



BMJ Open Our health, our research. Identifying public health research priorities among children and youth in a multiethnic population: protocol for a community-based participatory health research priority survey

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ABSTRACT

Introduction Emphasis on public involvement (PI) in health research has increased in the last 20 years. However, there is limited literature on PI in planning and conducting population-based health research. This study aims to identify child and adolescent health research priorities among children and stakeholder groups in Northern Norway by inviting PI groups to collaborate with researchers to develop and conduct a research priority survey.

Methods and analysis This is a community-based participatory research project. The methods for research prioritisation are informed by those developed by the James Lind Alliance. In addition, the survey design and engagement plans are developed in extensive collaboration with child and youth stakeholder groups. Nine PI groups have met three times to develop an anonymous child and youth health research priority survey, as well as strategies for recruitment and dissemination of results. All 5th–10th grade pupils in the Finnmark region will be invited to participate in the survey, as well as caretakers and adults working for and with children and youth. The survey results will be analysed in collaboration with the PI groups, and research priorities checked with existing research literature.

Ethics and dissemination The study is registered and approved by the Data Protection Authorities at the Finnmark Hospital Trust and the Expert Committee for Sami Health Research. Descriptions of methods applied and the survey results will be published in popular and scientific publications.

INTRODUCTION

The Arctic regions are facing challenges related to demographics such as a declining population, emigration from small municipalities and general weaknesses in the rural community infrastructure.¹ The North Norway

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study adheres to the United Nations Convention on the Rights of the Child Article 12 stating that every child has the right to express their views in all matters affecting them, and to have their views taken seriously.
- ⇒ The community-based participatory methods applied in the design of this study ensure public voices to be heard.
- ⇒ This health research priority survey is developed through a participatory process and will not be assessed for validity before use.
- ⇒ Strong public involvement in defining research priorities may potentially lead to disappointment if the results are not reflected in future research agendas.
- ⇒ Using a single survey link ensures anonymity, but allows for the possibility of participants taking the survey multiple times.

is characterised by rural, coastal and border areas. The northern region of Norway has a highly heterogeneous population with large cultural and socioeconomic differences and several ethnic minorities, comprising a population of approximately 75 000 inhabitants over a 46 600 km² area (a population density of 1.61 p/km²). Overall, life expectancy in the region is the lowest in the country, with notable variation between communities.^{2–3} Particular challenges relate to inequality in health and welfare service provision and access to competent care. In a cross-sectional national survey in Norway, youth in the Finnmark region reported more depressive symptoms, more loneliness, increased use of alcohol and more sexual harassment compared with other

regions. In addition, they reported less satisfaction with their own health and local environment.⁴ By involving and working with members of the public, our long-term aim is to reduce differences and contribute to increased quality, competence and efficiency in public health. The Finnmark Hospital Trust has initiated this research project in collaboration with municipal and regional authorities, as well as UiT The Arctic University of Norway and the Norwegian Women's Public Health Association (NKS).

Emphasis on public involvement (PI) in health research has increased considerably in the last 20 years. The proposed impacts of PI are increased research quality, relevance and credibility. It has been suggested that participating as equals in research can empower public participants and increase data accessibility relevant for the community.⁵⁻⁷

Traditionally in health research, academic researchers and research funders decide and drive research agendas. The assumption is that their agenda is, or will be, relevant to patients, caretakers, health professionals, policy makers and other potential research users.⁸ However, numerous reports suggest a mismatch between researcher's prioritisation and societal wishes and needs.⁸⁻¹⁰ Initiating PI late in the research process and providing public members with a singular management role (eg, in a steering committee) is found to result in little impact, compared with early and thorough engagement across the research cycle (from inception of the study idea through to disseminating results).¹¹

Some initiatives seek broad and early agreement on the priorities for health research. Examples of this are the James Lind Alliance Priority Setting Partnerships,^{12 13} the 'Dialogue Model – the BhURN project' developed by the Vrije Universiteit Amsterdam¹⁴ and 'A prospective vision' by the Fondation Motrice, France.¹⁵ These multistakeholder dialogues aim to let concerned parties such as patients, public members, formal and informal caregivers and community representatives collaborate with researchers and funders to prioritise, plan, conduct and disseminate research agendas.¹⁶ The above-mentioned initiatives may expand and go beyond the top-down user approach, thereby providing a more democratic model for knowledge production.¹⁷

