

# **Review of Nordic Health Data Research Projects on COVID-19**

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In response to the COVID-19 pandemic, NordForsk launched a call for research proposals focusing on health data research related to the SARS-CoV-2 virus. This initiative aimed to generate new knowledge about the virus and its impact on public health by leveraging the high-quality research infrastructures and public healthcare systems in the region. The initiative aimed to complement ongoing international efforts by focusing on regional healthcare systems and patient populations.

The call offered a total funding pool of NOK 57 million NOK. The funding was allocated into five collaborative projects with a focus on using health data to improve understanding of COVID-19.

This report summarises the feedback provided by researchers involved in the Nordic Health Data Research Projects on COVID-19, along with the impact data and outcomes reported by these projects.

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## Researcher Feedback

An online questionnaire was sent out to all (N=18) researchers who were granted funding through the call. With a response rate of 56% (n=10), all respondents provided positive feedback, particularly on the speed of the initiative and the opportunity to collaborate cross borders (Figure 1).

**Speed of Establishing the Research Call:** All respondents agreed that the rapid establishment of the COVID-19 research call early during the pandemic was crucial. This quick response allowed for timely coordination and action, which was necessary given the urgent global health situation.

**Cross-Border Collaboration:** The opportunity to collaborate across national borders was considered important or very important by all respondents. Given the similarities in healthcare systems and societal structures of the Nordic and Baltic countries, this collaboration allowed for an integrated approach to addressing the pandemic, with researchers strongly agreeing that such cooperation was essential to their research outcomes.

**Clear Communication:** The objectives and criteria of the research call were seen as clear and well-communicated. The respondents felt that the call's guidelines provided sufficient clarity to effectively align their projects with the overall goals of the initiative.

**Experience with NordForsk:** The overall experience with NordForsk during the application and project implementation phases was highly positive. With all respondents agreeing or strongly agreeing with the statement "the overall experience with NordForsk during the application and project implementation phases was positive."

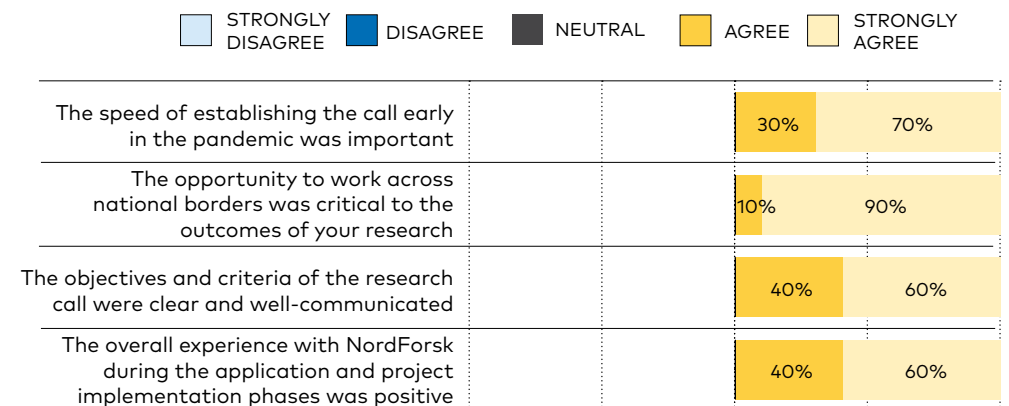


Figure 1. To which degree do you agree with the following statements (n=10).

## Key Factors for Rapid Research Initiation During a Crisis

Several key factors were reported by the respondents for successfully initiating research quickly during a crisis, such as the COVID-19 pandemic (Appendix 1).

One was the importance of networks and collaboration between researchers across countries. Pre-existing connections allowed researchers to quickly establish common ground and build trust, which enabled them to mobilise research efforts quickly. Good connections, especially among researchers with access to relevant datasets, were particularly valuable.

