research. The nodes based at Umeå and Lund University share subject matter interests (early life exposures and later health) and therefore are motivated to collaborate. For other groups, in particular those based at KI, close proximity is probably an advantage as they report collaborating to a large extent.

## Joint conferences, research seminars, and informal get-togethers

Some joint conferences have been organized; one at 21 September 2010 (leading to that a coordinating group of the PIs was organized), one 14-15 March 2011, and a third in September 2011 (“Register-based studies, experiences from different continents”) and another, with a similar structure, is planned for April 2012. Some research seminars appear to have been shared among the nodes <sup>2</sup>. Other internal seminars related to the SIMSAM work appear to have been organized but not advertised to the whole SIMSAM community (at least from perusing the various web-sites).

## Sharing of methodological developments

The hearing with all the PIs and co-PIs, which started off the two evaluation days, revealed that an increased general awareness of registry-based research in fields other than one’s own had been generated by the SIMSAM initiative. This, however, has not yet led to greater sharing of problem solving. There are two areas where this could lead to greater proficiency: (i) data management and (ii) analytical methodology. The former is partly met by what is already provided by SUNSTRAT and SUNDEM (on data handling). For the latter, we would expect the methodology packages funded as part of individual nodes (in particular Lund and MEB), to play this role, sharing methodological insights with the other nodes as well as identifying common methodological needs. In this way, the quality of data analyses produced by all nodes can be enhanced.

## Data cleaning and sharing of computer syntax or SAS programs

Individual nodes have spent much effort towards cleaning and managing data from several registers, for example developing SPSS syntax or SAS programs for documentation of variables, data analysis, etc. Only few of the nodes seem to be sharing the results of their efforts between project groups within the respective node – much less between the nodes. As the nodes were financed to increase register-based research in Sweden, the results from them should be made available to other researchers as well as for the authorities responsible for the registers from which data were obtained. The panel strongly urges the SIMSAM nodes to find ways to do that as soon as possible, following the example of one of the nodes that already successfully promotes this, to some extent, on its web site. The promotion of register-based research of Sweden is dependent on gaining expertise from others. Also, this type of sharing will lead to the enhancement, and assurance, of the quality of the methods used in Swedish registry-based research.

## Interaction with/use of/contribution to infrastructure

Some of the nodes have used the MONA system. There are also efforts towards developing new infrastructure components. There is an emerging discussion at the SIMSAM level with authorities and research infrastructures. SND is represented in the coordination group and there is a plan to invite also Statistics Sweden.

However, also in this area the ambitions of the original call have so far not fully translated into activities by the SIMSAM network. One likely reason for this is the current absence of a strong national research infrastructure partner to engage with in discussions and collaborations. Clearly, the SND cannot provide what is needed. Lately, the SIMSAM nodes have together set up and submitted a proposal

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<sup>2</sup> For example, “Drug prescription registers for epidemiological studies” in May 2011 (MEB node), “Early Life meeting focused on causality” upcoming in November 2011 (Umeå node).

for a national research infrastructure for register-based research. This was a major effort and a collaborative initiative that should be applauded. The research groups within SIMSAM are essential for contributing to the development of a national research infrastructure for register research and for defining its needs. However, a national infrastructure should be managed and operated in a sustainable setting, independent of any specific research project that may involve only certain distinct groups. It should have long-term tasks/responsibilities and funding, as pointed out in the SIMSAM INFRA application.

It is clear that a vibrant national research infrastructure is needed for this field.

## Individual comments for the SIMSAM graduate school and the SIMSAM nodes

### SIMSAM Graduate School – SINGS

The graduate school has so far provided eight one-week courses, in total. The courses have had good attendance from doctoral students in the SIMSAM network as well as from outside. The panel is satisfied with the courses that are offered by the Graduate School. They are relevant and most, but not all, are added value initiatives of the SIMSAM initiative. However, the panel is of the opinion that more could have been achieved with the funds allocated to the school, in particular to cover material not currently provided by the courses delivered so far but particularly relevant to this field of research, for example handling of missing data. The budget share for coordination and follow-up, up to 65-70% of the total, is too large.

