The Start Young study

Health-related quality of life and pain in adolescents and associated factors; a prospective cohort study of adolescents and their parents

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Health-related quality of life and pain in adolescents and associated factors; a prospective cohort study of adolescents and their parents

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Kristiansand, October 2022

Hilde

Sammendrag

Bakgrunn: Å ha god helserelatert livskvalitet (HRLK) i ungdomstiden er viktig i seg selv. Det er også viktig fordi mye av grunnlaget for HRLK senere i livet legges i denne perioden. Tidligere studier viser at et økende antall ungdom rapporterer om psykososiale problemer og helseplager som smerte, stress og ensomhet. Dette kan føre til redusert HRLK, og indikerer et behov for fortsatt helsefremmende arbeid blant ungdom. For å forstå HRLK og smerteproblematikk hos ungdom bedre, er det viktig å undersøke faktorer som er assosiert med HRLK. Økt forståelse av faktorer som er assosiert med HRLK kan forbedre utvikling og igangsetting av kunnskapsbaserte, helsefremmende tiltak blant ungdom, og hjelpe med å identifisere ungdommer som trenger støtte og hjelp. Denne kunnskapen er relevant for ungdom, foreldre, helsesykepleiere, annet helsepersonell, lærere, politikere og forskere.

Hensikt: Den overordnede hensikten med denne avhandlingen var å utvide vår kunnskap om HRLK og smerte ved å undersøke sosiodemografiske, psykososiale, smerte-, søvn-, helsekompetanse- og COVID-19-relaterte faktorer assosiert med HRLK i et skolebasert utvalg av norske ungdommer og deres foreldre i løpet av to ungdomsår.

Metode: Avhandlingen er basert på en prospektiv kohort studie blant et skolebasert utvalg av norske ungdommer og deres foreldre, fra ungdommene var ca. 14 til 16 år. Data som omhandler HRLK, smerte, sosiodemografiske faktorer, stress, ensomhet, søvn, mestringstro, selvfølelse, helsekompetanse og COVID-19-relaterte bekymringer ble samlet inn ved hjelp av elektronisk spørreskjema. Ved første datainnsamling deltok 696 ungdom og 561 foreldre. Ved andre datainnsamling (to år senere) deltok 215 ungdom og 320 foreldre. Fire artikler er tilknyttet avhandlingen hvorav artikkel I-III er basert på tverrsnittsdata og artikkel IV er basert på longitudinelle data. Bivariate-, regresjons- og mediasjonsanalyser samt linear mixed model for repeterte målinger er brukt som metoder i artiklene.

Resultat: Artikkel I viste at 14-15 år gamle ungdom rapporterte høy HRLK. Jenter rapporterte dårligere skår på HRLK, mestringstro, selvfølelse, smerte, søvn, ensomhet og stress sammenlignet med gutter. Videre resultater viste at mestringstro, selvfølelse, ensomhet og stress var sterkest assosiert med HRLK hos ungdommene.

Artikkel II viste at 14-15 år gamle ungdom med smerte rapporterte mer stress, ensomhet og mangel på søvn og lavere selvfølelse, mestringstro og HRLK sammenlignet med ungdom uten smerte. Flere jenter enn gutter rapporterte smerte. Funnene indikerer at ungdom med vedvarende smerter kan være en sårbar gruppe. Hos ungdom med vedvarende smerte fant vi at sammenhengen mellom smerteintensitet og HRLK dimensjonene fysisk velvære, psykologisk velvære og autonomi- og foreldrerelasjon var mediert av selvfølelse, men ikke av mestringstro.

Artikkel III viste at 16-17 år gamle ungdommers HRLK var redusert ett år inn i COVID-19-pandemien sammenlignet med funn fra tidligere norske studier og europeiske normdata. Foreldres HRLK var sammenlignbar med norske normdata før pandemien. Jenter og mødre rapporterte lavere HRLK og flere COVID-19-relaterte bekymringer sammenlignet med henholdsvis gutter og menn. Videre fant vi at kjønn, helsekompetanse og COVID-19-relaterte bekymringer var assosiert med ulike dimensjoner ved både ungdommers og foreldres HRLK.

Artikkel IV viste en reduksjon i ungdommenes HRLK fra 14- til 16-års alder. For tre av de fem HRLK -dimensjonene rapporterte jenter lavere HRLK ved både 14 års alder (tidspunkt 1) og 16 års alder (tidspunkt 2) sammenlignet med gutter. Videre resultater viste at stress, ensomhet og smerte var signifikant, uavhengig assosiert med en reduksjon i HRLK endringsscore for fire HRLK dimensjoner, som betyr at disse variablene bidrar til lavere HRLK-skår ved 16 års alder sammenlignet med ved 14 års alder. Skår for fysisk og psykologisk velvære ble

redusert over tid, ungdommene skåret lavere på tidspunkt 2 sammenlignet med tidspunkt 1, og mannlig kjønn var assosiert med reduksjon i dimensjonen venner og sosial støtte sammenlignet med kvinnelig kjønn. Våre data indikerer dermed at gutter skåret lavere på venner og sosial støtte på tidspunkt 2 sammenlignet med tidspunkt 1 når man sammenligner med skår gitt av jenter. I kontrast til dette var mestringstro og selvfølelse assosiert med en økning i HRLK endringsscore for henholdsvis fire og to dimensjoner, som betyr at disse variablene bidrar til høyere HRLK-skår for de aktuelle HRQOL dimensjonene ved 16 års alder sammenlignet med ved 14 års alder.

Konklusjon: Avhandlingen gir innsikt i kompleksiteten ved ungdommers HRLK og viser hvordan smerte, stress, ensomhet, for lite søvn og COVID-19-relaterte bekymringer har sammenheng med lavere HRLK hos ungdom, og hvordan mestringstro, selvfølelse og helsekompetanse har sammenheng med høyere HRLK. Avhandlingen gir også innsikt i sammenhengen mellom HRQOL og ulike sosiodemografiske faktorer. Resultatene viser en reduksjon i ungdommenes HRLK fra 14- til 16-års alder. Ett år inn i COVID-19-pandemien viser våre resultater at 16-17 år gamle ungdommers HRLK er redusert sammenlignet med funn fra tidligere norske studier og europeiske normdata, mens HRLK hos foreldrene er sammenlignbar med norske normdata før pandemien. Avhandlingen tydeliggjør hvordan de nevnte faktorene har sammenheng med ulike HRLK dimensjoner tilknyttet ungdommers nåværende HRLK og endringer i deres HRLK, og understreker viktigheten av å vurdere og fremme selvfølelse og mestringstro som viktige resiliens-faktorer for ungdommers HRLK. Videre gir avhandlingen innsikt i smerteproblematikk hos ungdom, og viser at ungdom med smerte rapporterer mer stress, ensomhet og mangel på søvn, og lavere selvfølelse, mestringstro og HRLK sammenlignet med ungdom uten smerte. Det anbefales en individuell, helhetlig tilnærming til smerter hos ungdom samt økt fokus på resiliens-faktorers sammenheng med smerte.

Summary

Background: Having good health-related quality of life (HRQOL) during adolescence is important in itself, and a significant part of the foundation for HRQOL later in life is laid here. Previous studies show that an increasing number of adolescents report psychosocial problems and health complaints such as pain, stress, and loneliness. This may lead to reduced HRQOL and indicates a need for continued efforts in health promotion among adolescents. To better understand HRQOL and pain in adolescents, it is important to investigate factors associated with HRQOL. Increased understanding of factors associated with HRQOL can improve the ability to develop evidence-based health promotion and intervention programs and help to identify adolescents who need support and help. This knowledge is relevant for adolescents, parents, public health nurses, other health-care professionals, teachers, politicians, and researchers.

Objective: The overall aim of this thesis was to expand our knowledge of HRQOL and pain by investigating sociodemographic, psychosocial, pain-, sleep-, health literacy and COVID-19-related factors associated with HRQOL in a school-based sample of Norwegian adolescents and their parents during two years of youth.

Methods: This thesis is based on a prospective cohort study among a school-based sample of Norwegian adolescents and their parents, from when the adolescents were 14 to 16 years of age. Data on HRQOL, pain, sociodemographic factors, stress, loneliness, sleep, self-efficacy, self-esteem, health-literacy and COVID-19-related worries were collected using an electronic questionnaire. Data collection was carried out before and during the COVID-19 pandemic. At the first data collection, 696 adolescents and 561 parents participated. In the second data collection (two years later), 215 adolescents and 320 parents participated. Four papers are related to this thesis, of which Papers I-III are based on cross-sectional data and Paper IV is based on longitudinal data.

Bivariate-, regression- and mediation analyses and linear mixed model for repeated measures have been used as methods in the papers.

Results: Paper I showed that 14–15-year-old adolescents reported high HRQOL. Girls scored worse on HRQOL, self-efficacy, self-esteem, pain, sleep, loneliness and stress compared to boys. Further results showed that self-efficacy, self-esteem, loneliness and stress were most strongly associated with HRQOL in adolescents.