A major concern in health research is decreasing participation rate over time.¹⁸ A recent Finnish study confirms numerous reports demonstrating that participation rates in health examination surveys have decreased in all subgroups of the population.¹⁹⁻²¹ However, the participation distributions of occupational class and level of education changed prominently over the last 20 years, resulting in an accelerated decline among groups with low occupational class and educational levels.¹⁸ One argument for PI is quality enhancement, including participation and retention strengthening.²²⁻²⁵ Evidence suggests that involvement from the public will make it easier to recruit members predicted to have high non-participatory rate, for example, delegates of low occupational class and educational level.^{19 26 27}

At the same time, preparing and completing a study in the North Norway demands particular awareness about local history. The former is justified by the assimilation and marginalisation of minority populations (online supplemental table S1), enforced by the Norwegian state since the late 18th century.²⁸ This issue includes Sami and Kven cultural and linguistic devaluation, yet also unethical medical research in treatment of biological material within early race hypothesis exploration, as well as colonisation of indigenous Sami areas. Hence, PI in child and adolescence health priorities is necessary for research quality improvement and participation and for balancing dominance and power in knowledge production.

The distribution of representatives among public advisors remains controversial in current PI.²⁹ Some researchers have called attention to a need for greater clarity with respect to the constitutions of publics and various deliberate methods.³⁰ However, to attain complete representativeness is not practically feasible for every research project. While most research on PI focus on defining terms, proposing methods and analysing practices within disciplines, less is known on process and aims when selecting involvement participants and their representativeness of the population at large.³¹⁻³³ It is therefore important to acknowledge motives and promoting factors that make stakeholders participate in research planning, and thereby reduce possible tokenism in health research.

A common practice when involving patients and public representatives is to capture former and current patients and carers' experiential knowledge about the research question; typically, by informing, consulting with and engaging public representatives with relevant lived experience during development of the research and in decision-making processes.³⁴ The rationale is that their knowledge from lived experience will complement the scientific expert knowledge that influences the formulation of research questions, hypotheses and study design.¹⁶ Recently, some authors have emphasised impact of PI on broader initiatives, containing large samples (eg, whole genome sequencing, biobanks and genome editing).^{29 34 35} However, most reports and reviews about PI impact are based on clinical trials.^{9-11 36} To our knowledge, there is limited literature evaluating PI in planning and completing a multipurpose population-based health survey. Knowledge of the design, feasibility and impact from multistakeholders on public health prioritisations is therefore warranted. In addition, the proposed study focuses on child health in a multiethnic population. Taken together, such democratically generated health knowledge will complement current knowledge³⁷⁻⁴³ for PI in health research.

METHODS AND ANALYSIS

Study aims

This study aims to identify democratically generated public health priorities in Finnmark, Norway.

The study objectives are to:

- ▶ Identify public health priorities from the perspectives of children and stakeholders in child public health.
- ▶ Disseminate the results broadly to enable specialist healthcare, municipalities, the County Municipality and the County Governor to act based on the identified priorities.

Study design

This study will apply both quantitative and qualitative methods. We will describe demographical variables, rating and ranking of health research topics and qualitatively examine the respondents' written comments from an open-ended survey question. The design is based on community-based participatory research informed by the James Lind Alliance methodology. The study has PI in all stages of the research process. The main output of the PI is an anonymous digital self-administered survey for stakeholders in child and youth health and well-being in Finnmark. In this context, we define stakeholders broadly to include the children and youth themselves, as well as adults that share an interest in the health and well-being of young people, both as employees, volunteers and/or caretakers. This includes both administrative levels as well as people working with and for children and youth in their daily work. The digital health research priority survey will be conducted among 5th–10th grade primary and lower secondary school pupils, and among caretakers and adults working with or for children (both employees and volunteers) in the Finnmark region. The survey will invite the respondents to: (1) grade each of the 16 child and youth health research topics derived from PI group workshops, (2) prioritise the top three research topics and (3) allow the respondents to state their own top research topic(s) not covered in the survey (open-ended question). Additionally, the respondents will provide demographic variables for descriptive quantitative analysis.

The coproduction process

PI groups

We have strategically recruited members for PI groups by personal invitation and snowball sampling in five preselected municipalities representing the diversity of the Finnmark region. The participation is based on written consent. We have established a total of nine PI groups with representation across Sami, Kven, Norwegian and immigrant groups in the relevant areas: four groups of upper secondary school pupil representatives and five groups of health and social care, school, municipality, parent and carer representatives. Each group consists of four to eight individuals to ensure broad public representation across social, geographical and cultural settings. This includes variations in education/occupation (teachers, school principals, child and healthcare workers, nurses, youth club workers, church employees, police, advisors, politicians, etc), country of origin, urban and rural residency, ethnicity, preferred language and interests (sports, drama, gaming, etc).

