Improving digital mental health services with and for national minority, Indigenous and refugee youth in Norway: The InvolveMENT research project protocol

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Table of Contents

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Abstract

Background: Worldwide, minority youth less commonly receive culturally sensitive mental health services than the majority peer population. In Norway, limited research exists on the mental health and service use among youth from national minority (Forrest Finns, Kven/Norwegian Finns, Jews, Roma, and Romani), Indigenous (Sámi), and refugee backgrounds. Although the Norwegian government provides a public communication channel for youth, including mental health information and support, digital services have not been adapted to meet the needs of these groups. There is no research to determine the use, acceptability, effectiveness, cost-effectiveness and safety of these services for these youth.

Objective: The main aim of the InvolveMENT project is to improve the mental health of national minority, Indigenous and refugee youth. The project's objectives are, for these groups of youth, to: (1) Determine mental health and digital support needs, and possible barriers and facilitators to service use; (2) Assess use of and satisfaction with digital services to meet their mental health needs; (3) Explore their perspectives on digital mental health services; (4) Develop recommendations which can be used to adapt digital services to meet their needs and rights; and (5) Assess the use, acceptability, satisfaction, effectiveness, cost-effectiveness and safety of adapted services.

Methods: The four-year InvolveMENT project consists of four phases: 1) Establishing a longitudinal cohort consisting of national minority, Indigenous and refugee youth, using surveys to assess their mental health, wellbeing, digital support needs, utilization and satisfaction with digital services, and possible barriers and facilitators to service use. 2) Conducting qualitative interviews with minority youth to explore their perspectives, and synthesizing data from phase 1 and 2 for a mixed methods analysis. 3) Involving youth, and healthcare and other professionals to develop proposals to adapt and improve the existing digital services. 4) A randomized controlled trial (RCT) and a qualitative study to evaluate the adapted services.

Results: Cohort and qualitative study designs are completed. An ethics application has been submitted, and recruitment is scheduled to begin after its approval.

Conclusions: The InvolveMENT project has the potential to enhance the accessibility and quality of healthcare services, early interventions, reduce inequality in service provision for minority groups, and strengthen collaboration between youth, public and research organizations. Through this, it has the potential to improve mental health of youth from these groups. Findings might be transferable to other minority groups, both nationally and internationally. Clinical Trial: ISRCTN21223142. Available at

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Trial registration: **ISRCTN21223142** https://doi.org/10.1186/ISRCTN21223142

Keywords: Indigenous; national minority; refugees; youth; mental health; digital services; Norway

Competing Interests: None

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Introduction

About ten percent of youth worldwide are diagnosed with mental disorders [1]. Internationally, youth from Indigenous and national minority groups have poorer mental health than the general population. For example, a systematic review found that Indigenous populations had suicide rates 20 times higher than the non-Indigenous populations, with the highest rates in youth aged 15–24 years [2].

The Indigenous population in Norway is the Sámi. There is limited knowledge about the mental health of Sámi youth. In the time period from 1970 to 1998, suicide rates among Sámi youth were twice that of the majority population of youth in Norway [3]. Internationally, asylum seeking and refugee youth have high rates of mental disorders such as post-traumatic stress disorder, anxiety and depression [4–7]. In Norway, up to 42% of asylum seeking and refugee youth have been found to fulfil the criteria for psychiatric disorders [8]. A recent review reporting on the mental health of the Roma population in Europe found a higher proportion of mental disorders among children compared to the majority population and limited access to mental healthcare [9]. There is however no knowledge about the mental health in Norway among youth belonging to the five national minority groups: Forrest Finns, Jews, Kven/Norwegian Finns, Roma and Romani [10].

Mental healthcare service use among national minorities, Indigenous and refugee youth

The mental healthcare needs of national minority, Indigenous and refugee youth in Norway have only been assessed to a limited extent [8,10,11]. Service use may be low and drop-out rates high. There are cultural and language barriers, difficulties in developing trust, marginalisation of minority groups, a lack of immigrant staff and interpreters, and ineffective care coordination [12,13]. Limited effort has been made to adapt services to meet their needs, in spite of the right to health pursuant to the International Covenant on Economic, Social and Cultural rights (art. 12), made into Norwegian law in 1999. Although the Sámi Norwegian National Advisory Unit – Mental Health and Substance Use (SANKS) offers services to support the Sámi population, youth more often seek help from friends, partners or family members [11,14], and scientific knowledge about their digital service needs is lacking. Apart from a single hospital-based mental health clinic, the Transcultural Centre at Stavanger University Hospital [15,16], no clinics in Norway specialise in or have adapted services to meet the mental health needs of asylum seeking and refugee youth. Studies which focus on the different groups of youth’s cultural background (i.e. culturally sensitive studies) are needed to determine how to develop services that are culturally relevant and appropriate to support minority youth [17–19].