Paper II showed that 14–15-year-old adolescents with pain reported more stress, loneliness and lack of sleep and lower self-esteem, self-efficacy and HRQOL compared to adolescents without pain. More girls than boys reported pain. The findings indicate that adolescents with persistent pain seem to constitute a vulnerable group. In adolescents with persistent pain, we found that the associations between pain intensity and the HRQOL dimensions physical well-being, psychological well-being and school environment were completely mediated by self-esteem, but not by self-efficacy.

Paper III showed that the HRQOL of 16–17-year-old adolescents was reduced one year into the COVID-19 pandemic compared to findings from previous Norwegian studies and European norm data. Parents' HRQOL was comparable to Norwegian norms prior to the pandemic. Girls and mothers reported lower HRQOL, and more COVID-19-related worries compared to boys and men, respectively. Furthermore, we found that gender, health literacy, and COVID-19-related worries were associated with different dimensions of adolescents' and parents' HRQOL.

Paper IV showed a reduction in adolescents' HRQOL from the age of 14 to 16 years. For three of the five HRQOL dimensions, girls reported lower HRQOL at age 14 (Time 1) and at age 16 (Time 2) compared to boys. Further results showed that stress, loneliness, and pain were significantly, independently

associated with a reduction in HRQOL change scores for four HRQOL dimensions, meaning that these variables contribute to lower HRQOL scores at age 16 compared to age 14. The scores on physical and psychological well-being were reduced over time, e.g., the adolescents scored lower at Time 2 compared to Time 1, and male gender was associated with a reduction in social support and peers compared to female gender. Thus, our data indicate that boys scored lower on social support and peers at Time 2 compared to Time 1 when compared with scores given by the girls. In contrast, self-efficacy and self-esteem were associated with an increase in HRQOL change scores for four and two dimensions, respectively, meaning that these variables contribute to higher HRQOL scores at age 16 compared to age 14.

Conclusions: This thesis provides insight into the complexity of adolescents' HRQOL and shows how pain, stress, loneliness, lack of sleep and COVID-19-related worries are associated to lower HRQOL in adolescents, and how self-efficacy, self-esteem and HL are associated to higher HRQOL. It also provides insight into the relationship between HRQOL and various sociodemographic factors. The results demonstrate a reduction in the adolescents' HRQOL from 14 to 16 years of age. One year into the COVID-19 pandemic, our results show that the HRQOL of 16–17-year-old adolescents is reduced compared to findings from previous Norwegian studies and European norm data, while parents' HRQOL are comparable to Norwegian norms prior to the pandemic. The thesis clarifies how the above-mentioned factors are associated with various HRQOL dimensions related to their present HRQOL and changes in their HRQOL and emphasizes the importance of considering and facilitating self-efficacy and self-esteem as important resilience factors for adolescents' HRQOL. Furthermore, this thesis provides insight into the prevalence of pain in adolescents, and demonstrates that adolescents with pain report more stress, loneliness and lack of sleep and lower self-esteem, self-efficacy and HRQOL compared to adolescents without pain. An individual, holistic approach to adolescent pain and increased focus of resilience factors associated with adolescent pain is recommended.

List of papers

Paper I

Mikkelsen HT, Haraldstad K, Helseth S, Skarstein S, Småstuen MC, & Rohde G. *Health-related quality of life is strongly associated with self-efficacy, self-esteem, loneliness, and stress in 14–15-year-old adolescents: A cross-sectional study*. Health and Quality of Life Outcomes. 2020; 18 (1): 352.

Paper II

Mikkelsen HT, Haraldstad K, Helseth S, Skarstein S, Småstuen MC, & Rohde G. *Pain and health-related quality of life in adolescents and the mediating role of self-esteem and self-efficacy: A cross-sectional study including adolescents and parents*. BMC Psychology. 2021; 9 (1): 128.

Paper III

Mikkelsen HT, Skarstein S, Helseth S, Småstuen MC, Haraldstad K, & Rohde G. *Health-related quality of life, health literacy and COVID-19-related worries of 16- to 17-year-old adolescents and parents one year into the pandemic: A cross-sectional study*. BMC Public Health. 2022; 22: 1321.

Paper IV

Mikkelsen HT, Småstuen MC, Haraldstad K, Helseth S, Skarstein S, & Rohde G. *Changes in health-related quality of life in adolescents and the impact of gender and selected variables: A two-year longitudinal study*. Health and Quality of Life Outcomes. 2022; 20: 123.

Abbreviations

BPI:	Brief Pain Inventory
CI:	Confidence interval
COVID-19:	Coronavirus disease 2019
FEK:	Faculty of Health and Sports Science's Research Ethics Committee
GDPR:	General Data Protection Regulation
GSE:	General self-efficacy scale
HEVAS:	Health behavior survey among school pupils
HL:	Health Literacy
HLQ:	Health Literacy Questionnaire
HLSAC:	Health Literacy in School-Aged Children questionnaire
HRQOL:	Health-Related Quality of Life
LMM:	Linear mixed model for repeated measures
LPQ:	Lübeck Pain-Screening Questionnaire
MCS:	Mental component sum scores
NSD:	Norwegian Centre for Research Data
OTC:	Over-the-counter
PCS:	Physical component sum scores
PROM:	Patient-Reported Outcome Measure
PSQ:	Perceived Stress Questionnaire
QOL:	Quality of Life
RAND-36:	The 36-Item Medical Outcomes Study Short Form
REK:	Regional Research Ethics Committee of Norway
RSES:	Rosenberg Self-Esteem scale
SES:	Socioeconomic status
SD:	Standard deviation
SUS:	Pain, Youth and Self-Medication study
ULS:	UCLA Loneliness Scale
WHO:	World Health Organization

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1 Introduction

The United Nation's Sustainable Development Goal 3 highlights that it is essential for sustainable development to ensure healthy lives and promote well-being at all ages [1]. Further, the World Health Organization (WHO) [2] states, "Investments in adolescent health bring a triple dividend of benefits for adolescents now, for their future adult lives, and for the next generation. Their health and well-being are engines of change in the drive to create healthier, more sustainable societies" [2 p4].

Adolescence is an important transitional phase in life between childhood and adulthood. This life phase is central in the development of capabilities related to health and well-being; it is a period in which future patterns of adult health are established [3-5]. Most international and Norwegian adolescents report good overall health and well-being [6, 7]. However, in both international and Norwegian adolescent populations, there seems to be an increasing number who report psychosocial problems and health complaints such as pain, stress, and loneliness [4, 6-10]. Over the last two decades, pain problems in adolescents have increased and are considered to be a substantial public health challenge in industrialized countries [11-16]. This indicates a need for continued efforts in health promotion among adolescents.

My PhD study is positioned within a health promotion and public health perspective. To know how and where to intervene when aiming to promote adolescent health, knowledge about adolescents' own perspectives is needed. Thus, research reflecting their points of view is important. This considered, health-related quality of life (HRQOL) research is relevant because "HRQOL is a multidimensional construct covering physical, emotional, mental, social, and behavioral components of well-being and functioning as perceived by patients and/or other individuals" [17, 18]. Having good HRQOL during adolescence is important in itself, and a significant part of the foundation for HRQOL later in life is laid here. The WHO emphasizes that more data is required to identify the key determinants of ill health, e.g. pain, in adolescents [19]. Measuring HRQOL in adolescents is an important complement to more objective measures of health. It can provide useful information about how adolescents evaluate their HRQOL,

outline factors that influence HRQOL, and indicate how the HRQOL of adolescents might be improved. This information is relevant for public health nurses, other health-care professionals, parents, teachers, politicians, and researchers.

Research on HRQOL in adolescents complies with overall strategies for public health in Norway. The Norwegian White Paper No. 19 (2018–2019) "Public Health Report – A Good Life in a Safe Society" [20] points out the importance of health promotion from a broader perspective and emphasizes that good health and quality of life (QOL) is important not only for the individual but also for society. The report highlights that public health work involves promoting QOL and underlines that the government will prioritize early interventions to promote QOL for children and adolescents. Additionally, the Norwegian government has announced that it will develop a national strategy for QOL and that QOL will be used as a supplementary measure of societal development in Norway [21].

To better understand HRQOL in adolescents, it is important to identify and investigate factors associated with HRQOL. HRQOL is influenced by both individual and environmental characteristics [22]. There is some knowledge of factors associated with HRQOL among adolescents. However, there is a need to expand existing knowledge and investigate HRQOL in a non-clinical population and in the social context of the family. Furthermore, there is a need to expand our knowledge of pain problems among adolescents and of how pain influence on HRQOL. Based on previous research [23-33] and a thorough discussion among the researchers in the Start Young group, this thesis focus on sociodemographic factors, stress, loneliness, sleep, self-efficacy, self-esteem, health literacy and COVID-19-related factors which are all clinically relevant factors reported in previous HRQOL and pain research. Increased understanding of factors associated with HRQOL and pain can improve the ability to develop evidence-based health promotion and intervention programs and help to identify adolescents who need support and help. More knowledge of factors that may contribute to the promotion of HRQOL and a reduction in pain problems in adolescents is highly relevant for school health care. This knowledge might also be used for interventions within families to weaken the effect of a potential negative family pattern and provide preventive and targeted help and actions. There is limited knowledge of how HRQOL might change during youth years

and of any predictors of these potential changes in nonclinical samples of adolescents. Thus, it seems highly relevant to longitudinally investigate HRQOL and factors associated with HRQOL in adolescents and their parents.