PI approach and methods

Researchers and stakeholders (including children) have coproduced a population-based survey to be used in Finnmark's multicultural communities. Stakeholders are also involved in designing recruitment and dissemination strategies to optimise representativeness and dissemination of results. The coproduction methods with stakeholders draw on creative, flexible and culturally sensitive methods and coproduced with our partners and the groups themselves. We have used a qualitative participatory methods approach to document and evaluate the coproduction, so that characteristics of successful code-sign impact can be published widely for replication elsewhere. The team designed engagement activities in line with Lundy's Voice model.⁴⁴ This model suggests that four conditions are needed for meaningful involvement. First, a safe and inclusive space to share views. Second, appropriate information and facilitation to express their views. Third, an audience to hear their views. Fourth, opportunities for their views to have an impact. We created flexible and diverse avenues for involvement in the development of the survey as outlined below.

Training of public collaborators and researchers

To support a common understanding of the coproduction process, all PI members and researchers have attended either an online 'Public involvement in research' training programme or a pre-recorded introduction to PI in research prior to the initial PI group workshop.

Groupwork to coproduce the survey

Following the training, each PI group met three times over a period of 6 months (total of 27 meetings). Special attention was given to the different cultural backgrounds and first languages of people in the groups, for example, Sami, Norwegian. The establishment of relationships with the groups and the research team included joint decisions on which language to use in discussions, and how the organisation of the groups could be made sensitive to cultural preferences.

The first coproduction meeting with each group focused on establishing group identity, getting to know each other and agreeing terms of engagement. The group members were invited to share ideas for how we could work together to cocreate the survey, as these might have emerged during the training workshop. The researchers did not narrow the scope of possible research topics in the discussions with the PI groups. However, the discussions were initiated with an emphasis on identifying topics the PI members thought were affecting child and youth health in the region. The researchers prepared tools that the groups used in the cocreation work, adapted to the PI group members and based on continuous use of feedback following each meeting. The tools were informed by existing literature on creative methods in research^{45–47} and included the following: review and critique of previous population surveys conducted elsewhere, priority tools to agree the most important and



least important questions or themes to discuss and task-based discussions about what helps and hinders engagement in surveys. An example of a priority tool used in meetings was ranking themes or questions that could go into the survey by placing cards with descriptions of these on a pyramid, also called a q-sorts grid. In between meetings, researchers produced survey drafts, based on what the members said. The drafts were then reviewed and rewritten based on feedback and discussions in subsequent meetings. This also included feedback on universal design, for example, linguistic adaptations, the use of graphics and slider functionality for grading and the use of audio file instructions. The selection of research topics was based on feedback and discussions in PI group meetings. We initially agreed to include 10 research topics in the survey. However, in subsequent discussions with the PI groups we expanded to 16 topics to avoid the exclusion of important topics as defined by the PI group members.

In parallel with survey content completion and design, the researchers have consulted the groups on how the survey best might reach out to the Finnmark population and how to ensure a representative population sample. Group recommendations and advice from individuals met through informal approaches were compared with literature on recruitment and dissemination strategies. Similar engagement was initiated in regard to survey result dissemination.

The survey will be piloted within the respective networks and organisations of the PI members. Qualitative feedback and suggestions of improvements after piloting will inform a revision of the questions and clarifying items to establish the utility of the questionnaire. Finally, inclusion criteria and recruitment strategies for the digital survey have been developed and adjusted in collaboration with PI groups to facilitate high attendance and broad representation.

Conducting the health research priority survey

Survey participants and recruitment

Participants invited to the survey are 5th–10th grade pupils (10–15 years of age) in all primary and lower secondary schools in Finnmark (58 schools, approximately 5000 pupils), and employees and volunteers in all 19 municipalities working with or for children and youth. This includes employees working with or for children and youth on political level, in administration and in health and social care services, and volunteers working in interest organisations, sports teams, cultural activities, youth clubs, churches, etc. Additionally, parents of all 5th–10th grade students will be invited. We will invite schools to conduct the survey in a classroom setting during school hours. The class teacher will introduce the survey based on pre-distributed instructions (manual and video-recorded instructions). We will recruit employees and volunteers by email invitations in collaboration with municipal and organisation administrations and by publicly available contact information. Caretakers will be informed of the study and simultaneously invited to

participate through relevant and established communication platforms between schools and caretakers (email, handouts, digital platforms/apps, etc).