Digital mental healthcare services for national minority, Indigenous and refugee youth

Young people often use the internet to access information about mental health [20]. Digital mental health interventions may facilitate service access for national minority, Indigenous and refugee youth by addressing geographic, economic and social disparities [21,22]. However, there is an evidence gap and culturally sensitive, effective and safe modes of digital healthcare delivery must be further developed and tested [22,23].

DigiUng is a Norwegian public cross-sectoral collaboration, run by the *Directorate for Children, Youth and Family Affairs*, and the *Directorate of Health*. It has developed the public communication channel *ung.no* to provide information, healthcare, and support services for youth. However, these services have not been adapted to meet the mental health needs of national minority, Indigenous, and refugee youth, and there is no research evidence regarding their acceptability, effectiveness, cost-effectiveness, and safety for these groups.

Aim and objectives

The overall aim of the *InvolveMENT* project is to improve the mental health of national minority, Indigenous, and refugee youth. This will be done by adapting digital mental health services to meet their personalised information and support needs.

The objectives are:

1) To determine mental health and digital support needs, and barriers and facilitators to service use, for national minority, Indigenous, and refugee youth.
2) To assess the use of and satisfaction with digital services, including the public communication channel *ung.no*, to meet the mental health needs of national minority, Indigenous, and refugee youth.
3) To explore perspectives of national minority, Indigenous, and refugee youth on digital mental health services.
4) To develop recommendations to be used to adapt digital services to meet the needs and rights of national minority, Indigenous, and refugee youth.
5) To assess the use, acceptability, satisfaction, effectiveness, cost-effectiveness, and safety of the adapted digital services to meet the support needs of national minority, Indigenous, and refugee youth.

Methods

Design

The *InvolveMENT* project involves a multi-disciplinary, multiphase, mixed methods research design [24] to adapt digital mental health services to meet the mental health needs of national minority, Indigenous, and refugee youth in Norway. The participants define which group(s) they belong to and this may also include asylum seekers who consider themselves to be refugees. The project will use the Trials within Cohorts (TwiCs) design to test the acceptability, effectiveness, cost-effectiveness, and safety of adapted digital services. The TwiCs design will support fast and efficient recruitment to the RCT, reduce attrition rates and increase generalizability of results [25,26]. One year rolling recruitment is used to compensate for natural attrition.

A participatory design approach is used to adapt digital services [21], involving national minority, Indigenous, and refugee youth, healthcare and welfare workers, and representatives of service providers. Close collaboration, cultural sensitivity and empowerment of participants is used to develop strong partnerships and to ensure co-ownership. The project encourages and facilitates multi-sectorial collaboration between the services and support and interest organisations for national minority, Indigenous and refugee youth; healthcare and service providers; and University based research centres. The collaborative component with active involvement of youth strengthens the relevance of the research to meet the needs of these groups of youth. Youth representatives, representatives of health and service providers, healthcare workers and coresearchers from minority groups are involved in all phases of the project, including planning, interpretation and dissemination of results [26].

Digital services provided for youth in Norway

The most commonly used digital services provided for youth in Norway is the public communication channel *ung.no* (https://www.ung.no). The digital platform aims to facilitate access to information and answer young persons’ questions, and it refers youth onto other services when needed [27]. It provides links to freely available interactive self-help tools, organisations and services where youth can chat or talk to professionals or peers, including about their mental health issues. Examples of such services include *Youth Mental Health Norway*, and *Say-it-with-words*.

Description of work packages (WPs)

The *InvolveMENT* project is divided into four work packages (WPs) as depicted in figure 1, which will be described in the following sections.