My PhD study is a part of the Start Young – Quality of Life and Pain in Generations study, a Norwegian mixed-method four-year prospective study on HRQOL and pain among adolescents and their parents. The PhD study is built on data collection from baseline and the two-year follow-up of the Start Young study. Data collection was carried out before and during the coronavirus disease 2019 (COVID-19) pandemic.

This thesis and the four related papers contain several focuses: adolescents, parents, HRQOL, pain, sociodemographic factors, stress, loneliness, sleep, self-efficacy, self-esteem, HL and COVID-19-related worries. To our knowledge, no other published study has used this combination of factors to investigate HRQOL and pain in adolescents. Although pain in adolescents is highlighted as one of the main focuses of attention throughout this thesis, it is important to note that the main emphasis of this thesis is related to HRQOL in adolescents. Structured literature searches to find relevant literature on HRQOL and pain in adolescents were performed while planning the study in 2018, frequently throughout the PhD study, and lastly, in September 2022.

2 Background and theoretical framework

In this section, I will start by describing the phase of adolescence and then introduce and define QOL, HRQOL and health. I will also present Ferrans and colleagues' [22] revised Wilson and Cleary model to further explain HRQOL and its associated factors. Next, I will define pain, describe what characterizes pain in adolescents, and describe the multidimensional biobehavioral model of pediatric pain by Varni and colleagues [34, 35] to better understand the association between pain and HRQOL in adolescence. Finally, I will briefly define and describe important factors associated with HRQOL and pain in adolescents: sociodemographic factors, self-esteem, self-efficacy, loneliness, stress, sleep, COVID-19-related worries, and HL. The description of the factors COVID-19-related worries and HL will only be described in relation to HRQOL. All the above-mentioned factors will be further elaborated during section 2 and in the review of previous research in section 3.

2.1 Adolescence – an important transitional phase in life

Adolescence is defined by the WHO as the life phase between childhood and adulthood, from ages 10 to 19 [36]. This is the definition I chose for this thesis. The Latin word *adolescens* means growing up [3], indicating that adolescence is a phase of human growth and development. This period is influenced by puberty and brain development – leading to new sets of behaviors and capacities [37, 38], which also makes it a vulnerable and challenging period in life with respect to an increase in autonomy and independence from caregivers and social role transitions [3, 39, 40].

Adolescence is considered an important transitional phase in life that is essential to the development of capabilities related to health and well-being; it is a phase where future patterns of adult health are established [3, 4, 37]. According to the WHO [41], adolescents have a key role to play in the response to their own well-being and health. However, to play this role, they need protection from harm, on the one hand, and support to make independent decisions, on the other [41]. The ways in which adolescents make decisions affecting their health and well-being are highly influenced by peers [4]. Viner and colleagues [37] emphasize that positive and supportive peers, together with safe and supportive families and

schools, are crucial in helping adolescents attain good health and well-being in the transition to adulthood.

Adolescents' lives are shaped by their environment. For most adolescents, the key arenas in which their lives take place are together with family and friends and in relation to school and leisure activities [42]. In recent decades, society has been characterized by not only increasing individualization and materialism that impacts adolescents' lives through more opportunities, freedom, and flexibility but also a feeling of more responsibility related to self-discipline and self-realization that puts their mental health under pressure [42-45]. Social media and an increased use of information technology have become an integral part of adolescents' lives, leading to not only benefits but also negative impacts on their well-being [7, 46-49]. Furthermore, the spread of COVID-19 leading to a pandemic [50] has affected adolescents' lives, as well as society in general, in an exceptional way through national and international strategies aiming to limit transmission and health risks due to COVID-19 [30, 50, 51].

2.2. QOL, HRQOL and health

My PhD study focuses on the term HRQOL; however, the terms QOL and health has highly influenced the literature and research field. Often, the terms HRQOL and QOL and also HRQOL and health are used interchangeably. Thus, I will start by introducing and defining all of these terms. The next two subsections are partly based on an exam I wrote during my PhD period [52].

2.2.1 QOL

The concept of QOL, which appeared in the mid-1950s, represents a general striving toward a comprehensive or holistic view of the individual [53]. QOL concerns the value a person provides to different areas of their life. But trying to provide a conclusive and shared definition of QOL and indicating how to best measure it are still true challenges. The values recognized are unique for each person, and people vary as to how important different areas of life are to their QOL [54]. Two important perspectives within QOL are the eudaimonic and hedonic well-being views. The eudaimonic view focuses on meaning, purposefulness, strengths and self-realization resources, while the hedonic view relates to happiness and well-being in terms of life satisfaction, positive emotions

and pain avoidance [55, 56]. The eudaimonic view may not be as clearly articulated by adolescents as the hedonic. This might be because concepts like purposefulness and self-actualization are too abstract, and that a different vocabulary is needed to capture these aspects [57]. Still, some studies have successfully measured aspects of eudaimonic wellbeing in children and adolescents [58, 59]. It is clear that QOL means different things to different people and that QOL takes on a different meaning according to the area of application [60]. Different QOL definitions reflect the disciplines from which they are derived, including psychology, sociology, medicine, and nursing. In the literature, it is often stated that there is no generally agreed definition of QOL and that there is significant conceptual confusion regarding QOL. According to Ferrans and colleagues (2005), the term QOL has been used to mean a variety of constructs, such as well-being, life satisfaction, health status, physical functioning, symptoms, psychosocial adjustment, and happiness [22]. Overall, however, there are some characteristics that seem to be key aspects of the QOL concept: 1) QOL is a concept that expresses a subjective experience, it concerns the person's own perception of their situation. 2) QOL is a multidimensional concept that most often encompasses physical, psychological, social, and existential aspects of life. 3) QOL is a normative concept where the meaning and the values an individual has in life is central [60-63].

QOL in the health context may be viewed at several levels, and Spilker [63] have presented a well-known model that divides QOL into three levels portrayed as a pyramid (see Figure 1). The first level on top represents overall assessment of well-being, and this may be described as an individual’s overall satisfaction with life. This level is concerned with for example, a person's happiness, satisfaction, meaning or realization of goals linked to life as a whole. The second, intermediate level in Spilker’s pyramid represents generic assessment of the broad life domains: physical, psychological, social, economic, and spiritual. This level is often referred to as the level of HRQOL and is concerned with the person's experience of general health conditions. According to Spilker, the exact identity and number of QOL domains may vary. Nonetheless, these broad domains cut the overall pie (level 1) into different pieces of domains (level 2) [63]. Spilker’s third level on the bottom includes the components of each specific domain. For example, it may include disease-specific symptoms or disability such as a person's experience of conditions linked to specific diseases or

ailments. The three levels interact with- and can impact each other [61, 63]. Spilker's second level, representing HRQOL, is the focus of this PhD study.

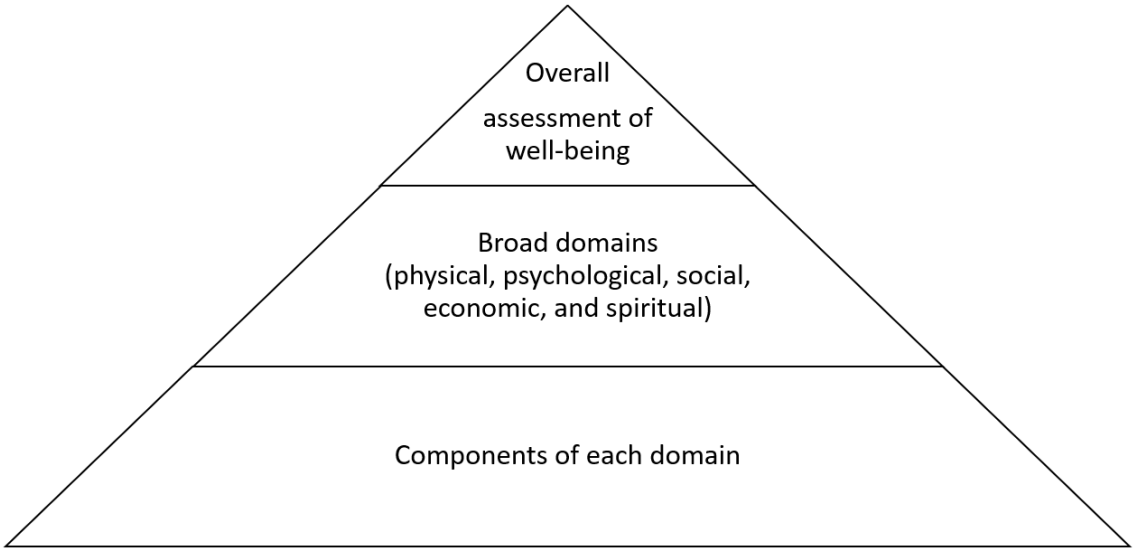

Figure 1. Spilker's three-level model for QOL [63].