Access to existing data and the ability to move data across borders were also reported as important components. Researchers emphasised that having access to national datasets, even if they varied in completeness and quality, provided a good foundation for answering urgent research questions. In particular, the availability of continuously updated, valid healthcare data, such as national healthcare registers. Moreover, researchers stressed the importance of transparency in data access and called for public authorities to make data available to other research groups, not just those within the government, to facilitate research efforts.

Another element was the involvement of stakeholders who were willing to fund research in critical directions. The funding provided by NordForsk was seen as essential for these collaborations and for facilitating rapid results. Flexibility in funding, including the timing and start dates for researchers, was also appreciated.

Additionally, researchers expressed the importance of long-term funding for successful projects. Some suggested that there should be funds available for the continuation of promising projects beyond the initial research period. This would allow for further development of successful research outcomes and ensure that the benefits of the research could extend beyond the immediate crisis.

Finally, importance of institutional support from authorities responsible for handling data was underlined. They called for sufficient resources to be allocated for managing data applications and retrieving data, as bottlenecks in these processes could hinder rapid research.

In conclusion, the key factors for rapid research initiation during a crisis included strong pre-existing networks, access to timely and transparent data, the availability of flexible and timely funding, and the ability to quickly assemble skilled research teams.

### Takeaways

- **Pre-existing networks and collaboration:** Strong international connections enabled rapid mobilisation of research efforts.
- **Access to and sharing of data:** National datasets and cross-border data sharing were central for addressing urgent research needs.
- **Transparency in data access:** Public authorities should provide open access to data for research groups.
- **Flexible and timely funding:** NordForsk managed to provide quick funding and establishment of the call, which enabled research in a timely manner.
- **Institutional support for data management:** Adequate resources for data handling are critical to prevent delays in research.

## Lessons Learned for Future Rapid Response Research Initiatives

Through the questionnaire, researchers shared valuable lessons from their experience with the call, which could help improve future rapid response research initiatives (Appendix 2).

One of the main takeaways was the importance of short deadlines for applications and rapid evaluation by research funders. Speed and capability in announcing research funding is considered central for a timely response.

Leveraging existing contacts and networks was instrumental in facilitating cross-national collaboration. For example, in Norway, a project mentioned fluid collaboration between authorities to access data. In contrast, a project in Denmark had difficulties with more complex and less cohesive collaboration between data authorities, creating a potential bottleneck for research.

Another lesson was the need to find quick solutions, particularly in terms of data access.

Researchers suggested that the ability to quickly access relevant data, whether through established data-sharing agreements or flexible research strategies, was essential. The ability to perform analyses without pooling data, for instance, was another highlight as a useful method to circumvent delays caused by data integration issues.

Here too, there were suggestions to prepare further funding in advance for successful projects, to take the opportunity to build on the work and collaborative infrastructure that has already been established during earlier phases of a project.

Researchers also noted the challenge of working with rapidly evolving data systems during the pandemic. While there was a demand for real-time data on COVID-19, the frequent structural changes in data formats, such as those experienced with Danish healthcare data, created difficulties for efficient research. Some expressed concerns about incomplete or unfinished databases, which could hinder the ability to conduct rapid response research. One suggested solution was to maintain multiple versions of healthcare registers in parallel to avoid disruptions caused by database updates. This would prevent data gaps and ensure continuity in data availability. Furthermore, they called for the establishment of a data strategy before a crisis occurs, one that could be adapted to the situation and involve a broader range of researchers in the process.

To summarise, the most important lessons reported by the projects include the need for speed in funding announcements and evaluations, the critical role of partnerships and data access, and the value of continuity in research initiatives. Additionally, flexibility in handling rapidly changing data environments and establishing robust data strategies in advance for enabling rapid response research during future crises.

### Takeaways

- **Speed in funding and evaluation:** Short deadlines and rapid evaluation by research funders are important for timely responses in crisis situations.
- **Quick data access solutions:** Flexibility in data-sharing agreements and alternative strategies are central for avoiding delays.
- **Continuity and preparedness in funding:** Pre-arranged funding mechanisms and readiness to build on established collaborative infrastructures in case of crisis.
- **Handling evolving data systems:** A pre-crisis data strategy to avoid disruptions during rapidly changing situations.