The panel suggests the research school add one flagship course that is aimed at an international audience of students – particularly from the Nordic countries but also from elsewhere. This could be built on the international symposium that was held at Karolinska Institutet recently. In the SIMSAM application it is stated that a wide variety of courses will be offered, which is not the case today. The school should aim at offering courses of a wider variety and more frequently. This would be possible through a closer collaboration with the SIMSAM coordinating group, the SIMSAM nodes in Stockholm both at the Karolinska Institutet (MEB and UGIR) and Stockholm University (SUNSTRAT and SUNDEM). It would also be an advantage if all relevant post-graduate courses offered at Karolinska MEB, Karolinska UGIR, SUNSTRAT, SUNDEM, Lund Early life, and Umeå were collected and presented at the Graduate School's and SIMSAM's future website.

### SIMSAM Lund – Early life

SIMSAM LUND has a good webpage with links to the other nodes. The organization seems to be flat with each PI working independently. There is reported collaboration between the work packages although the detail and extent of this collaboration among the PIs is not clear from the documentation given to the panel (e.g. with regards to sharing register data, metadata, syntax for data cleaning, etc.). There is not yet substantial evidence of contribution from this node toward building a national infrastructure, possibly because of the delays discussed above. On the positive side, the node is planning the provision of a help desk and the taking up of a more open service role. This could be done in collaboration with the other nodes. Also, the node contributed to the SIMSAM INFRA application.

The panel is concerned about the consequences of the current restructuring of two WPs, especially the loss of methodological competence. In the original application, WP6 interacted with all the other WPs, and this change might therefore be extremely problematic for the work of the node. This should be dealt with also by the coordinating group as it affects the delivery of methodological research of the whole current SIMSAM initiative.

## **SIMSAM KI – MEB**

This is an active and productive research group with an excellent international research network. The web page is good. The organization seems flat with separated WPs that are individually important, but closer collaboration should lead to greater synergy for the node as well as for the other SIMSAM nodes. There is strong focus on research that could be more actively advertised under the SIMSAM umbrella. It is positive that there are collaborative initiatives with the other SIMSAM nodes. Emphasis has been put on establishing a national infrastructure through SIMSAM-INFRA initiative and technology assessments for this purpose it is a valuable contribution. There is a methodology work package that would be expected to produce more in accordance with the original aims and to link to work of the whole initiative during the remainder of funding period.

## **SIMSAM SU – SUNDEM**

This is a highly active group and a leading environment that is also part of Linnaeus Center on Social Policy and Family Dynamics in Europe (SPaDE). Synergies with other SIMSAM nodes are developing. They have important experience with research databases within Statistic Sweden that could be of benefit to medical and health research. The node contributes to the development of infrastructure with tools for MONA access. This is positive, but they need to make sure this is done on a national level and that tools will be available to researchers also outside SIMSAM. The group has a part-time press manager that possibly could contribute to the work of the coordinating group too, thus to SIMSAM national profile.

Positive initiatives further include a senior advisory group and a Nordic collaboration for register data research.

## **SIMSAM SU – SUNSTRAT**

This is an active and dynamic node with an excellent international network. The group has extensive collaboration with SUNDEM and is also very involved in SIMSAM collaboration outside SU. The “crash” courses on data handling are a positive initiative that possibly could be used by others. The node contributes to building and sharing tools (cleaning of data, etc.), some are available through the personal web site of the PI but consideration should be given to providing them on a common SIMSAM webpage or national platforms for tool exchange, as suggested above. The guest research program is advertised on the web page as well as links to the other SIMSAM nodes. The node has an advisory board and Nordic reference group. Closer collaboration/connections with epidemiologists and medical researchers should be emphasized further.