2.2.2 HRQOL

Considering the aim of this thesis (see section 4), it was considered most appropriate to investigate HRQOL in this PhD study, as we were interested in aspects of QOL that are related to health. According to Ferrans and colleagues (2005), the term HRQOL was intended to narrow the QOL-focus to the effects of health, illness, and treatment on QOL by excluding aspects of QOL unrelated to health (e.g., political, cultural, or societal attributes) [22]. The term HRQOL is now widely used in health science, but it has not been easy to reach consensus of the meaning of this concept either due to, among other things, different opinions regarding what aspects or dimensions that should be included. However, quantitative, and qualitative empirical data from children, adolescents, and adults support conceptualizing HRQOL into dimensions of physical, emotional and social function and wellbeing [64-66]. As an example, the results from a large study involving 8-17-year-old children and adolescents from six different countries showed that physical, emotional and particularly social wellbeing and function was of relevance for HRQOL in both boys and girls from all participating countries [64]. The multidimensionality of HRQOL measures may provide clinicians and researchers with information about the impact of health conditions (e.g., pain) on different HRQOL dimensions. Further, the

multidimensionality may serve as a framework for identifying and developing strategies to promote HRQOL and develop tailored interventions in adolescents [17, 67].

In this PhD study, HRQOL is defined as: "a multidimensional construct covering physical, emotional, mental, social, and behavioral components of well-being and functioning as perceived by patients and/or other individuals" [17, 18]. This definition by Ravens-Sieberer and colleagues emphasizes a holistic perspective and the subjectivity/uniqueness of HRQOL as experienced by the individual person. It should be noted that the description of HRQOL presented in Papers I-IV is differently worded. In Papers I-IV, HRQOL was described as follows: "HRQOL is a multidimensional construct that includes the individual's subjective perspectives on the physical, psychological, social, and functional aspects of health" [17]. The intention behind this rewriting of the definition by Ravens-Sieberer and colleagues was to emphasize the subjectivity related to HRQOL and describe aspects of health that are included in HRQOL.

2.2.3 Health

Health and HRQOL have considerable common content, but also important differences. They can be overlapping concepts with a common core, but each with its own independent part [68]. The WHO defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [69]. The inclusion of social well-being and the emphasis on more than the absence of disease are considered key aspects of the WHO definition. This definition of health was one of the earliest statements that recognized and stressed the importance of the dimensions physical, mental and social in the context of disease [60]. But the concept of health, even when defined broadly and positively such as the WHO-definition, is theoretically distinct from HRQOL [70] HRQOL is more comprehensive than health per se, and include aspects of the living circumstances and the environment that may or may not be affected by health [70, 71]. The concept of health tends to be more related to a biological, natural scientific understanding of a human being than do HRQOL, which is more related to a psychological and humanistic framework of understanding. As an example, health may include objective and external criteria such as genetic or physiological factors. However, such factors would not be

included in HRQOL which is more related to internal, subjective assessments. According to Mæland, health is more related to performance and function, while HRQOL to a higher degree reflects a persons' experience and condition [68].

2.2.4 Conceptual model of HRQOL

There is a need for causal models that clearly indicate the elements and determinants of HRQOL [22, 72]. Several conceptual models and theories have been proposed to further explain HRQOL. Within health-care disciplines, the Wilson and Cleary [73] model has been widely used for different groups and populations, including adolescents [74-77]. The model describes the relationship between biological/physiological conditions, symptoms, and HRQOL-related aspects and how these are in turn influenced by characteristics of the individual and of the environment. These relationships can be thought of as existing on a continuum of increasing biological, social, and psychological complexity, and the Wilson and Cleary model depicts this continuum. The model has been subject for repeated empirical testing, and a strong support for the model have generally been provided by these tests [72, 78]. The model is considered to be a middle-range theory of HRQOL that combines the social paradigm with the medical paradigm [79].

Ferrans and colleagues [22] have suggested a revised version of the Wilson and Cleary model with the purpose of providing suggestions for applying each of the components and of facilitating HRQOL use in health care and nursing (see Figure 2). They have revised the original model in three substantive ways: 1) adding arrows to show that both individual and environmental characteristics influence biological function, 2) deleting nonmedical factors, and 3) deleting the labels on the arrows, which tend to restrict characterization of the relationships Further, they provide a theoretical background for the main components of the model and give examples of instruments for measuring these components. The five boxes in the center of the model are five types of measures of patient outcomes; 1) biological and physiological factors (focusing on the function of cells, organs, and organ systems), 2) symptoms (focusing on subjective experiences – e.g., physical, psychological, and emotional symptoms), 3) functioning/functional status (focusing on the individual's ability to perform particular defined tasks), 4) general health perceptions (subjective in nature, integrating all the components that come earlier in the model), and 5) overall

QOL (subjective well-being related to how satisfied or happy the individual is with life as a whole). These five levels are further influenced by characteristics of the individual (e.g., symptom amplification, personality, motivation, values, and preferences) and their environment (e.g., psychological support, social and economic support, and social and psychological support). However, it is emphasized that the associations are complex and that the horizontal arrows in the model indicate what is hypothesized to be the dominant causal associations. In many cases, there may also be reciprocal or bidirectional associations [22].

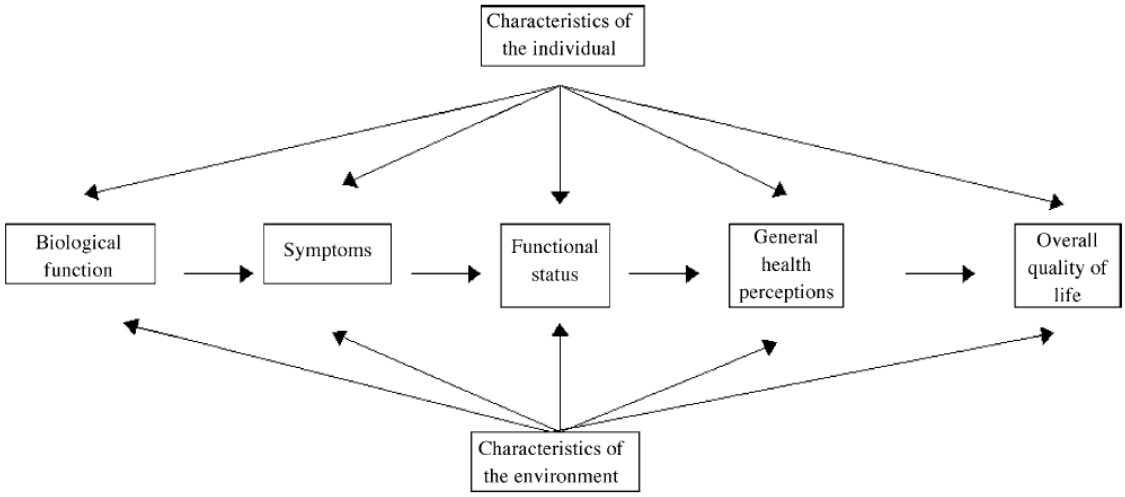

Figure 2. Conceptual Model of HRQOL. Revised Wilson and Cleary Model by Ferrans and colleagues (Used with permission from the author).

According to a systematic review of the literature by Bakas and colleagues [80], Ferrans et al.'s [22] revised model appears to have the greatest potential to guide HRQOL practice and research. Bakas and colleagues [80] recommend Ferrans and colleagues' model because they added environmental and individual characteristics to the popular Wilson and Cleary model to better explain HRQOL. A recent systematic review showed that the revised model has been used in several studies to guide HRQOL research, and that previous research provides support for the model's hypothesized associations [81].

In this thesis, I will use the revised model of Ferrans and colleagues [22] to provide a theoretical understanding of the relationship between HRQOL and the variables included in my PhD study. Related to my study, the characteristics of

the individual include age, gender, ethnicity, self-esteem, self-efficacy, sleep, and HL. The environmental characteristics include loneliness and who the adolescents live together with, with the main focus on their parents (including socioeconomic status (SES) assessed through the parents' educational status, job status, and economy), parental pain factors, the parents' HRQOL, and (indirectly) the COVID-19 pandemic. The symptoms include pain, stress, and COVID-19-related worries. Finally, general health perceptions are presented as HRQOL (see Figure 3). The components of biological function, functional status, and overall QOL are not included in Figure 3 as they are non-applicable considering the variables included in this PhD study. In this study, HRQOL will be assessed by KISDSCREEN-27 (measuring five HRQOL dimensions) and KIDSCREEN-10 (a singular index that represents global HRQOL). These instruments are presented in detail in section 5.5.2. Although KIDSCREEN-10 represents global HRQOL, this is not considered to be the same as overall QOL given that KIDSCREEN-10 is derived from ten items in KIDSCREEN-27 [18, 82] and thus not measuring how satisfied or happy the individual is with life as a whole. However, although not all components from the model of Ferrans and colleagues are relevant for this PhD study, the proposed theoretical framework depicted in Figure 3 is considered to be useful to provide a theoretical understanding of HRQOL in adolescents and how the variables included in this PhD study may be related to HRQOL. I believe this model is especially useful to broaden the understanding of how characteristics of the individual and of the environment might influence symptoms and HRQOL. Previous research that provides support for this theoretical framework's hypothesized associations will be further elaborated in chapters 2 and 3 of this thesis, but I will provide three examples to support the usefulness of this model regarding our study's variables; 1) Studies have shown that adolescent symptoms such as pain is associated with lower levels of HRQOL [24, 83-85]; 2) Previous studies have also found an association between individual characteristics, such as self-esteem, and HRQOL and between self-esteem and pain, showing that higher levels of self-esteem are associated to higher levels of HRQOL and less pain [23, 26, 86, 87]; 3) Studies have found an association between environmental characteristics, such as loneliness, and HRQOL and between loneliness and pain, showing that higher levels of loneliness are associated to lower levels of HRQOL and more pain [88-90].