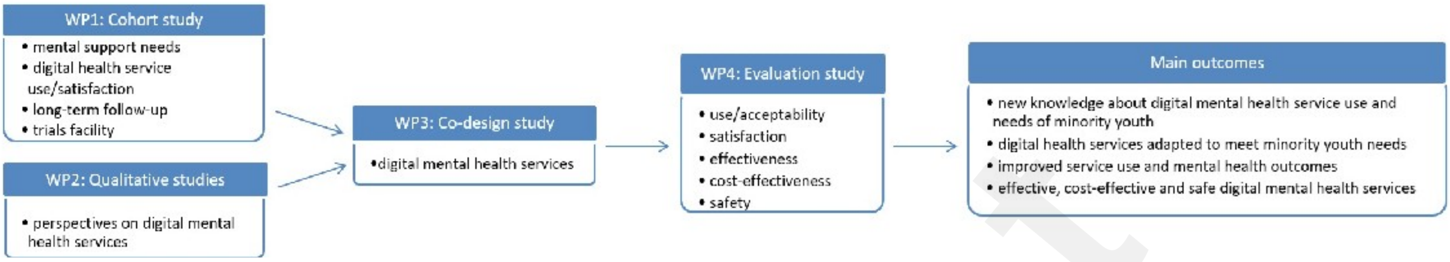

Figure 1. Work packages

WP1: Assessing needs, barriers and facilitators to service use (cohort study)

The main purpose of WP1 is to determine the mental health and digital support needs, and barriers and facilitators to service use, for national minority, Indigenous and refugee youth. Furthermore, we will assess the use of and satisfaction with the public communication channel *ung.no* and other digital services to meet the mental health needs of these groups of youth. To achieve this, we will establish a population-based cohort, consisting of 1,500 youth aged 16–25 years with national minority, Indigenous and refugee backgrounds. National minorities include Forrest Finns, Jews, Kven/Norwegian Finns, Roma, and Romani; Indigenous youth include the Sámi youth population; and refugees include those who originate from the Middle East, The Horn of Africa, and the surrounding countries.

Information about the project will be distributed through secondary schools, higher education, healthcare services, language learning centres, organisations representing the different groups of youth, social media, and other channels as appropriate for each of the groups of youth. Participants will be recruited from all parts of the country to ensure diversity in perspectives. Data will be collected at baseline, 12 and 24 months, available in most of the different youth groups' languages. A questionnaire has been adapted with input from youth minority representatives and other partners to ensure its relevance to meet the needs of the different groups of minority youth. The items include participants' demographics, self-reported mental and somatic health, life satisfaction, wellbeing, information and support needs, experiences and needs regarding digital mental health services, including knowledge, use of and satisfaction with digital services, including the public communication channel *ung.no*. To assess self-reported mental health, questions about mental health symptoms: the Patient Health Questionnaire (PHQ-9) [28], the short version Generalized Anxiety Disorder (GAD-2), as well as outcomes focusing on concerns about environmental and climate changes, war and terror, feelings of loneliness, and experiences of violence, bullying, discrimination or racism. Somatic health is reported using the Children's Somatic Symptoms Inventory (CSSI-8) [29]. Wellbeing is measured using the World Health Organization Well-Being Index (WHO-5) [30] and The Flourishing Scale [31].

The participants are asked about their use of and satisfaction with formal and informal support and/or therapeutic services (e.g. family, friends, specific providers of healthcare and other public services). Specific questions assess use of and satisfaction with digital services, including familiarity with the existing services, frequency of use, and relevance to the participants' minority backgrounds. Moreover, participants are asked about their opinions about the importance of specific aspects relating to the provision of services, including their views on the importance of the ethnic competence, knowledge about religions and language skills of the persons who deliver the services.

The survey will be available in youth groups' languages. Draft versions have been piloted in English, Norwegian, Arabic and Dari, with a total of 1,500 participants with youth coming from the majority Norwegian population and youth with immigrant backgrounds [32,33].

Data analysis will include univariate analyses for descriptive statistics, whereas factors associated with service use will be assessed using correlation analyses, regression models, multiple regression models to explore multiple predictors and adjust for confounders, e.g. generalized linear models, linear and generalized additive models for non-linear associations between predictor and outcome. Temporal changes using mixed models are used to assess factors affecting service use.

WP2: Exploring perspectives (qualitative studies)

The purpose of WP2 is to explore the perspectives of national minority, Indigenous and refugee youth on digital mental health services, including the public communication channel *ung.no*. This will be done through a series of qualitative studies.

Participants will be recruited through the cohort established in WP1. We will recruit 50 to 100 youth aged 16 to 25 years from the different groups of youth.

