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The governance of the SAMINOR Study and integration of the CARE principles

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ABSTRACT

The SAMINOR Study represents a unique data collection on health and diseases among the multiethnic population – including the Sámi population in Norway – making it a case study for discussing Sámi research data governance in a health context. This article describes how Sámi interests and needs in the SAMINOR Study are governed by two steps of a research application review process consisting of the SAMINOR project board and the Sámi Expert Ethical Committee for Sámi Health Research. We explore how these two steps align with the CARE principles for Collective Benefit, Authority to Control, Responsibility, and Ethics, which are global principles for Indigenous data governance and promote Indigenous data sovereignty. The CARE principles stress the importance of Indigenous self-determination and control, tangible benefits, ethical use, and the promotion of Indigenous values and equity. We found compliance between most of the main and sub-principles but observed the need to address reuse and data sharing more explicitly. The CARE principles do not consider ownership of research data, which for the SAMINOR study is outside of Sámi people's control, hence we question whether Indigenous data sovereignty is achieved for the SAMINOR data.

SAMINOR iskosa áimmahuššan ja gurahallan movt CARE prinsihpat láktasit dasa

ABSTRÁKTA

SAMINOR iskkus ovddasta earenoamáš diehtočoakkáldaga Norgga sápmelaččaid dearvvašvuoda ja eallindábiid birra, ja heive ovdamearkan go ságastallat sámiiid dutkandieđuid stivrema birra, dearvvašvuoda oktavuodas. Dát artihkal govvida movt sámiiid beroštumit ja dárbbut SAMINOR iskosis hálddašuvvot guovtti oasis dutkanohcamušaid dárkkistanproseassas, namalassii SAMINOR prošeaktalávdegoddi bokte ja Sámi ehtalaš áššedovdikomitea bokte. Mii guorahallat movt dát guokte oasi gurret CARE:a vuodđoprinsihpaid kollektiiva ovdamuni, ráđđenválddii, ovddasvástádusa ja etihka ektui, mat leat globála prinsihpat álgoálbmoga dieđuid stivremis. SAMINOR iskkus lea fuopmášahtti diehtogáldu sápmelaččaid dearvvašvuoda birra ja dat lea ovdamearkan das movt CARE:a prinsihpaid lea vejolaš heivehit ja láktit sámiiid dearvvašvuodadutkamii. CARE prinsihpat deattuhit álgoálbmoga iešmearridan – ja ráđđenválddii, konkrehtalaš ovdamuniid, ehtalaš geavaheami ja álgoálbmoga árvvuid ja ovttárvosašvuoda. SAMINOR iskkus čájeha ahte dat guovtti oasis dutkanohcamušaid dárkkistanproseassa ja CARE prinsihpat láktasit bures oktii, earret go lea sáhka dáhtaid nuppes geavaheami birra, dáhtaid juohkima ja dáhtaid oamasteami birra Go sámiiid kollektivvalaččat eai oamas SAMINOR dáhtaid, de ferte gažadit leatgo oláhan dáhtaid sorjjasmeahttunvuoda.

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KEYWORDS

SAMINOR Study; Research data governance; Ethics; Sámi; Indigenous self-determination; CARE principles

Introduction

This article focuses on the governance of the data collected in the SAMINOR Study: a Population-based Study on Health and Living Conditions in Regions with Sámi and Norwegian Populations (hereafter SAMINOR). SAMINOR is a comprehensive research project conducted in northern – and mid-Norway in three phases

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(Broderstad, Hansen, and Melhus 2019; Brustad et al. 2014; Lund et al. 2007). SAMINOR was initially designed to contribute with valid statistical knowledge about Norway's Indigenous people, the Sámi, as there are no existing national registers including this information. The solution was to include the entire population in pre-selected age groups and ask about language use and self-perceived identity. The SAMINOR data contains data on the Sámi, Kven, and Norwegian populations living in the selected and traditional areas of the Sámi people. The data is collected to enable governmental bodies to make informed decisions based on research for the purpose of promoting the health and living conditions of the population living in the selected area, with a special focus on the Sámi people, culture, language, and communities.