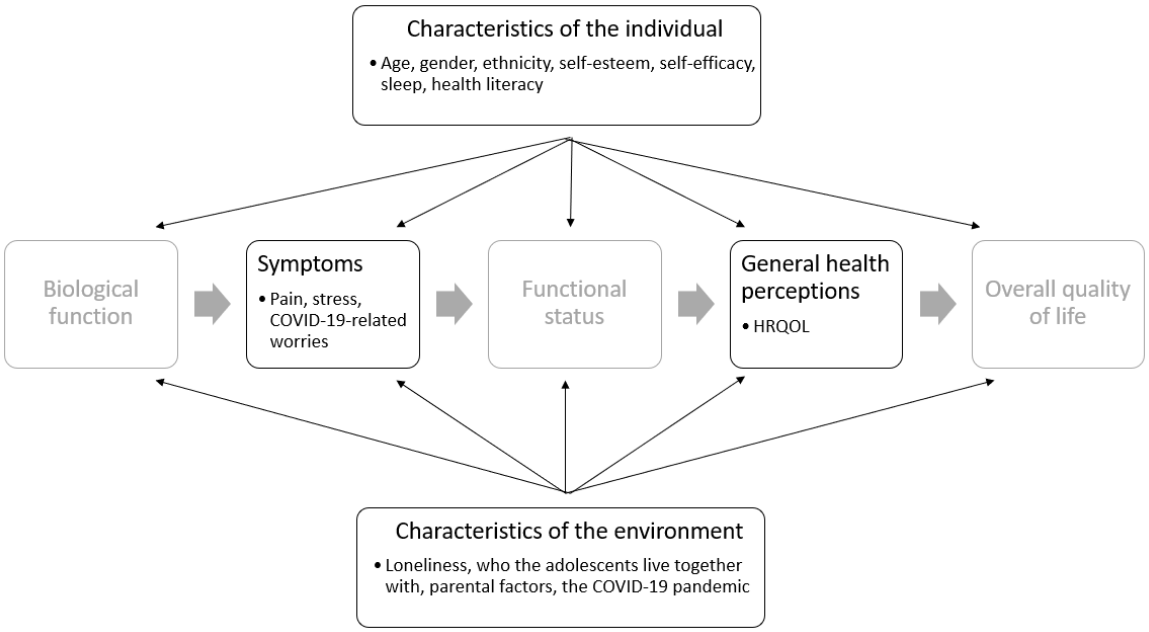

Figure 3. Theoretical model of HRQOL and associated variables in this PhD study, inspired by the revised Wilson and Cleary Model by Ferrans and colleagues.

2.3 Pain

Several pain definitions exist; however, the definition by the International Association for the Study of Pain (IASP) has become internationally accepted and adopted by health-care professionals, researchers, and organizations such as the WHO. In this PhD study, we use the IASP's revised pain definition to define pain, which is as follows: "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" [91]. Moreover, IASP emphasizes that pain is always a subjective experience and that a person's report of pain should be respected and accepted as such [91]. The importance of accepting the person's experience of pain is also highlighted in McCaffery's well-known definition: "Pain is whatever the experiencing person says it is, existing whenever he says it does" [92].

2.3.1 Pain in adolescents

Over the last two decades, pain problems in adolescents have increased and are considered to be a substantial public health challenge in industrialized countries

[11-16]. In a recent study involving Norwegian adolescents, one in five adolescents reported neck/shoulder pain, and among these, most reported neck/shoulder pain co-occurring with other pain problems and depression [93]. Pain in adolescents is a complex phenomenon influenced by biology and sociodemographic, within-person (e.g., self-efficacy, self-esteem, stress, sleep), and between-person (e.g., peer relationships, family/parents, school) factors [12, 14, 33, 91, 94-99]. Pain problems in adolescents can negatively affect their daily functioning and daily life, leading to negative consequences such as peer relationship problems, school absenteeism and impaired school functioning, stress, poor sleep, a high consumption of over-the-counter (OTC) analgesics, avoidance of sports and activities, reduced HRQOL, and the risk of recurrent pain in adulthood [24, 33, 83, 100-111]. Pain lasting longer than three months is defined as persistent or chronic pain [112]. Persistent pain is considered highly prevalent in adolescents [8], and it may have a negative impact on the individual, family, and society [113-116].

2.3.2 A holistic model for understanding pain in adolescence

Considering the wide complexity of adolescent pain, it has been recommended to view pain in light of a holistic model [117]. In this thesis, I will use the multidimensional biobehavioral model of pediatric pain by Varni and colleagues' [34, 35] to better understand the association between pain and HRQOL in adolescence (Figure 4). This model illustrates that pain may arise from different precipitants or conditions, such as stress, injury, and disease, and that intervening variables such as genetics, age, gender, perceived social support, coping strategies, family environment, and cognitive appraisal may influence pain and HRQOL [34, 35]. In my PhD study, selected factors in adolescents (sociodemographic factors, stress, sleep, self-esteem, self-efficacy, loneliness, HRQOL, and pain characteristics) and in their parents (sociodemographic factors, HRQOL, and pain characteristics) were included. Regarding these factors, we consider stress to be a precipitant within this model, and we consider sociodemographic factors, sleep, self-esteem, self-efficacy, loneliness, and parental factors to be intervening variables. All the selected factors have been identified as factors associated with pain and HRQOL in adolescents [12, 14, 23, 25, 28, 33, 84, 94-98, 113, 118-122].

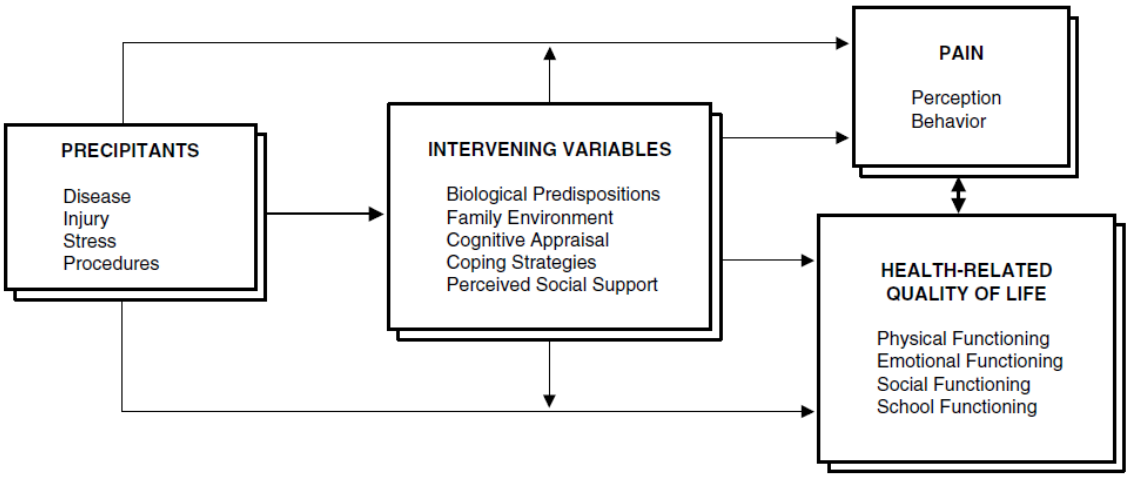

Figure 4. A holistic model for understanding pain in adolescence (Used with permission from the author).

2.4 Factors associated with HRQOL and pain in adolescents

The reason for why we chose to investigate pain, sociodemographic factors, self-esteem, self-efficacy, loneliness, stress, sleep, HL and COVID-19-related worries as HRQOL associated factors was based on previous research [23-33] and a thorough discussion among the researchers in the Start Young group. Other known HRQOL associated factors such as depression, anxiety, pubertal development, bullying, social media use and body image could also have been interesting to focus on. However, the Start Yong study is positioned within a health promotion perspective, and we considered it important to not only focus on maladjustment and risk factors, but also include resilience and protective factors (such as self-efficacy and self-esteem) in our survey. Because the Start Young's survey had to be completed within one school hour (45 minutes) at the baseline data collection, we had to limit the number of questions included in the survey. I have previously defined and described HRQOL and pain. In this section, I will briefly define and describe the remaining factors included in our study.

2.4.1 Sociodemographic factors

Sociodemographic factors combine a person's social and demographic factors, such as age, gender, family structure, marital status, ethnicity, migration background, religious affiliation, education level, employment status, and

household income. Such factors are often used to describe and characterize research samples, as well as assess the factors' impact on the outcome.