## Nordic Added Value

The Nordic added value produced was primarily driven by cross-border collaboration, the leveraging of existing Nordic strengths, and the establishment of scientific networks (Appendix 3.). These elements combined in favour of the scope and impact of the research initiative.

One project emphasised how forming a consortium of three partners from Sweden, Norway, and Finland allowed them to capitalise on each country's particular strengths. By pooling resources and expertise, the consortium was able to access and analyse comprehensive health data that would not have been available within a single country. This cross-border collaboration provided unique datasets that facilitated more extensive research and contributed to the overall success of the project.

Another project highlighted the importance of building on the established infrastructures present in the Nordic region, such as biobanks and population-based health registers. The existing health data systems in Sweden, Norway, and Denmark, in this case, allowed researchers to quickly access and link large-scale datasets. This provided a foundation for conducting advanced register research, and enabled the project to make contributions that would not have been possible in regions with less developed data infrastructures nor without cross-border collaboration.

In addition to using existing data, projects benefitted from sharing resources and expertise across borders. One project reported significant added value through the collaboration of three full nodes from Sweden, Denmark, and Norway, which enabled the joint development of mathematical models for analysing health data. The ability to share methodologies and collaborate on data analysis allowed the project to generate high-impact results, including models that can be applied beyond the immediate scope of the pandemic.

The establishment of scientific networks was also seen as key source of added value. In one project, researchers from multiple Nordic countries came together to build a network that facilitated the exchange of data, models, and methods. This network fostered collaboration across borders and allowed the project to rapidly produce joint publications and policy recommendations that informed public health responses.

A particularly impactful example came from a project that successfully linked mental health datasets from Estonia and the Nordics. The project leveraged data registers and biobanks to study the mental health trajectories of individuals across these countries during the pandemic. The ability to link these datasets across national borders provided a unique perspective on the mental health impacts of COVID-19, enabling the project to generate findings with broader regional relevance.

Overall, the added value produced by these projects stemmed from their ability to harness the strengths of the Nordic region's health data infrastructures, foster collaboration across countries, and establish collaboration networks. Each project demonstrated benefits of working within a shared regional framework, allowing for greater innovation, data sharing, and research impact.

## Reported Outputs and Outcomes

The call produced a total of 89 academic publications, contributing to the body of knowledge around COVID-19. Considering the circumstances, this indicates an exceptional level of research activity and output, with researchers publishing findings that informed both regional pandemic responses and further research.

Twelve instances of concrete impact on policy were reported across three of the projects. These include citations in policy documents or clinical guidelines, contributions to guideline committees, or influencing the training of practitioners or researchers.

The 95 reported dissemination activities, such as presentations, news articles in media, conferences, and public engagements demonstrates the projects were actively involved in communicating their findings to broader audiences.

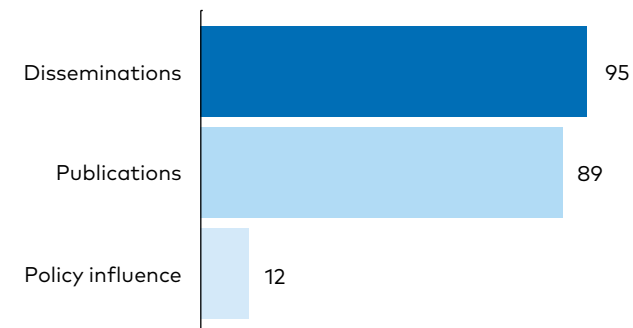


Figure 2. Reported publications, policy influence and dissemination instances.

## Publications

### Addressing the smoking paradox in the etiology of COVID-19 through population-based studies

Caspersen IH, Lill Trogstad, Maria Rosaria Galanti, Sakari Karvonen, Sebastián Peña, Ahmed Nabil Shaaban, ... Per Magnus. (2021). Tobacco use and SARS-CoV-2 infection: Results from MoBa. Poster presentation. Annual Conference for the Norwegian Epidemiological Association (NOFE), Bergen, Norway.