Research projects utilizing data or biological material from SAMINOR should have clear collective benefits for the Sámi people and/or the population in the studied areas. SAMINOR is managed by the Centre for Sámi Health Research (CSHR) at the Department of Community Medicine (DCM), at UiT – The Arctic University of Norway (hereafter UiT). Before data from SAMINOR can be released and used for research, the project applications need to be reviewed and approved by the SAMINOR's project board, the Regional Committee for Medical and Health Research Ethics North (REK), and the Sámi Ethical Expert Committee for Sámi Health Research (SEEC) established and appointed by the Norwegian Sámediggi (Sámi Parliament). Additionally, a Data Protection Investigation Assessment (DPIA) has to be conducted, and a data management plan and a risk assessment must be written. The aim of this article is not to describe the laws and regulations applicable to the SAMINOR and the comprehensive review process of research applications. Instead, we focus on how Sámi peoples' interests in data are safeguarded in two steps of the review processes; specifically, how the review conducted by the SAMINOR project board and the SEEC corresponds with the global CARE principles which stand for Collective benefit, Authority to Control, Responsibility, and Ethics (Carroll et al. 2020). These principles have not been operationalized for Sámi research data, but they are important as they support Indigenous interests in data and provide an innovative strategy for Indigenous data governance (Carroll et al. 2021).

Data from the SAMINOR Study

The overarching goal of SAMINOR is to contribute with knowledge on health, diseases, and living conditions in multiethnic areas in the north, benefiting the population in the studied regions, i.e. the Sámi, the Kven, and the Norwegian populations. SAMINOR includes data collected in the SAMINOR 1 Survey (Lund et al. 2007), SAMINOR 2 Questionnaire and Clinical Surveys (Broderstad, Hansen, and Melhus 2019; Brustad et al. 2014), and the ongoing third survey, i.e. information given by questionnaires, from analyses of biological samples (e.g. urine, blood, and hair), clinical measurements, demographic data collected from the National Population Register on gender, birth year, municipality of residence, and in SAMINOR 1, marital status and place of birth. The ongoing third survey is designed as a mixed-methods epidemiological research project wherein results from qualitative interviews were considered when determining what questions were included in the questionnaires. SAMINOR is a health registry (Regulation on Population-based Health Surveys 2018) that initially started with a license from the Data Protection Authority (reference number 2002/1525-2). From 2018, the General Data Protection Regulation (GDPR) requires a DPIA for research projects originating from SAMINOR (Personal Data Act 2018). The duty to report to REK is regulated by the Health Research Act (Health Research Act 2008). The laws and regulations at national levels that apply to all health surveys and research are beyond the scope of this paper, however, they are important to mention.

The SAMINOR health registry is stored in UiT's data repository, the EUTRO database, and on a safe platform (Services for Sensitive Data) at the University of Oslo. UiT is the legal data controller of all the collected data from SAMINOR and UiT provides infrastructure that ensures safe storage of the data.

Biological samples are stored in the Core Facility for Biobank at UiT. These samples represent a valuable resource for researchers investigating various aspects of health, using biomarkers, parameters from environmental exposures, and genetics.

Individual informed consent

In all SAMINOR surveys, all inhabitants of preselected geographical regions and age groups were invited to participate and participation was voluntary. Invitees received information about the coming surveys by