Data will be collected through a combination of individual and focus group interviews with the different groups of youth. The interviews will focus on youths' understanding of mental health, needs for digital services, with needs specific to culture, language and gender; pathways to mental health support; experience of service availability, approachability, acceptability and appropriateness, including trust in services and professionals. We estimate 40-60 individual interviews, and up to 17 focus group interviews with 3-7 participants in each group (table 1).

Table 1. Overview of planned qualitative interviews[1]

Youth group[2]	Individual interviews (n=39–60)	Focus group interviews (est. n=65)
Refugees[3]	15–20	2–3 (n=3–7 per interview)
Sámi	6–10	2–3 (n=3–7 per interview)
Kven	6–10	2–3 (n=3–7 per interview)
Jewish	3–5	1–2 (n=3–7 per interview)
Roma	3–5	1–2 (n=3–7 per interview)
Romani	3–5	1–2 (n=3–7 per interview)
Forrest Finns	3–5	1–2 (n=3–7 per interview)

1. The numbers of participants reflect the number of youth belonging to each group.
2. A young person may define her/himself as belonging to more than one group.
3. Includes those who have a legal status as asylum seekers.

Interviews will as far as possible be carried out in the participants' preferred language, with the use of professional interpreters as needed. Interview guides have been developed with input from representatives from the different groups of youth and the project partners. Interviews will be audio-recorded and transcribed verbatim.

The data will be analyzed using qualitative content analysis [34] or similar types of analyses. A mixed methods analysis will also be carried out by combining qualitative data (WP2) with data from the cohort surveys (WP1), using triangulation with assessment of convergence, complementarity and discrepancy between data [35].

WP3: Developing recommendations (co-design study)

The purpose of WP3 is to develop recommendations to be used to adapt digital services, including the public communication channel *ung.no*, to meet the needs and rights of national minority, Indigenous and refugee youth. This will be achived through a co-design process, including about 50 professionals and youth.

Youth from the different minority groups will be recruited through the cohort established in WP1, the interview studies in WP2, and the youth representatives and youth coresearchers in the project. Professionals will be recruited from primary and specialist health services (e.g. school nurses, psychologists, and GPs); and social welfare and other professionals (e.g. from child welfare, and employment office). A total of 6-8 workshops are planned, each including 4-7 youth and 4-7 professionals.

Data will be collected through observations and fields notes during workshops. The co-design process will also use data from the mixed methods analysis based on WP1 and WP2; youth perspectives gathered at a seminar organized with and for youth as part of the *InvolveMENT* project, and input from youth and project partner representatives during project meetings, seminars, workshops, etc.

The data will be used to develop recommendations for adaptation of digital services to meet the needs and rights of youth with minority backgrounds. Youth will be involved in planning, recruitment, and facilitation (inclusion from start to conclusion), ensuring their right to be heard at systems level pursuant to the children’s convention, article 12 [36]. The recommendations will be presented for service providers, so they may determine how to utilize these recommendations in the best way possible.

WP4: Evaluating the implemented recommendations (evaluation study)

The purpose of WP4 is to evaluate the implementation of the recommendations developed in WP3 into digital mental health services for youth. This will be done through a randomized controlled trial (RCT), accompanied by a qualitative study.

A. Randomized controlled trial (RCT)

The purpose of the RCT is to assess the use, acceptability, satisfaction, effectiveness, cost-effectiveness and safety of the adapted digital services to meet the support needs of national minority, Indigenous and refugee youth.

Participants will be recruited to the RCT from the cohort established in WP1. An estimate of 25% of these youth suffer from mild to moderately severe symptoms of depression (PHQ-9 scores 5-19) [9,12,37]. Together with an estimated drop-out rate of 20%, this indicates a sample size of 300 youth for the RCT (given an equal randomization ratio). A rolling recruitment method will be used over a period of one year. Inclusion criteria are scoring from mild to moderately severe symptoms of depression on PHQ-9. A random selection will be made to determine whether the youth will receive a link to the digital services which have been adapted as a result of WP3 (intervention group), or a link to equivalent digital services which have not been adapted according to WP3 (control group).

The RCT will use the same survey instruments as in WP1. Baseline data in the RCT is collected in the WP1 cohort at the 1-year survey (prior to changes implemented to digital services), while follow-up data is is collected at the 2-year survey.