Caspersen IH, Álvaro Hernández, Sebastián Peña, Sakari Karvonen, Ahmed Nabil Shaaban, Maria Rosaria Galanti, ... Per Magnus. (2023). Cigarette smoking and risk of SARS-CoV-2 infection: Do Mendelian randomization studies provide an answer? Oral presentation. Annual Conference for the European Chapter of the Society for Research on Nicotine and Tobacco (SRNT-E), London, UK..

Caspersen IH, Trogstad L, Galanti MR, Karvonen S, Peña S, Shaaban AN, ... Magnus P. (2023). Current tobacco use and SARS-CoV-2 infection in two Norwegian population-based cohorts. *BMC public health*, 23(1), pp. 846. doi: 10.1186/s12889-023-15822-5

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### **Mental morbidity trajectories in COVID-19 across risk populations of five nations**

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### Nordic COLlaborative HEalth REgister Network for Covid-19 Epidemiology

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## Appendix 1

*Based on your experience, what do you believe are the key factors to successfully initiating re-search quickly during a crisis? (For example, other support functions from research institutions, acc...*

Good connections between researchers with available datasets

Having a good cross country network - that enabled us to establish a common ground and trust within hours.

Having access to data!

The presence of influential stakeholders willing to fund research in critical directions  
Partners should know each other in advance, but not necessarily all. Availability of data and movement of this across borders

That we could set up a skilled and experienced Nordic team quickly. We were then able to retrieve national data from different countries with varying completeness and updated at different times which gave rich and unique data to answer our research questions.

Funding like this call is crucial for speeding up and facilitating relevant collaborations for important and quick results.

I think your initiative was good. Perhaps there should be some funds for continuation after the research period is over. Not for all, but the successful projects.

Timing and flexibility with funding, and starting dates of new researchers.

Existing network of research groups with established data access and /or the possibility for a rapid data collection. We managed to connect researchers and countries with existing data from similar questionnaires and national medical record linkages.

The most important factor for conducting rapid and relevant research using real-world health-care data (such as the Nordic national healthcare registers) is timely access to valid data that are sufficiently updated (continuously or frequently with short intervals) and released without a long delay (short data lag time).

Reliable and fast access to data becomes even more crucial during a crisis such as a pandemic, where there is an increased demand for data. Although data needed for analysis by public authorities should clearly have a high priority, it is important that data are accessible for other research groups as well in a transparent manner.

Sufficient resources for handling data applications and retrieving data should be prioritised to avoid unnecessary barriers and bottlenecks that impede rapid research. Support from institutions and authorities that are responsible for data is essential.

## Appendix 2

*What are the most important lessons you learned from this project that could help improve future rapid response research initiatives?*

*Short deadlines for applications and rapid evaluation from the research funders would improve response*

*The Berett data that was established in Norway was an example to learn from. I.e. collaboration between different data authorities that secured up-to-date data. Dnmark has a lot to learn here!*

*Establishing partnerships is crucial to cross-national efforts. To this project it was crucial to capitalize on existing contacts/networks. Also, the restriction to Nordic and Baltic Countries, that have an established tradition in conducting population-based studies.*

*Involve always the data owners*

*The speed of announcing research funding. The importance of granting the best teams for funding with enough funding to make a difference.*

*Find solutions that work immediately. (ie. have plan for quick access to data and do metaanalyses without pooling data for example.).*

*It's a good way to move into a new important area for many researchers.*

*Nordic collaboration in math&stats worked out nicely.*

*1. Broadening the list of countries to include other neighboring countries (Estonia, Latvia, Lithuania) is crucial for increasing sample sizes and comparisons between countries in the same region. This is increasingly important in light of the recent change in the geopolitical climate.*