From birth and through life, there exist gender differences related to biology and physiology, the onset of puberty, and cognitive, emotional, and social development [3, 38, 123], indicating it is necessary to assess gender. Further, research on the development of health, health behaviors, and well-being during adolescence has emphasized the need to consider SES and investigate possible socioeconomic inequality in health [13, 26, 97, 124-131]. SES usually refers to information about education, employment status/occupation, and income. Low SES is associated with short education, low occupational status, and low income. A person's state of health seems to follow a step-by-step pattern: the higher an individual is in the socioeconomic hierarchy, the better their health and well-being. This phenomenon is often called the social gradient in health [130, 132, 133]. It has been concluded that health inequalities during adolescence exist across countries [131, 134]. Studies have shown that families with low SES have lower HRQOL scores, reduced physical and mental health, and they report pain more frequently [12, 13, 26, 97, 121, 124-130, 135-138]. Family structure, including who the adolescents live together with, and ethnicity are other important factors related to adolescents' health [13, 139-142].

2.4.2 Self-esteem

Self-esteem refers to a person's positive or negative attitude toward themselves [143] and is considered an important protective or resilient factor in life [144]. Resilience is an interactive concept that refers to the finding that some individuals have a relatively good psychological outcome despite an experience of adversity or the presence of risk factors [145]. Self-esteem is suggested to play a crucial role in the development of internal processes during adolescence, such as building identity and extrafamilial relationships [146], and higher levels of self-esteem are associated with higher levels of HRQOL and less pain in adolescents [23, 26, 86, 87]. Factors such as male gender, higher levels of parental care, and higher parental education are related to higher levels of self-esteem [147].

2.4.3 Self-efficacy

Self-efficacy is a concept that represents a self-confident view of one's capability to deal with certain stressors in life [148]. Bandura defines this concept as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives," and it may determine how one thinks, feels, motivates oneself, and behaves [149]. Self-efficacy is considered an important resilient or protective factor in adolescents [25, 148] and is associated with higher levels of HRQOL and less pain [25, 27, 150, 151]. According to Schwartzer and Warner, "a general sense of self-efficacy can help adolescents be resilient by helping them overcome stressful situations without suffering long-lasting harm" [148].

2.4.4 Loneliness

Loneliness is a negative feeling experienced when there is a discrepancy between desired interpersonal relationships and the relationships an individual perceives they currently have [152]. Accordingly, loneliness is an emotionally unpleasant feeling that emphasizes a cognitive element because it requires the perception that one's interpersonal relationships are not living up to one's expectation [153]. To not feel lonely, the physical presence of other people in one's social environment is insufficient; one needs to feel *connected* to people. That being the case, one can *be* temporarily alone but not feel lonely if one feels highly connected to one's family and/or friends – even at a distance [154]. Loneliness is a common emotional distress that can become an affliction for most people. Even high-status, popular individuals can feel lonely [154].

Adolescence is considered a life period in which biological, cognitive, social, and demographic changes may influence loneliness [155]. Considering adolescence is characterized by social changes, an increase in autonomy and independence from caregivers, and an increased importance of peer interaction [3, 156], adolescents are at risk of feeling lonely [155]. In adolescents, loneliness, especially when experienced over a prolonged period or often, is associated with physical and mental health problems, pain problems, low self-esteem, and reduced HRQOL [88-90, 153, 154].

2.4.5 Stress

Stress is a concept that, according to Lazarus and Folkman [157], refers to "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" [157 p19]. This definition indicates that stress arises when there is a mismatch between a person's perceived resources and the environment's expectations. An important premise in this understanding of stress is that the person's experience can be changed by adjusting either their experience of their own resources or the demands and expectations of the environment [157, 158]. If a person can deal with the stress that occurs, stress does not have to lead to strain. However, stress that persists over time and exceeds the person's resources can be harmful to their health and development [158]. Symptoms of stress in adolescents have been associated with lower HRQOL, problems such as pain, a high consumption of OTC analgesics, and reduced mental health and well-being [23, 86, 98, 159-162].

The many physiological and psychosocial changes during adolescence influence the type of stressors adolescents experience and how they respond to them [163]. It has been suggested that stress in adolescents is related to changes and trends in society, an increase in autonomy and independence from caregivers, social role transitions and expectations of being successful in several aspects of life, such as school performance, peer relationships, sports, and social media [5, 7, 49, 158, 164-166].

2.4.6 Sleep

Sleep plays a critical role in normal functioning during adolescence [167]and is a primary aspect of adolescent development [168]. Adolescents' ability to feel, think, learn, and behave during daytime hours is critically influenced by sleep [168, 169]. Moreover, adolescents with insufficient amounts of sleep report problems such as daytime sleepiness at school [168]. Insufficient sleep may contribute to poorer well-being and more health complaints (e.g., pain) in adolescents [33, 170, 171], and sleep is considered highly important for adolescents' HRQOL [170-174].

Across different countries and cultures, empirical evidence suggests that adolescents do not get the recommended nine hours of sleep per night [169, 171]. Previous studies have found several barriers to healthy sleep among adolescents – for example, lower parental supervision of bedtime, later preferred sleep timing, early school start time, longer study time, perceived stress, and electronic technology use in the evening [28, 169, 170, 175, 176].

2.4.7 COVID-19-related worries

The WHO characterized the spread of COVID-19 as a pandemic in March 2020, triggering an international public health emergency [177]. The pandemic has led to major changes in the lives of people of all ages through strategies aimed at limiting COVID-19 transmission. The potential COVID-19 health risks are significant, and people have been encouraged to take care of their own health and protect others by social distancing, practicing hand hygiene, wearing face masks in public places, limiting their social contacts, and staying informed and following advice given by national and local public health authorities [50, 51]. Moreover, the pandemic has caused lockdowns, quarantines, increased homeschooling and remote working, and limited or closed leisure activities. Altogether, these factors have affected adolescents and parents in an exceptional way – causing, for example, reduced HRQOL, increased rates of loneliness and stress, deteriorated mental health, and COVID-19-related worries [29, 30, 178-186]. COVID-19-related worries reported by adolescents and parents/adults in studies during the initial phase of the pandemic were often related to the state of becoming sick yourself or family/friends becoming sick and worries about infecting others and not being able to meet with extended family and friends, as well as about the adolescents' school situation, the parents/adults' work situation, and finance-related concerns [182-184, 187-189].

To contribute to more knowledge about HRQOL in adolescents and parents during the pandemic, questions about COVID-19-related worries and HL were included in the two-year follow-up of the Start Young study. This happened two years into my PhD period and resulted in a revision considering the papers planned in relation to my PhD study. We had first planned on writing three papers. However, to gain more knowledge of HRQOL, HL, and COVID-19-related worries of 16- to 17-year-old adolescents and parents one year into the

pandemic, we chose to write an extra paper (in total four papers) – Paper III is a result of this.

2.4.8 Health Literacy

COVID-19-related advice and information must be understood and acted upon for protective strategies against COVID-19 to be successful. Hence, people's HL has been emphasized as a crucial factor in dealing with and managing the pandemic [31, 190]. Moreover, previous studies have shown that HL is associated with HRQOL in adolescents and adults both before and during the pandemic [31, 32, 191-193].

HL is a skill-based process that can be used to identify and transform health-related information into knowledge and action, making it vital for a person's ability to navigate the health-care system and manage health [194]. HL is a term of increasing importance for public health and health care [195] and has become a priority for health in the 21st century. The HL field is building on numerous overlapping definitions. However, according to Sørensen (2019), the definition variations are related to the details regarding specific aspects of HL, rather than profound differences among the definitions. Sørensen emphasizes that the similarities are greater than the differentiating factors [194]. In this thesis, I use Nutbeam's definition of HL: "HL is the personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health" [196].

HL in adolescents should be recognized as a personal asset that can take on many forms and dimensions. Adolescents' knowledge acquisition is influenced by, for example, personal interpretation, parents/family, peers, media and sociocultural ideas, morals, and norms. Learning and developing HL-relevant knowledge and skills takes place in ways unique to the adolescent and their family's specific situation [197].

3 Previous research on HRQOL and pain in a general population of adolescents

3.1 HRQOL and pain in relation to sociodemographic factors

Age is a factor that seems to have an important impact on adolescents' HRQOL and pain. Results from previous research indicate that adolescents have lower HRQOL scores than children and that HRQOL often declines during adolescence, indicating important age differences in HRQOL [123, 140, 198, 199]. Langeland and colleagues (2019) found a significant decrease in girls' and boys' HRQOL from the first to the third year of upper secondary school (adolescents aged 16–19 years), and their results showed that 29.4% of the adolescents in the first year and 40% of the adolescents in the third year rated their HRQOL poorly. This may indicate there is an additional sensitive period at this time related to adolescents' HRQOL [200]. Longitudinal studies in general adolescent populations have shown that HRQOL seems to decline during adolescence, with a more pronounced decrease in girls' HRQOL over time compared to boys' [200-202]. A large study among 21,590 children and adolescents from 12 European countries found that age and gender differences exist for most KIDSCREEN-52 scales [202]. This may be explained by the physical, psychological, and social developmental changes during adolescence [3, 38, 123, 202, 203]. Otto and colleagues suggest that the transition period between childhood and adulthood affects girls' and boys' HRQOL differently [25]. This may be explained by an earlier onset of puberty in girls – involving bodily changes and changes in hormonal states associated with behavior and mood, which may all affect adolescents' HRQOL [123]. Considering pain, previous studies have demonstrated a higher prevalence of pain in adolescents compared to in children, and that the prevalence of pain tends to increase with age [7, 8, 14, 33, 86, 93].