leaflets, an information brochure, and an invitation letter. In all surveys, participants were informed about the purpose, use/reuse of the data, the possibility that data can be linked to public registries, measures to protect personal data by use of de-identified data, storage of data for the future, the possibility to be contacted after the survey (either for medical reasons or follow-up surveys), and they were informed about the possibility to withdraw from the survey at any time, including deletion of samples and information collected (except if the data have been used). In all surveys except the SAMINOR 2 Questionnaire Survey, participants were informed about clinical measures, the collection, use and storage of biological samples, the potential use of blood samples for genetic testing, and the possibility that clinical examination might reveal abnormalities that would cause them to contact their primary physician. All the participants that took part in clinical examinations signed a consent form. In the Questionnaire Survey, participants consented by ticking off this option in the questionnaire. In the consent form for the SAMINOR 1 Survey, participants actively consented to have their data used for research, to have their biological samples stored and used for health research, to have information linked to public or medical registries, accepted that genetic analyses could be conducted, and accepted to be contacted for medical reasons. In the SAMINOR 2 Clinical Survey, participants signed a consent form accepting to participate and specifying if they accepted to receive information about their health. When consenting to the SAMINOR 3 Survey, participants also declared that they had understood the information given and could ask questions about the survey before giving consent.

In Norway, all citizens have an 11-digit national identification number that individuals have throughout life. Any linkage to public or medical registries, such as cancer, cause of death, cardiovascular, infection, medication, medical birth, patient, social security, and education records, is done by use of the national identification number. The confidentiality of participants' identities is maintained through all stages of storage and use of data and protected by a key stored at Statistics Norway (SAMINOR 1 and SAMINOR 2 Questionnaire Study) or by CSHR.

SAMINOR steering group and a project board

SAMINOR is led by a steering group which consists of a representative from the Sámi Parliament, the Northern Norway Regional Health Authority, the Troms and Finnmark County Councils, the Norwegian Association of Local and Regional Authorities (KS), a representative of the Southern Sámi Health Network, an external scientific representative, and an internal representative from CSHR. The Head of DCM at UiT is the leader of the steering group. The steering group steers the SAMINOR in principle and strategic matters, is engaged in SAMINOR's budget, is engaged in the annual plans to secure financial resources and makes the final decisions for new data collection. The academic director of the CSHR (currently the last author, ARB) is also the Head of the SAMINOR and the secretary for the SAMINOR steering group. To get access to the SAMINOR data (questionnaire data, information from the blood samples, clinical examinations) or biological material, researchers must have approval from the SAMINOR project board. The board consists of employees from CSHR and an external researcher and is appointed by the Head of SAMINOR. The project board reviews proposals by assessing if the purpose of the research question is in accordance with the participant's consent and specific guidelines set by the SAMINOR steering group. The SAMINOR guidelines aim to ensure optimal use of the data from SAMINOR, i.e. compliance with SAMINOR's objectives, protection of participant interests, and fair access to material and information.

The application form to the SAMINOR project board requires a detailed project description, publication plan, list of variables, information about security measures for data storage, and the legal basis for receiving SAMINOR data. The application undergoes an evaluation based on academic and social relevance criteria, ethical considerations addressing research in a Sámi community, and alignment with SAMINOR's guidelines and goals. Special expert input may be sought before the project board makes a final decision. If the applicants have no previous knowledge of Sámi culture, history, language, or SAMINOR, the SAMINOR project board can obligate the applicants to include a scientific member from the CSHR as a co-author to ensure that SAMINOR's guidelines and Ethical Guidelines for Sámi Health Research (Sámediggi 2019a) are adapted during the project. For the use of material from the SAMINOR biobank, the SAMINOR project board evaluates and provides advice to the Head of SAMINOR, who makes the final decision. In case of a breach of agreement, the project leader will be contacted, and in case of continued disagreement, the right to data might be withdrawn.

Sámi collective consent

The Sámi collective consent is given by the SEEC. This authority is delegated to this body by the Sámediggi – the Norwegian Sámi Parliament. Sámi collective consent must be obtained for any research using data from the SAMINOR Study. The requirement of collective consent stems from the Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material (Kvernmo et al. 2017) (hereafter Proposal for Ethical Guidelines) prepared by a committee appointed by the Sámi Parliament Council in 2016. The Proposal for Ethical Guidelines emphasizes respecting the diversity and uniqueness of Sámi culture and communities and addresses the unethical historical discriminatory research practices, for example, the skull measurements conducted during the Social Darwinism period in the late 1800s that favoured racial supremacy to non-Sámi (Evjen 1997; Kyllingstad 2014). Based on these proposed guidelines, general ethical guidelines called Ethical Guidelines for Sámi Health Research (Sámediggi 2019a) were created, which the Norwegian Sámi Parliament endorsed when they established the SEEC (Sámediggi 2019b).