In 2019 (latest updated county statistics, SSB/Statistics Norway), Finnmark had a total population of approximately 75 000, whereas the youth population (5th–10th grade pupils) was approximately 5000. A total of approximately 8500 families (couples and single parents with children 0–17 years of age) were registered in Finnmark in 2019. The number of teachers in primary and lower secondary schools in Finnmark was approximately 1500, and additionally 500 other employees (other occupations) were involved in pupil work at primary and lower secondary schools. Furthermore, school nurses, physiotherapists, occupational therapists, child protection consultants and child and youth consultants employed in municipalities and the County Municipality were approximately 500. Other health and social care workers and administrative employees involved in child and youth health, social care and education have proven difficult to determine.

Sample size calculation

The total number of participants in this survey will depend on the range of our recruitment strategy and the schools' ability and desire to collaborate in the survey implementation among primary and lower secondary classes in the region. Based on the formula^{48 49}

$$\text{sample size} = \frac{\frac{z^2 \times p(1-p)}{e^2}}{1 + \left(\frac{z^2 \times p(1-p)}{e^2 N} \right)},$$

where N=population size, e=margin of error and z=level of confidence 1.96, we have estimated a minimum of 357 completed survey responses for the pupil and adult populations, respectively, to attain a 95% confidence level with 5% margin of error (table 1).

The survey consists of five demographic variables indicating municipality of residence, age categories (primary school (5th–7th grades)/lower secondary school (8th–10th grades)/adults (<18years)), self-perceived identity and dominant language(s). Part 2 consists of 16 research

Table 1 Sample size estimation with 10% and 5% margins of error

Population size	Sample size	
	95% confidence level, 10% margin of error	95% confidence level, 5% margin of error
Pupils 5th–10th grades, 5000	95	357
Caretakers, estimated 50 000	95	357
Employees involved with children and adolescents, estimated 3000	94	341

Box 1 Overview of 16 research topics

1. Fashion and body image issues.
2. Social media habits and screen time.
3. Loneliness and alienation.
4. Use of alcohol and other substances.
5. Leisure activities.
6. Beliefs and religion.
7. Culture and identity.
8. Harassment, violence and violations.
9. Nature-based activities.
10. Travel far or move to attend school or find a job.
11. Polar nights and days in Finnmark.
12. Poor economy.
13. Healthcare services.
14. Physical activity.
15. Mental health.
16. Living with impairments.

topics (box 1) to be rated on an 11-point numerical scale (0–10) measuring individuals’ perceived importance for further research on the topics.

Part 3 consists of a priority setting exercise, ranking three of the previous topics on first, second and third places, respectively. Part 4 consists of one open-ended question, asking for any other research topic related to child and youth health not covered previously in the survey. The survey is developed and administered using REDCap, a browser-based metadata-driven electronic data capture software. The survey is set up for single survey login to ensure anonymity.

Time period

The survey will be conducted during the first quarter of 2023 (figure 1). The length of the data collection phase will allow for adaptation to the local context of schools and municipalities.

Data analysis plan

The survey will provide both rating and ranking of the PI-driven research topics as well as open-ended questions and comments indicating peoples’ areas of priority for better public health research. Descriptive statistics on frequencies, central tendencies and dispersion in

each topic will be reported and explored in IBM SPSS Statistics version 28.0.1.0, based on literature recommendations.⁵⁰ Frequencies in ranking will be explored and ranking frequencies will be reported. Differences in demographical groups will be analysed with parametric or non-parametric comparisons of means dependent on normality, group size differences and sample size. All written comments relating to the respondents’ proposed research topics in part 4 will be examined qualitatively and coded for emerging categories and themes by two independent members of the research team (ELI and GB). Themes and discrepancies will be discussed, and a final scheme of themes will be prepared. In the analysis, we will categorise and refine the results into summary research questions that are clear and understandable, and addressable to research using search tools for systematic reviews (eg, PICO^{Patient/Problem/Population, Intervention, Comparison, Outcome}/SPIDER^{Sample, Phenomenon of Interest, Design, Evaluation, Research type})^{51–53} where appropriate. Similar or duplicate questions from the open-ended question will be combined. Out-of-scope questions will be compiled in a separate list for documentation of the analytical process. The summary questions will be checked against existing literature by conducting brief searches for systematic reviews, and details on types and sources of evidence will be documented. Questions inadequately addressed by previous research will be compiled along with details on types and sources of evidence used to check priorities.