The impact of gender on adolescents' HRQOL and pain has been discussed in several studies both internationally and in Norway. Gender differences in HRQOL have been observed in general adolescent populations, with adolescent girls tending to report lower HRQOL than boys [24, 25, 128, 198, 204, 205]. This has also been confirmed in Norwegian studies [24, 200]. Most studies report that girls and boys have similar HRQOL during childhood but that gender

differences are more present among adolescents, including a more pronounced decline in HRQOL among girls [128, 198, 204]. From the age of 12, female adolescents seem to be in a worse position than males regarding their HRQOL [202]. It has been suggested that the pattern of gender differences in HRQOL over time may indicate a gender-specific vulnerability during adolescence [201]. To increase the knowledge of gender differences related to adolescents' HRQOL, previous results need to be replicated in different cultural settings [198], and more detailed studies of the specific HRQOL dimensions affected by gender and age are needed [198, 201]. Furthermore, studies have shown that pain is more prevalent among girls [7, 8, 14, 33, 86, 93].

Adolescents' relationship with their family and the family structure may influence their HRQOL [13, 40, 139, 140, 142, 206]. A qualitative study found that adolescents consider good family relationships, especially the relationship with their parents, as important for their QOL. Experiencing a good balance between freedom and control and having parents an adolescent can talk to and feel secure with is important for the adolescent–parent relationship [40]. Living together with both parents has been associated with better HRQOL compared to living mainly with one parent [13, 139, 140, 142]. However, results are conflicting, and the literature review by Sletten and Bakken (2016) indicates that the increase in adolescents' psychological problems does not seem to be explained by the fact that more adolescents do not live together with both parents [42]. Considering pain, previous studies have shown that parent history of pain may increase the risk for adolescent pain [95, 118, 207]. It has been suggested that the relationship between adolescent and parental pain may be explained by complex interactions between genetics, learned pain behavior and environmental factors [95, 118-120]. Furthermore, studies have shown that coming from a family with a low SES is associated with lower HRQOL scores, a higher risk of pain problems, and other health complaints that are negatively associated with adolescents' HRQOL [13, 26, 97, 124-129, 135]. Together, this indicates the importance of assessing sociodemographic factors to better understand HRQOL and pain in adolescents.

HRQOL studies among general adolescent populations within different countries demonstrate noticeable differences in HRQOL scores between countries [125, 128, 202, 208], pointing out the importance of the national contexts for

adolescents' HRQOL. According to Michel and colleagues (2009), the differences in adolescents' HRQOL scores across European countries assume an innate influence of countries' socioeconomic and cultural factors on adolescents' HRQOL [202]. Importantly, as society rapidly changes, including an increase in individualization, materialism, social media and information technology use, and the impact of the COVID-19 pandemic, updated knowledge of adolescents' HRQOL and changes in adolescents' HRQOL within different national contexts is needed.

Insight into the population's QOL and into factors that affect people's lives in a positive or negative direction can make politicians and authorities more capable of creating a healthier and fairer society and developing strategies to promote QOL [21, 209]. In Norway, a national QOL survey in the adult population has been conducted twice [210, 211]. The results indicate that the QOL of Norwegian adults is generally high but skewed. Those who report poor QOL are especially people who have poor economy, are unemployed, have low education levels, have reduced physical or mental health, live with disabilities, and are queer. Moreover, the lowest QOL is reported among the youngest people (18–24 years) [210-212]. For Norwegian children and adolescents, researchers lack a systematic overview of how QOL or HRQOL varies, as the population is not included in the national QOL survey. The nationwide surveys Ungdata [213] and the Health behavior survey among school pupils (HEVAS) [214] contain questions about how satisfied adolescents are with life in general and with their health, relationships with friends and parents, the local environment, leisure activities, and school. Ungdata and the HEVAS findings suggest that most Norwegian children and adolescents in Norway have a good QOL [6, 7]. Ungdata results from 2018 to 2020 show that 85% of Norwegian adolescents were satisfied with their lives, and most adolescents reported having a good QOL and good relationships with friends and parents and being satisfied with school, teachers, leisure activities, and their local environment [6]. HEVAS results from 2020 show that most Norwegian adolescents in the age groups 11, 13, and 15 years reported good health and high life satisfaction and were satisfied with school. Girls reported lower life satisfaction and poorer self-reported health compared to boys. Further, the results show that although the differences are small, adolescents with high SES had generally healthier health habits and better

health than those with low SES. However, in contrast, girls from high SES families reported more school-related stress than girls from low SES families [7].

Although Ungdata surveys and the HEVAS study provide important data on various aspects of adolescents' lives, such as their well-being and health issues, they do not use measures specifically developed to assess HRQOL. Other studies have been conducted in general Norwegian adolescent populations using validated HRQOL instruments [27, 31, 122, 150, 174, 200, 215, 216], but there is a need for updated studies on adolescents' HRQOL in general Norwegian adolescent populations using validated and reliable HRQOL instruments. Normative data on Norwegian adolescents' HRQOL is warranted to provide insight into the population's HRQOL and into possible differences in HRQOL between different groups. Using validated HRQOL instruments could also make it easier to compare Norwegian results with international adolescent populations. Moreover, longitudinal HRQOL studies covering the transition period from lower secondary to upper secondary school are scarce [200] and should thus be prioritized.

Few longitudinal studies have been conducted on HRQOL in general adolescent populations [25, 200, 201]. Most studies on adolescent HRQOL are cross-sectional. Among the longitudinal studies, there have been more studies on adolescents with specific conditions, such as chronic illness [217], obesity [218], cerebral palsy [219], and epilepsy [220], within the context of a parent–child agreement [221], or among adolescents with disadvantaged backgrounds [222]. The results of these studies vary according to the instrument used and the type of adolescent population studied. Thus, they provide limited generalizability to general adolescent populations. From a health promotion perspective, this indicates that more knowledge of how HRQOL in general adolescent populations may change during adolescence is needed.

3.2 HRQOL and pain in relation to pain-related factors, self-esteem, self-efficacy, loneliness, stress, sleep, COVID-19-related worries, and HL

Adolescent pain is associated with lower levels of HRQOL [14, 24, 83-85, 150, 223]; hence, the increase in pain prevalence is worrying. Furthermore, an increasing number of adolescents are reporting a high intake of OTC analgesics such as paracetamol and nonsteroidal anti-inflammatory drugs to treat not only pain but also other conditions, such as anxiety and stress [161, 224-226]. This development gives cause for concern, especially because frequent consumption of OTC analgesics may lead to health problems such as liver failure or drug-induced headaches [227-229]. To better understand pain in general adolescent populations, more knowledge of perceived triggers of pain, factors associated with pain, adolescents' use of OTC analgesics in relation to pain management, and the association between pain and HRQOL is warranted. Previous studies have also emphasized the need to increase the understanding of HRQOL in parents of adolescents experiencing pain, as pain may negatively affect the parents' HRQOL [116].

Studies have shown that the resilient factors self-efficacy and self-esteem have a positive impact on adolescents' HRQOL and pain, with higher levels of self-efficacy and self-esteem being associated with higher levels of HRQOL and less pain problems [23, 25-27, 87, 96, 150, 151, 174]. These resilient factors are also associated with higher levels of HRQOL despite experiencing psychosomatic symptoms such as pain and stress [23, 87, 150], and self-efficacy and self-esteem may empower adolescents to positively adapt and live beyond their pain [150]. Furthermore, studies have found that in the presence of positive and negative psychological factors, gender and age lose their predictive value for the HRQOL dimensions psychological well-being and autonomy and parents' relation [23]. Adolescence is considered a challenging life phase in many ways. To promote adolescents' HRQOL, more knowledge of factors that may have a positive impact on adolescents' lives and on their HRQOL seems valuable and highly important. Furthermore, more knowledge of protective and resilience factors associated with adolescent pain is needed because previous studies on adolescent pain have mainly focused on risk factors and maladjustment [96, 230, 231].

The feeling of loneliness is associated with problems and negative feelings during adolescence, such as low self-esteem, pain problems, and reduced HRQOL [88-90, 153, 154, 232]. Adolescents' relationships with peers are considered vital to their experience of HRQOL [40]. A recent study demonstrated that loneliness is a strong indicator of low self-esteem and low mental well-being in adolescents from Nordic countries [89]. Most Norwegian adolescents do not report feeling lonely; however, more than 1 in 10 adolescents state that they are very much bothered by loneliness [6]. Furthermore, the COVID-19 pandemic has been associated with increased rates of loneliness among adolescents [10, 179]. Together, this is worrying and indicates the need for more knowledge of the prevalence of loneliness among adolescents and the impact loneliness may have on adolescents' HRQOL and pain.

Stress symptoms are associated with lower HRQOL, reduced mental health and well-being, and problems such as pain and a high consumption of OTC analgesics in adolescents [23, 98, 159-162, 233]. There are large variations among adolescents related to the experience of stress and pressure in everyday life, but school seems to be the area that most adolescents find stressful [6, 7, 49, 166]. However, less is known about which HRQOL dimensions are most affected by stress, and few studies have investigated the impact of stress on adolescents' HRQOL over time while simultaneously assessing other factors. Freire and Ferreira (2018) investigated the relationship between HRQOL and both positive and negative psychological dimensions. Their results demonstrate that stress symptoms are associated with adolescent perceptions of decreased autonomy and parents' relation [23]. More research into stress and the relationship between stress and HRQOL and also stress and pain in adolescents is needed, as it may provide important information about the impact of stress on different aspects of life, thereby helping to identify and develop strategies to promote HRQOL and reduce stress and pain in adolescents.