Sámi peoples' right to self-determination is enshrined as a right in the UN Covenant on Civil and Political Rights, mainly articles 1 and 27 (UN 1966), ILO Convention 169 on Indigenous and Tribal Peoples in Independent States (ILO 1989), and the UN Declarations on the Rights of Indigenous Peoples (UN 2007), expressed in the principle of collective consent. The right to self-determination is also applicable to the field of health research. Sámi collective consent is needed for any health research that includes Sámi people or individuals, in regions where Sámi are in the majority, or for research on Sámi language, culture, traditions and/or history. The Ethical Guidelines for Sámi Health Research highlight the need for a distinct ethical evaluation when research includes information about ethnicity (Sámediggi 2019a). In Norway it is prohibited to include information on ethnic background in registries (including patient records), however, ethnic background, identity, or affiliation can be collected for research purposes wherein participation is voluntary, as in SAMINOR (Datailsynet n.d).

Applying for a Sámi collective consent means that the SEEC reviews the risks and collective benefits associated with the project, assesses whether the project descriptions consider and respect the Ethical Guidelines for Sámi Health Research and how they plan to integrate this into their work, and evaluates if and how user involvement or partnership is planned (Sámediggi 2019b). Embedded in the Ethical Guidelines for Sámi Health Research are core values important for meaningful collaboration or partnership between health researchers, institutions, communities, individuals, and populations. The core values state that relationships must be based on respect (respecting Sámi language, culture, values, and traditions), reciprocity, equality, responsibility, cultural safety, and Sámi self-determination throughout all phases of a research project, irrespective of its purpose, design, or method. Sámi user involvement and/or influence of Sámi communities/informants should be present from the idea phase to project completion, so the research project results in an equitable collaboration. The guidelines stress the importance of adequate knowledge within the project team regarding Sámi health, traditions, history, traditional knowledge, and social conditions in Sápmi to ensure that research projects and participants' engagement are done in a culturally secure context, acknowledging and accommodating Sámi cultural factors, values, and practices relevant to the study's purpose. The Ethical Guidelines for Sámi Health Research emphasize that research on human biological material must be approached respectfully. This entails transparent communication regarding the purpose of collecting material, methods of collection, storage, sharing, export, types of material analysis, and destruction. The guidelines further recognize the collective rights of the Sámi people to benefits arising from the utilization of Sámi human biological material (Sámediggi 2019a).

The CARE principles

The CARE principles (Collective Benefit, Authority to Control, Responsibility, and Ethics), are universal principles intended to promote Indigenous data governance (Carroll et al. 2020). The CARE principles aim to ensure that local, tribal, or Indigenous guidelines are followed and that Indigenous peoples are given access to, use, control of, and benefit from the data. The CARE principles therefore promote Indigenous data sovereignty, which in its original form refers to data management according to the laws given by a nation-state (Carroll, Rodriguez-Lonebear, and Martinez 2019; Snipp 2016), whereas Indigenous data sovereignty in the context of data governance is translated to Indigenous peoples' right to self-determination (UN

2007) and includes exercising control over collections, ownership and application of data through governance mechanisms (Rainie, Rodriguez-Lonebear, and Martinez 2017).

The CARE principles were founded on data user guidelines developed by Indigenous communities, activists, and scholars in mainly CANZUS states, i.e. Canada, Australia, Aotearoa New Zealand, and the United States, as a response to the FAIR principles for open data (Findable, Accessible, Interoperable, and Reusable). The CARE principles promote Indigenous self-determination by ensuring that Indigenous data is shared on Indigenous terms (Carroll et al. 2020; Carroll et al. 2021). The principles are people- and purpose-orientated, intertwined with each other, mutually reinforcing, and grounded in the right of Indigenous self-determination. However, ownership of data is not explicitly addressed by the CARE principles.