*2. However, it was extremely unfortunate that the list of countries were not expanded for the following call "Welfare among Children and Young People in the Post-Pandemic Nordics" and hence Estonia was excluded from the next funding opportunity directly linked to the same topic, despite having excellent large datasets to contribute with and the existing collaborative standard operating procedures which were established during the 2-year "Perspectives on Nordic Health Data Research on Covid-19" collaboration project. I hope NordForsk will drive to be more inclusive in the future and especially pay attention to the continuation opportunities of the additional countries that were involved in previous calls on the same topic.*

*Although agility is important, serving demands for new data during a crisis (during the pandemic for example Covid-19 tests, vaccinations, and Covid-19 diagnosis codes for hospital admissions), it is also important with reliable and valid data in a well-established structure and format. A quickly changing data landscape, such as the repeated changes in structure of Danish patient data during the last years, or large unfinished database projects (exemplified by the Danish Medical Birth Register) may hinder efficient rapid response research. Ideally, multiple generations/versions of registers should exist in parallel for a certain period to avoid critical data breaks and long data gaps. Data documentation is also essential. Preferably, a data strategy including the aspects of fast data access for researchers should be in place before a crisis occurs. The strategy could be revisited and adapted to the particular situation very early in the crisis and appropriate revisions made during the crisis. It could be an advantage for the data responsible institutions/authorities to involve a broader group of researchers in the process of facilitating access to well-defined essential datasets. This would make it possible to leverage the capacity and expertise of the broader research community during the health crisis and improve future rapid response research initiatives.*

## Appendix 3

Project title	How was Nordic added value produced
Addressing the smoking paradox in the etiology of COVID-19 through population-based studies	<p>The consortium formed between the three partners involved in the project has yielded a unique scientific collaboration, through the exploitation of register-based data of equally good quality. This scientific collaboration has achieved three goals:</p> <ol style="list-style-type: none"> <li>1. Provided a genuine example of triangulation of the same research question with data having strengths and weaknesses that complete one another. Triangulation is widely advocated in epidemiologic studies that are inherently prone to bias. In fact, if results from different studies are consistent despite different and known sources of bias the resulting knowledge is strengthened</li> <li>2. Provided the possibility of pooling data, thus increasing precision of the results, and facilitating the coming analysis of contextual factors and of subgroups (e.g. gender)</li> <li>3. Prompted in-depth analyses of existing data and additional articles that were not originally included in the project plan for the award</li> <li>4. At a meta-level, the consortium developed a fruitful model of collaboration based on intensive levels of scientific and managerial interaction (meeting every 3-4 weeks from the start of the project); collaborative spirit; training spin-off for junior researchers; and efficient use of digital platforms. All this has happened despite the constrain imposed by the pandemic.</li> </ol>
Data streams and mathematical modeling pipelines to support preparedness and decision making for COVID-19 and future pandemics	<p>The project consists of 3 full nodes from Sweden, Finland and Norway, and a smaller group from Denmark. Our mission is to analyse the Covid-19 pandemic, similarities and differences between the Nordic countries, to learn more about the Covid-19 pandemic and effective preventive measures to reduce spreading. Three post docs have been hired, one from each country, with collaboration between including also senior researchers. The network has a monthly one hour Zoom meeting, gathering 20-30 researchers each time, with shorter presentations followed by scientific discussions. The network has arranged three workshops, one in Sweden September 2021, Finland May 2022 and Norway February 2023, each time with 30-40 participants from the 4 Nordic countries.</p> <p>The program has initiated several Nordic research collaborations which have already resulted in many publications, and more are yet to come. It is our hope and belief that the network will continue collaboration also after the project funding ends.</p>