ETHICS AND DISSEMINATION

Written consent was obtained from each participating PI group member, including parent consent for participants under 16 years of age. For research purposes, the written consent included permission to record the PI workshop meetings.

Applying a novel and innovative participatory methodology approach for PI will enable collaborative research on the part of scientists, practitioners, service users and the public. Participatory research specifically seeks dissenting views essential for the process of knowledge production.^{54 55} The project adheres to the Ethical Research Involving Children (ERIC) guidelines and best

Our Health - Our Research Gantt chart	2022				2023			
	1	2	3	4	1	2	3	4
Public involvement in planning the survey								
Establish Public Involvement Groups	■	■						
Development of questionnaire and strategies for recruitment and dissemination		■	■					
Piloting the survey among stakeholder groups			■	■				
Conducting the health research priority survey in Finnmark								
Recruit participants and conduct the survey					■	■		
Analysis of results and comparison to existing research literature						■	■	
Popular and scientific dissemination of results							■	■

Figure 1 Project timeline.



practice statements,⁵⁶ and responds to the United Nations Convention on the Rights of the Child Article 12,⁵⁷ which states that every child has the right to express their views in all matters affecting them and to have their views taken seriously. We have aimed to address barriers for involving children, such as opportunities to participate,⁵⁸ scheduling of time and arenas for meetings,⁵⁹ power dynamics between adult researchers and children, potential vulnerability⁶⁰ and establishing contact with school health services.

The study implies no new treatments or extra examinations. Personal data protection assessment has been submitted and approved by the Data Protection Authority. Sami collective consent of the study is provided by the Ethics Expert Committee for Sami Health Research. We will adhere to the ERIC guidelines and best practice statements.

The authors represent a variety of professional and experiential positions, such as healthcare professionals in both primary and specialist healthcare (physiotherapists, medical doctors, occupational therapists), family counsellors, advisors and leaders in public administrations responsible for regional public health, academic scholars experienced in both public health, patient and public involvement and indigenous research and persons holding user and caretaker experiences. All but one live in the region. The authors represent both Norwegian and Sami origins and bring various complementary perspectives on child and youth public health in the region.

We plan for coauthorship with the PI members of scientific articles, participation on conference presentations, holding workshops in the municipalities, collaboration with schools and communication of research results in multiple languages through media platforms and popular science channels.

DISCUSSION

This project aims to identify population-based priorities for better health and welfare services. To meet this aim, the study brings together a comprehensive cross-sectoral collaboration between the Finnmark Hospital Trust, Troms and Finnmark County, the County Governor, Sør-Varanger and Kautokeino Municipality, the Guidance Center Northern Norway—NKS, researchers at UiT The Arctic University of Norway, the University of Exeter and public members and service providers. Results from the priority survey will provide an important knowledge base regarding children's public priorities in health in the region. This will enable the Troms and Finnmark County Municipality, the County Governor, municipalities, professionals and user organisations to target interventions to accommodate the public opinions, needs and prioritisations. The project is highly policy relevant since we seek to explore and implement novel strategies to democratise and balance the power relations in knowledge production in multiethnic populations. The democratisation of new knowledge production is essentially viewed in the light of

regional, historical and cultural contexts. By designing a project in which the multiethnic population themselves identify public health priorities and communicate them to authorities, communities are empowered to make a change. Moreover, by applying scientific methods, this action will address warranted needs about specific local challenges. Findings, and methods used, will provide a template for other regions to target sustainable goals concerning preventive health, social inequalities and natural and cultural heritage protection.

This study will be close to policy making and service provision, as highlighted by the collaborating project group and its members. In the longer term, the project may contribute to strengthening health promotion and improve communities' capacity to reveal important areas to further investigate, develop and plan service provision. Through the partnership design and collaboration with public and service groups across sectors an immediate effect is ensuring responsive, inclusive, participatory and representative knowledge production. While the Finnmark region is unique in Norway, it has similarities with other remote regions globally, for example, Canada, Australia, New Zealand and the USA. We expect our findings to be of relevance to other areas in the world where indigenous people and minority and majority populations live together. Our approach will address strategies to identify public priorities at common interest that ensure an affirmative effect for academia. Finally, it may counteract a major concern within applied science, namely a declining interest and attendance among the public.

We anticipate that the results will facilitate discussions and the implementation of regional and local interventions based on the identified public priorities.

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