The principles were designed to data ecosystems and data lifecycles, wherein the SAMINOR fits the latter. As the principles are general, there may be different ways for how to practically integrate or operationalize the CARE principles. A paper by Garba et al. (2023, 7) suggests integrating the CARE principles into “... research infrastructure such as project applications, contracting, IRB [Institutional Review Boards] review, researcher training, metadata fields, data management and repository policies, funding requirements, and community engagement.” We present how two steps in the review process, performed by the SAMINOR project board and the SEEC in conjunction with the release and use of SAMINOR data, align with the CARE main and sub-principles (CARE Principles 2019; Carroll et al. 2020).

Evaluation of the application of CARE principles

Table 1 provides an overview of the CARE main and sub-principles and how these principles correspond with two steps of the research application review process that oversee Sámi people’s interests. The two steps are the SAMINOR project board, which assesses if the use is in accordance with participants’ consent and the SAMINOR’s purpose, and the SEEC, which ensures that the Ethical Guidelines for Sámi Health Research, such as Sámi user involvement/partnership, are followed. Figure 1 summarizes what needs to be addressed in the future to obtain complete compliance with the CARE principles.

Discussion

The two steps in the review process serve as an example of how to achieve a responsible and culturally sensitive management of health survey data on the Sámi people and their communities that corresponds with



Figure 1. The CARE principles are intertwined with each other. The texts outside the coloured circle note some challenges faced when applying the two-step review process overseeing Sámi rights in health data (i.e. SAMINOR data) and the CARE main and sub-principles. © Authors, licensed by CC BY-NC 4.0.

Table 1. Two steps in the research application review process, conducted by SAMINOR's project board and the SEEC, and their correspondence with the CARE main (in bold) and sub-principles (with a number) (CARE Principles 2019; Carroll et al. 2020).

<i>The CARE main- and sub-principles</i>	<i>1st step of review: SAMINOR project board</i>	<i>2nd step of review: SEEC</i>
Collective benefit. <i>Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data.</i>		
<i>C1. For inclusive development and innovation.</i>	Yes. Any use of SAMINOR data should give benefits to the Sámi and the multi-ethnic populations in the region.	Yes, given that equality in partnership gives innovation and development from a Sámi perspective.
<i>C2. For improved governance and citizen engagement.</i>	Yes, partially. SAMINOR data is important for decision-making in health issues in rural areas and for Sámi policy development.	Yes. Ensures that the Sámi people/individuals are included as partners.
<i>C3. For equitable outcomes.</i>	Yes. Govern that research projects measure potential ethnic differences in health outcomes (Sámi vs non-Sámi).	Yes. Governs Sámi self-determination through participatory research.
Authority to control. <i>Indigenous Peoples' rights and interests in Indigenous data must be recognized and their authority to control such data be empowered. Indigenous data governance enables Indigenous Peoples and governing bodies to determine how Indigenous Peoples, as well as Indigenous lands, territories, resources, knowledge and geographical indicators, are represented and identified within data.</i>		
<i>A1. Recognition of rights and interests.</i>	Yes. Participants in the SAMINOR have given a prior, free, and informed consent.	Yes. The SEEC aims to protect Sámi collective rights and interest in data.
<i>A2. Data for governance.</i>	Yes. The SAMINOR project board aims to ensure that research is relevant and beneficial to the Sámi and multi-ethnic populations in the region.	Yes. The establishment of SEEC aims to empower Sámi people and increase Sámi self-determination by requiring Sámi partnership.
<i>A3. Governance of data.</i>	Yes. The SAMINOR project board governs the release and use of SAMINOR data.	Yes. The Norwegian Sámi Parliament governs the use of research data through SEEC, especially information on ethnic belonging/identity/affiliation.
Responsibility. <i>Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self-determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous Peoples.</i>		
<i>R1. For positive relationships.</i>	Yes. The project board ensures that users of SAMINOR data have Sámi cultural and historical understanding of what the data and the epidemiological variables collected represent and how to use them, for example, the use of Sámi ethnicity/affiliation.	Yes. SEEC requires a description of how "equality" in partnership is planned.
<i>R2. For expanding capability and capacity.</i>	Yes, partially.	Yes. The SEEC is given the capacity to safeguard the creation, collection, and application of Sámi health data.
<i>R3. For Indigenous languages and worldviews.</i>	Yes, partially. The data collected in SAMINOR is from a "Sámi point of view", i.e. collected by Sámi researchers and in SAMINOR 3, with mixed methods design.	Yes, partially
Ethics. <i>Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.</i>		
<i>E1. For minimizing harm and maximizing benefit.</i>	Yes. The overall aim with the project board is to ensure that users of SAMINOR data minimize harm and maximize benefits to the Sámi and multi-ethnic populations living in the regions.	Yes. The SEEC aims to secure that health research do not cause harm, i.e. stigmatize or portray Sámi people, culture, or knowledge as "deficit", or poorer or stereotypical.
<i>E2. For justice.</i>	No. Not specifically addressed by the SAMINOR project board.	Yes.
<i>E3. For future use.</i>	Yes. Data from the SAMINOR used in research projects should be deleted after the project is ended.	No. Future use and reuse of data are not addressed in the Ethical Guidelines for Sámi Health Research.