To assess the use/acceptability of the intervention, i.e. the adapted digital mental health services for youth, we will use data from the RCT to determine the proportion of participants who report using it. An Intention-to-treat (ITT) analysis will be used to test the effectiveness of the offer of interventions, whereas an instrumental variables (IV) analysis will be applied to determine the effectiveness of the received intervention [38]. The primary outcome will be PHQ-9 at 12 months of the trial. Sub-group analyses will be carried out for different minority groups. Results will provide data on variability in depression outcomes in the different groups. Safety will be assessed by determining the proportion of participants with deteriorated mental health status (e.g. higher PHQ-9 scores). Service satisfaction will be tested by asking participants about their satisfaction with the services.

A cost-effectiveness analysis (CEA) of the intervention for youth will be carried out by undertaking a cost-consequences analysis (CCA) [39]. It will compare individuals taking advantage of the adapted services with those who do not. The analysis will take a societal perspective, relating costs associated with introducing the new intervention(s) and attributable to youths' mental health, school absence, and work productivity (if they are in work), as well as their quality of life.

B. Qualitative study

The purpose of the qualitative study is to explore youth experiences with the adapted digital services to meet the support needs of national minority, Indigenous and refugee youth, as well as the safety of and youth satisfaction with the services.

For the qualitative study the number of participants will be determined by the information power of the data [40]. We estimate that 25–45 participants will be needed. This may also include participants who were not in the RCT, but who are presented with the adapted digital services.

Data collection in the qualitative study will consist of a combination of individual and focus group interviews with the different groups of youth. The interviews will focus on participants' experiences of the adapted digital services. A total of 15-20 individual interviews and 4-8 focus group interviews, each with 3-7 participants, will be carried out. Professional interpreters will be used if needed or wanted.

We will use qualitative content analysis [34] or similar types of analyses to analyze the data. Furthermore, we will conduct a mixed methods analysis, including a combination of qualitative data with data from the RCT, using triangulation with assessment of convergence, complementarity and discrepancy between data [35].

Ethics and dissemination

Ethical considerations

The TwiCs design requests potential participants to consent to provide researchers with person-identifiable information, to be contacted again and for the data they provide to be used to assess the effectiveness of a range of interventions [25]. Only those offered the experimental intervention are informed about the non-usual care intervention. This informed consent approach is more comparable to "real world" clinical practice, and it is thought to be more ethical than the traditional “everything to everyone up front” approach to informed consent [41,42]. Use of this approach is growing with TwiCs studies obtaining ethical approval in 10 countries [40], including in youth mental health research [43].

According to the World Medical Association (WMA) declaration of Helsinki, vulnerable groups should be allowed to participate in research if it is responsive to their health needs and priorities, and they receive appropriate protection. There are strong arguments from legal and ethical points of view for carrying out this project, as the voices of these youth are rarely or never heard. They are underrepresented in medical research, in spite of public policies and legislation.

Contrary to anonymous surveys, youth in the *InvolveMENT* project provide researchers with contact information which opens up for suggesting additional healthcare support, e.g. in the event of self-harm or suicidal thoughts. We will develop safety procedures at project start to outline how healthcare professionals should act when participants need increased support or treatment referral. We will plan for culturally sensitive information and interviews for participants to minimise the likelihood of being wronged or misunderstood. Participants will be from 16 years of age, and therefore hold the legal right to make their independent decision concerning participation. Ethics approval has been granted from the Regional Committees for Medical and Health Research Ethics (ID 780840). Moreover, an application for collective consent for Sami youth participants has been approved by the Expert Ethics Committee for Sami Health Research (ID 1133459). Sensitive data will be store on a Sensitive Data Services (TSD) server.

Dissemination

A common communication strategy includes a variety of communication and publication activities (table 2).

Table 2. Overview of dissemination activities

Communication channels	Dissemination activities	Main target audiences
Scientific journals	Scientific articles	Scientific community, professionals, youth, interest organisations
Reports	Project reports	Decision-makers (national & international) e.g. the Norwegian Directorate for Children, Youth and Families, the Norwegian Directorate of Health, scientific community, Norwegian Research Council
Academic reports	PhD Theses, Master Dissertations	Scientific community, Norwegian Research Council
Book	Digital book on digital mental health services for minority youth	Education providers, professionals, youth, interest organisations
Popular science journals	Popular science articles	Scientific community, professionals, youth, interest organisations
Media (national/regional)	Interviews and articles	Youth, parents, schools, the public, professionals
Conferences/seminars	Oral & poster presentations	Scientific community, professionals, youth
Organisations	Presentations, journal articles	Youth, professionals, scientific community
Social media (e.g. TikTok, Snapchat, LinkedIn, Instagram, Facebook, X)	Brief news, video clips	Youth, parents, the public, interest organisations, scientific community