Project title	How was Nordic added value produced
SCOPE- Scandinavian studies of COvid-19 in PrEgnancy	<p>The SCOPE project has created outcomes and impact of greater value for the countries involved than could be achieved through national activities alone. The SCOPE research team has utilised registry data from Denmark, Norway and Sweden. The research based on the extensive Scandinavian data-sources has increased the understanding of how COVID-19 affect pregnant women and their pregnancies. Our research has accounted for and exploited similarities and differences among the countries, thus an added value to the Nordic collaboration. With this project, we have established a Nordic collaboration and strengthened our expert network and infrastructure. Due to difficulties of pooling individual data, we have conducted several pooled meta-analyses on data across the Scandinavian countries (Denmark, Sweden, Norway) which has given us a wider study population and the great advantage of increasing sample size. It has also enabled us to conduct comparisons across countries. SCOPE has followed data from 230 000 annual births in Norway, Denmark and Sweden and is the largest cohort in the world to study COVID-19 in pregnancy. The research has provided unique tools not found elsewhere because of the integrated data from different nationwide health registers with socio-demographic registers. The research has tuned in on selected vulnerable groups, for example lower socioeconomic groups, pregnant women and their offspring. Policy restrictions and impacts of the pandemic outbreak has varied substantially, even between the Nordic countries. Similar findings in several countries may support biological effects of COVID-19 in pregnancy. Another added value of the SCOPE collaboration so far is that we have provided networking opportunities for younger researchers in the project. Although the travel restrictions due to Covid impacted the physical mobility during the project, we were able to have a physical meeting with the Scandinavian team where we discussed our findings and strengthened our collaboration and further plans. We have secured continuous contact through our steady schedule of bi-weekly meetings on our digital platform Teams. Despite the limitations of a digital platform, the project team has been actively engaging in scientific discussions that have resulted in analysis and publications. In our publications, senior scientists and younger scientists have worked closely together and younger researchers have taken lead roles in our publications, strengthening Nordic collaborations and network building among the Nordic countries, paving the way for further funding (Nordforsk) building on the established team.</p>

Project title	How was Nordic added value produced
Nordic Collaborative HHealth REgister Network for Covid-19 Epidemiology	<p>We have successfully established a scientific collaboration between researchers at four Nordic universities: University of Copenhagen, University of Oslo, Uppsala University and University of Gothenburg. We have also collaborated with researchers in the United Kingdom (Scotland) and other European countries. Data retrieval, data harmonisation and initial analyses are ongoing. The Nordic countries have unique healthcare and administrative registers covering all residents and enabling follow-up of individuals across the entire lifespan while maintaining confidentiality of the information. The use of these registers in Nordic COHERENCE will enable us to produce high-quality evidence on COVID-19 relevant for patients, health care professionals and public health. Evidence during the Covid-19 pandemic has been accumulated through a multitude of studies using available data from many countries, often spanning short periods and according to a short-term need for knowledge on this new threat to public health. Nordic COHERENCE will be able to offer a broader perspective on the COVID-19 pandemic from its inception and through the different phases, introduction of new virus variants with different disease patterns, and the impact on the population and health care system. We will investigate vulnerable populations and identify risk factors for severe disease. The ability to conduct identical analyses across the involved countries provides an opportunity for comparisons of the course of the pandemic, with the possibility to evaluate the impact of different public health measures and policies implemented. This is expected to provide important knowledge on how to handle a pandemic in the future.</p>
Mental morbidity trajectories in COVID-19 across risk populations of five nations	<p>The Nordic-Estonian cohort- biobank-, and register resources established or gathered through the COVIDMENT program constitute a world-wide unique platform to gain critical insight into the influence of the COVID-19 pandemic on population mental health as well as mental health development within risk groups specifically hit by the pandemic. The varying weight of the pandemic across the Nordic countries and Estonia, as well as the varying national mitigating strategies across countries opens for comparative exploration of the role of these factors on population mental health impact. Also, the pooled data across the participating countries open for powerful analyses of the impact of COVID-19 infection on long-term symptoms (e.g. long COVID) among patients and their families, as well as in other groups specifically hit by the pandemic. Our findings on the correlation between population depressive symptoms and national COVID-19 incidence as well as on long-term mental health effects among individuals suffering severe COVID-19 illness have been published in leading scientific journals and gained global attention through extensive media coverage around the world. With many more cutting-edge publications coming up, the COVIDMENT program will inevitably shape the clinical- and national policy responses to the current and future pandemics in the Nordic-Baltic region and beyond.</p>