Abbreviations: SEEC, Sámi Ethical Expert Committee for Sámi Health Research; CSHR, Centre for Sámi Health Research.

the CARE principles. The focus of the SAMINOR project board is mainly to ensure that planned research projects comply with participant consent, fulfil SAMINOR's aims (i.e. collective benefits for Sámi and the broader society), comply with research ethics, and oversees that data users have Sámi cultural knowledge. The SEEC ensures that planned research projects comply with the Sámi Ethical Research Guidelines for Health Research and actively promote equality in partnerships, and shared decision-making between researchers and Sámi individuals, peoples, or communities. Moreover, both processes aim to provide tangible benefits for the Sámi and the broader population residing in the investigated areas.

Our evaluations of the CARE principles (CARE Principles 2019) with the two steps in the review process suggest that the main and sub-principles of "collective benefits" are to a large extent fulfilled. However, as SAMINOR has limitations with regard to the age spans and geographical regions included, it is likely that those that the study is restricted to will benefit more than those not included.

The second main principle "authority to control", with its sub-principles, are largely fulfilled as the two steps in the review process is a system developed by the Sámi Parliament together with Sámi academics for governing use of Sámi health research data. The first sub-principle, "recognizing rights and interest," is fulfilled as data from SAMINOR is not released unless individual and Sámi collective interests have been

reviewed. Overall, the two steps in the review process acknowledge that Sámi people need data and protocols, similar to the Ethical Guidelines for Sámi Health Research (Sámediggi 2019a), to safeguard Sámi rights and interests in data. The second sub-principle, “data for governance,” is exactly what SAMINOR provides. SAMINOR may be one of a few, if not the only, sources of data that provide information on the health and living conditions of the Sámi people as it includes data disaggregated by ethnicity, i.e. data for good decision-making by Sámi and non-Sámi politicians. However, the data from SAMINOR has its limitations regarding who were invited to participate and where from, which challenges whom the data may be relevant for (generalizability). The third sub-principle, “governance of data,” is addressed as the two steps in the review process are conducted by Sámi members or Sámi representatives with insight knowledge about SAMINOR, Sámi culture, history, societies, and/or languages, which enables them to know what acceptable and necessary research is, through a Sámi lens.