## **SIMSAM Umeå**

The group has a strong research output (the scientific report is available on the web site) and an extensive international network. The node receives important funding contribution from Umeå University. The staff list includes a large number of people, including many senior researchers, which makes them the largest group within SIMSAM. They also have the highest number of PhD students but relatively few post-docs. It is positive that almost all PhD students are enrolled in the graduate school. Furthermore, they have an active guest researcher program and an active methodology work package. There is currently no collaboration between the node and MONA or SND. The group has taken the lead in coordinating the SIMSAM nodes. Their willingness to lead the collaborative efforts is positive. They have also, since the appointment of the coordinator, published six SIMSAM newsletters where news and summaries of meetings are reported. Umeå University is, as the other involved universities, a hub for surveys and register-based research and biobanks. It is unclear to the panel in what way the Umeå SIMSAM node collaborates with these initiatives (ESS, EPIC, SHARE, MONICA, Demografiska databasen) and takes advantage of local expertise relevant to register-based research.

## **SIMSAM KI – UGIR**

This is a strong group in a specific field, with an extensive international research network. This node is an example of a clinical research group that in a sense “uses” the SIMSAM effort to enhance their research and put it to use in clinical practice. This is an important example to follow for other clinical researchers because efficient utilization of the register “gold mine” includes interaction with clinical medicine. The node collaborates with SUNDEM and the other SU nodes. The strategy has been to include many post docs which is important for establishing the research in a short term. The group has also been successful in recruiting bio-statistical support.



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## REFLECTIONS ON THE REVIEW PROCESS

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The panel thanks the SIMSAM nodes and their universities for providing written information and the SIMSAM representatives for participating in the hearing. The task of the evaluation panel was only partly supported by the written information provided by the nodes/universities, as the questions posed to them did not cover the main issues listed in the Terms of References for the evaluation. For instance, there were no items regarding how they had worked to enhance register-based research outside their own group, what actions they had taken towards increasing their cooperation to promote register-based research in Sweden and internationally, or which interactions with and contribution to register infrastructure in Sweden they had created, etc. Also, it would have been beneficial for the work of the panel to have had time to prepare specific questions for the SIMSAM nodes before the hearing and to have a longer hearing session, possibly including short individual interviews with representatives from each node.

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# APPENDIX 1

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## **The SIMSAM research nodes**

Microdata research on childhood for lifelong health and welfare (SIMSAM Umeå)  
*Umeå University, Professor Anneli Ivarsson*

Register-based Research in Nordic Demography (SUNDEM)  
*Stockholm University, Professor Gunnar Andersson*

Social Stratification Dynamics – Inter- and intra-generational processes (SUNSTRAT)  
*Stockholm University, Professor Erik Bihagen*

Register-based research of diseases and surgery of the upper gastrointestinal tract (SIMSAM KI – UGIR)  
*Karolinska Institutet, Professor Jesper Lagergren*

Transmitted and Acquired Determinants of Health across the Life-Span (SIMSAM KI – MEB)  
*Karolinska Institutet, Professor Ye Weimin*

Interdisciplinary research on early life exposure and health: A registry-based lifecourse perspective with modern epidemiological and statistical approaches (SIMSAM Early Life)  
*Lund University, Professor Anna Rignell-Hydbom*

## **The SIMSAM Graduate School**

Stockholm Interdisciplinary Graduate School in Register-Based Research (SINGS)  
*Karolinska Institutet, Professor Olof Akre*

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## APPENDIX 2

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### Panel members

Sverker Holmgren, Professor, Uppsala University, Sweden

Bianca De Stavola, Professor, London School of Hygiene and Tropical Medicine, England (participating through e-meeting and e-mails)

Stein Emil Vollset, Professor, University of Bergen, Norway

### Chair of panel

Kristina Alexanderson, Professor, Karolinska Institutet, Sweden

### From the Swedish Research Council

Eva Stensköld, Research Officer RI, panel secretary

Juni Palmgren, Secretary General RI