Results

We have completed recruitment to the project of youth representatives from all national minority, Indigenous and refugee youth groups which are the end users of the research. The panel now consists of 32 youth representatives. Ethics approval has been granted. A recruitment plan is developed and recruitment is estimated to start in December 2024. Draft versions of the cohort survey have been piloted in English, Norwegian, Arabic and Dari, with a total of 1,500 participants [30] and thereafter adapted with input from youth minority representatives and the other project partners. Youth minority representatives have also contributed with input to the qualitative studies. The survey is being translated into 13 languages (Arabic, Dari, Davvisámegiella [Northern Sámi], English, Farsi, French, Julevsábme [Lule Sámi], Kiswahili [Swahili], Kvääni [Kven], Norwegian, Romanés [Romanes], Tigrinja, and Åarjelsaemiengïele [Southern Sámi]).

Discussion

What does the study offer?

The *InvolveMENT* project will generate new research-based knowledge about the experiences with and needs for digital mental health services among groups of youth whose voices have only been heard to a small degree or not at all. It is the first time national minority, Indigenous and refugee youth and professionals providing services for these groups of youth are actively involved in assessing and developing digital mental health services. The involvement of these youth is novel and unprecedented. Extensive and active involvement of youth in co-design processes ensures that their needs are at the centre of the research for the development of adapted, equitable and sustainable healthcare support services.

Our ambition is to increase the proportion of minority youth seeking and receiving the digital support they need at an early stage. It may thereby contribute to early diagnosis, support and/or treatment for youth with mental health complaints. Building on existing public communication channels, we aim to develop equitable and sustainable digital mental health services that can contribute to strengthen the mental health of national minority, Indigenous, and refugee youth and help prevent development and prolongation of mental health complaints in these youth. Additionally, this is the first research project in Norway assessing the cost-effectiveness of health interventions for these youth. The trial will lay the foundation for future RCTs by determining variability in mental health among the different groups. The research will improve the quality of digital youth mental health services, making them more culturally sensitive, effective, person-centred and safe.

The setting up of a cohort using the TwiCs design offers multiple opportunities for testing other interventions during or beyond the four-year project. This is the first TwiCs design trial with these groups of national minority, Indigenous, and refugee youth. We will as part of the project expand our networks internationally and consider development of an international research project focusing on different groups of minority youth.

Limitations

The main risk of this project is the recruitment of national minority, Indigenous, and refugee youth for the cohort (at least 1500 youth) and for the qualitative study. There are no exact population figures for the included minority groups, but estimates suggest 20,000 (age group 16–25) and recruitment will take place through multiple channels. A recruitment rate of 7.5% is a conservative estimate as participation rates in youth surveys were 73–87% in the Norwegian *Ungdata* survey [44], and 77% in our pilot [33]; and minority youth will be informed that the project aims to hear their views and that they will influence service development, which will encourage participation. The substantial involvement of youth representatives and coresearchers from minority groups in the project will be a great advantage for the recruitment process.

Conclusions

The *InvolveMENT* collaborative research project will contribute to improve the quality, equity and efficiency of digital mental health services for groups of minority youth in Norway. The project will assess their use of and experiences with digital mental health services. Services can be adapted so they are culturally sensitive and meet the needs of national minority, Indigenous and refugee youth.

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We would like to thank all youth coresearchers and partner organisations for their inputs to the grant application resulting in the *InvolveMENT* project. Thank you to all the youth who have contributed to develop this project by sharing their knowledge and experiences with us, and to all partners for taking part in the project.

Authors’ contributions

PV conceived the initial project idea and led the development of the funding application. PV led the article manuscript writing process together with ER. All authors contributed to the project funding application, including their knowledge of the field of research (groups of youth and research design), and in writing parts of the funding text, as well as input to the article manuscript. AS, KLH and PV contributed to recruitment of partner organisations. LGM and LK have contributed with their perspectives as youth co-researchers. All authors read and approved the final manuscript.

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Conflicts of interest

None declared.

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Supplementary Files

Figures

Work packages in the InvolveMENT project.