The first of the responsibility sub-principles “for positive relationships” is recognized by both review processes, which ensure that knowledge about SAMINOR or Sámi cultural knowledge is included in research through partnership with Sámi academics or Sámi informants/knowledge holders. After SAMINOR 2 (Broderstad, Hansen, and Melhus 2019), the CSHR, which manages the SAMINOR, shared information from the collected survey with the participants by hosting public meetings in all the municipalities where data was collected, by writing newspaper articles, and by social media. CSHR also produces reports on health and living conditions to the administration of municipalities included in the survey and to national governing bodies, so that health policies and management could become research-based. These efforts may also contribute to the second sub-principle (R2) about enhancing data literacy in the population. In public meetings, information is conveyed face-to face, whereas newspapers together with reports make research data more available as these are written in a non-academic language and often in Norwegian or Sámi, which is easier to grasp for people as compared to scientific articles.

The third sub-principle, “for Indigenous languages and worldview” (R3), seems to be accomplished as Sámi academics with language and cultural knowledge have contributed to and conducted the SAMINOR. However, the various questions have not been validated for the Sámi people, i.e. whether a question measures the same phenomenon in the Sámi and non-Sámi contexts. The SEEC demands “equality” in the partnership with Sámi knowledge holders and those collecting/using Sámi data. However, this may be difficult to operationalize as “equality” in a partnership must be negotiated and may mean different things for the researcher and for the Sámi partner/knowledge holder (Østensjø and Askheim 2019). Moreover, according to our interpretation, the sub-principles “expanding Indigenous capability and capacity within infrastructure” (R2) together with “for Indigenous languages and worldview” (R3), addressed the importance of making institutions and data holders aware of and responsible for designing infrastructures responsive to Sámi needs, languages, worldview, and lived experiences. This means that institutions and data owners need to accept that Sámi people require additional means to safeguard their data due to the history of misusing research data (skull measurements that claimed Sámi inferiority: Evjen [1997]; Kyllingstad [2014]). The R2 and R3 sub-principles are linked closely to the last main principle and will be discussed more in the next paragraph.

Concerning ethics, both its main and sub-principles are addressed well by the current Ethical Guidelines for Sámi Health Research (Sámediggi 2019a), especially the first sub-principle guiding to “minimize harm and maximize benefit”. Additionally, a general ethical review is conducted by the REC review board, usually after SEEC and the SAMINOR project board have given their approval. The second sub-principle “for justice” addresses Sámi representation from the relevant Sámi community to adjust for the imbalance in power and resources. However, imbalance in power, for example, regarding who sets the research question and agenda, might not be solved even if Sámi are partners in all stages of research. Strengthening Sámi partnership by building the capacity of Sámi partners/users, for example, through education, can make Sámi partners/users capable of becoming equal partners. Moreover, although the SAMINOR project board does not address injustice directly, CSHR managing the SAMINOR was founded to address injustice in health data, i.e. lack of data and knowledge on Sámi people. Similarly, the establishment of SEEC addresses Sámi self-determination in health research, which contributes to rectifying former injustice in research concerning the Sámi.

The third sub-principle, “for future use”, is not explicitly addressed by either of the two steps in the review process as these often consider applications case-by-case and do not require a description of future use and

reuse of data in the review application forms. For example, the SAMINOR project board does not have specific protocols addressing procedures if journals request access to data to reproduce the results, other than prohibiting sharing of SAMINOR data. However, journals can request access to SAMINOR data in connection with publishing articles and are subject to the same requirements to data access as researchers. Future reuse of research data needs attention as there is a movement towards open research data and reuse of data. Therefore, enriching metadata to research data, including aggregated data, by using labels, notices or tags addressing provenance and directing users on limitations and obligations (Anderson and Hudson 2020), would be useful. Moreover, metadata on provenance would provide the necessary capacity for the Sámi people to safeguard Sámi interests in data.

The Proposal for Ethical Guidelines (Kvernmo et al. 2017) prepared the grounds for the Ethical Guidelines for Sámi Health Research (Sámediggi 2019a), which the Sámi Parliament has endorsed. The Proposal for Ethical Guidelines was based on collections of ethical frameworks for Indigenous peoples mainly from the CANZUS nations. Therefore, it might not be surprising that there is an overlap and integration of the CARE principles in the review process conducted by the SEEC. Although there is great compliance between the CARE principles and the two steps in the review process, there are still gaps in the ability of Sámi people to govern their interests in data and exercise data sovereignty. The distinction in the sub-principles “data for governance” and “governance of data” can be translated to the availability of data that enables people to govern their interests and needs and, hence, practice self-determination through the use of data in health issues and in general. Importantly, as long as data on Sámi ethnicity is not available in censuses or administrative registries, Sámi people lack “good data” on themselves at the same detailed level as the majority non-Sámi population in Norway. Therefore, Sámi people cannot govern Sámi interests and needs on the same terms as the majority non-Sámi population (Mestad and Dawson 2020).

The CARE principles are highly relevant for Indigenous and Sámi data and open the discussion of what might be “best practices” for Indigenous data governance in general. At the heart of the two steps in the review process and through the CARE principles lies an acknowledgement of the historical injustices and fear of misuse of data that Indigenous and Sámi people faced in research. Therefore, targeting the CARE principles for example by measures at the institutional level to safeguard Sámi interests in data, may contribute to rectifying historical injustice, and promote Sámi self-determination. However, one critique of the CARE principles is that they do not address possession or ownership of research data, as compared to the First Nations Principles of OCAP®, standing for Ownership, Control, Access, and Possession (FNIGC n.d.). Indigenous and Sámi people have the right to exercise self-determination, also with respect to research data (ILO 1989; UN 2007), and to fully exercise this right, it might be argued that Sámi should have data sovereignty, i.e. have control of the ownership of their research data. Therefore, the principle of “authority to control” may not have achieved its full potential in this case, because SAMINOR data is owned by UiT and not in the hands of the Sámi people. Jennings et al. (2023) recognize Indigenous ownership of data as a step for institutions and researchers in applying the CARE principles and recognizing Indigenous data sovereignty.

Despite this shortcoming in achieving Sámi data sovereignty for SAMINOR, a comparable two step governance process may be applicable and useful for other research areas. A scoping review examining if Indigenous data governance protocols were used in health research using routinely collected health data demonstrates that Indigenous data governance is forthcoming and in place in many countries (Engstrøm et al. 2024). The review counted 85 articles from 2013 to 2022, mostly including Aboriginal Australians, Torres Strait Islanders, Alaska Natives, American Indians, and First Nations. Among these, 34 described some characteristics of Indigenous data sovereignty practices, i.e. Indigenous peoples have control of the data, no sharing of the data due to ethical and privacy concerns, and the need for approval at the tribal level if data should be available for research.

Research institutions collecting and storing data can embed Sámi interests and expectations into data collections and infrastructures managing research data and act on the responsibility to increase Sámi people’s capacity and capability for data sovereignty on several levels. This could for example be done by finding innovative measures to safeguard Sámi data in data infrastructures, by endorsing the CARE principles to current data management, and by shared ownership of Sámi research data.

Conclusions

This article describes two steps in the review process put in place to ensure Sámi governance of SAMINOR data. These two steps serve as an example of how the CARE principles are operationalized in a Sámi health research context. The CARE principles have not explicitly been addressed to a Sámi context, but we find compliance between the two steps in the review process applied to SAMINOR and the CARE main and sub-principles. However, reuse or future use of Sámi research data has not been explicitly addressed other than the SAMINOR project board prohibiting sharing and reuse of data after the end of a project. Journals requesting access to SAMINOR data in connection with published articles are subject to the same requirements to apply for data access as researchers. Interestingly, the CARE principles do not address ownership of research data explicitly, but to have Indigenous data sovereignty, it is expected that data is owned by the Indigenous peoples themselves, as is not the case for the SAMINOR data.

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