Sufficient sleep is considered essential for adolescents' HRQOL, and higher levels of perceived daytime sleepiness are associated with lower levels of HRQOL [172]. A positive relationship has been demonstrated between sleep quality and HRQOL [28]. However, few studies have been conducted on the

association between sleep and HRQOL in general adolescent populations. Considering the importance of sleep for adolescents' development and functioning during adolescence [167-169], and the knowledge of significant barriers related to adolescents' sleep [28, 169, 170, 175, 176], more studies on the relationships between HRQOL and sleep in adolescents are needed. Insufficient and poor-quality sleep is also associated to the prevalence of pain in adolescence [33, 234]. Hence, more knowledge of sleep patterns in adolescents with pain is needed.

Adolescents and their parents have been greatly affected by the COVID-19 pandemic, and the strategies aimed at limiting the spread of the virus and its negative consequences have led to reduced HRQOL, deteriorated mental health, COVID-19-related worries, and increased rates of stress and loneliness [29, 30, 178-186]. More knowledge of COVID-19-related worries in adolescents and parents during the pandemic is needed to better understand the pandemic's impact on their mental health. Moreover, considering that stress and worries are associated with reduced HRQOL [23], research into the associations between HRQOL and COVID-19-related worries is needed.

The COVID-19 pandemic has highlighted the need for more knowledge of adolescents' HL, as adolescents are increasingly becoming more independent and thus responsible for how they choose to behave and act in relation to the COVID-19 protective strategies [31]. However, few studies have been conducted on adolescents' HL in Norway. It is also important to study the HL knowledge of parents of adolescents during the pandemic, as they are important role models for their children. Studies have demonstrated positive associations between adolescents' and adults' HL and their HRQOL [31, 32, 191, 192]. Nevertheless, there are few studies on the association between HL and HRQOL during the pandemic. More knowledge of this association could be valuable for health promotion and disease-prevention interventions and for policy during and after the pandemic.

Health challenges and problems that may have a negative impact on adolescents' HRQOL, such as pain, stress and pressure, loneliness, insufficient and poor-quality sleep and a high intake of OTC analgesics, seem to be increasing among adolescents internationally and in Norway [4, 6, 8-10, 13, 42, 161, 170, 173,

198]. The literature overview by Sletten and Bakken (2016) concludes that more longitudinal studies among adolescents are needed to better understand changes in the amount of mental and psychosocial problems reported in adolescents [25]. Furthermore, more knowledge of how the impact of factors associated with HRQOL might change during adolescence is warranted. Most longitudinal studies on adolescents' HRQOL include just a few selected variables, such as age, gender, and sociodemographic factors. Hence, longitudinal studies including several factors that may predict development in adolescents' HRQOL are needed, as they may provide important insight into adolescents' HRQOL [25, 200]. Moreover, both cross-sectional and longitudinal studies investigating the impact of factors associated with HRQOL simultaneously can increase the understanding of which factors future interventions among general adolescent populations should prioritize.

3.3 Gaps of knowledge

Updated knowledge of adolescents' HRQOL is needed as society rapidly changes, and the COVID-19 pandemic has also caused a need for more knowledge of adolescents' HRQOL during the pandemic. Few studies have investigated how HRQOL changes over time in nonclinical adolescent populations, and longitudinal HRQOL studies covering the transition period from lower secondary to upper secondary school are scarce. In Norway specifically, researchers lack a systematic overview of how QOL or HRQOL in adolescents varies, as they are not included in the national QOL survey and considering that normative data on Norwegian adolescents' HRQOL is lacking. Hence, updated studies on adolescents' HRQOL in general Norwegian adolescent populations using validated and reliable HRQOL instruments are needed.

To better understand HRQOL in adolescents and thus be able to intervene accurately and strategically, it is important to identify factors that may influence adolescents' HRQOL. Studies of the relationships between HRQOL and sociodemographic, psychosocial, and HL factors associated with HRQOL, as well as pain and sleep, are limited, and most HRQOL studies have considered only a small set of factors associated with adolescents' HRQOL. Longitudinal studies investigating a wide range of potential predictive factors of HRQOL change are scarce. To gain more knowledge of which factors future interventions

among nonclinical populations of adolescents should prioritize, it is necessary to investigate the influence of these factors on HRQOL simultaneously. Furthermore, more research into which HRQOL dimensions are most strongly associated to sociodemographic, psychosocial, and HL factors, as well as pain and sleep, is needed, as it may provide important information about how these factors are associated to different aspects of adolescents' lives. Based on earlier studies, we considered the following factors to be essential to expand our knowledge of adolescents' HRQOL: sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, stress, sleep, HL, and COVID-19-related worries.

Limited data have been collected on adolescent pain in nonclinical populations, and updated data on the prevalence of pain, the impact of pain on HRQOL, and pain triggers as perceived by adolescents is needed. Moreover, there are few studies of parental pain linked to adolescents' pain. Further, research into factors that characterize adolescents with and without pain is scarce, and knowledge of whether there are factors in adolescents with persistent pain that differ from factors in adolescents with a shorter pain duration is limited. Finally, more knowledge of resilience and protective factors associated with adolescent pain is warranted. Based on earlier studies, we considered the following factors to be essential to expand our knowledge of adolescents' pain: HRQOL, sociodemographic factors, self-esteem, self-efficacy, loneliness, stress, sleep, parental pain and parental HRQOL.

4 Aims of the thesis

Based on the knowledge gaps within HRQOL and pain research, the overall aim of this thesis was to expand our knowledge of HRQOL and pain by investigating sociodemographic, psychosocial-, pain-, sleep-, HL- and COVID-19-related factors associated with HRQOL in a school-based sample of Norwegian adolescents and in their parents during two years of youth.

The thesis comprises four papers with the following aims:

I: To assess the associations between selected sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL in 14- to 15-year-old adolescents (Paper 1).

II: To describe selected sociodemographic and psychosocial factors and pain in 14- to 15-year-old adolescents and their parents, assess how these factors are associated with adolescent pain groups (no pain, pain lasting less than three months, persistent pain), and lastly, explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and/or self-efficacy (Paper 2).

III: To describe HRQOL of 16- to 17-year-old adolescents and parents of adolescents, their HL and degree of COVID-19-related worries about one year into the pandemic, and to assess the strength of associations between gender, HL, COVID-19-related worries, and HRQOL (Paper 3).

IV: To investigate possible HRQOL changes in adolescents during two years of youth, from the age of 14 to 16 years, and assess the impact of sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL over time (Paper 4).

5 Methods

5.1 Study design

This PhD study is a prospective cohort study of adolescents and their parents. The study is a part of the Start Young – Quality of Life and Pain in Generations study [235], a Norwegian mixed-method four-year prospective study aimed at acquiring new knowledge about HRQOL and pain in adolescents and their parents and at investigating potential family and regional patterns. A research group from the University of Agder and the Oslo Metropolitan University is conducting and is responsible for the Start Young study.

The Start Young study includes four different phases. An overview of these phases is presented in Table 1. My PhD study is a part of Phases 1 and 3 of the Start Young study. Hence, this thesis and the four related papers are built on data collection from baseline in 2018–2019 (Phase 1 – from now on rephrased as Time 1 in this thesis) and from the two-year follow-up in 2021 (Phase 3 – from now on rephrased as Time 2). Different designs and methods were used with the intention of providing the most appropriate prerequisites for addressing the specific aims of the four papers and the overall objective of this thesis. Papers I–III have a cross-sectional design, while Paper IV has a longitudinal design.

Table 1. Overview of the Start Young study's four phases

Start Young – Quality of life and pain in generations			
Phase 1 The family perspective (Agder and Oslo/Akershus)	**Phase 2** Pain in the family Qualitative interviews (Agder and Oslo)	**Phase 3** Associates of HRQOL and pain in adolescents: 2-year follow-up (Agder and Oslo/Akershus)	**Phase 4:** Associates of HRQOL and pain during years of youth: 4-year follow-up (Agder and Oslo/Akershus)
HRQOL, pain, and coping with pain in Norwegian adolescents (9th grade) and their parents Cross-sectional data collection from Norwegian adolescents and their parents using well-established international questionnaires measuring HRQOL and pain	*Illuminate family patterns in adolescents and parents with pain* Recruitment of adolescent/parent families reporting recurrent pain in the cross-sectional study: a) adolescents/parents with severe pain; b) adolescents/parents with pain from minority cultures	*HRQOL, pain, and coping with pain in Norwegian adolescents (11th grade): a 2-year follow-up study*	*HRQOL, pain, and coping with pain in Norwegian adolescents (13th grade) at a 4-year follow-up*

5.2 Study samples

A random cluster sample was used in the Start Young study. The target population was adolescents in a nonclinical setting and their parents from the southeastern part of Norway. This geographical region consists of approximately 1.6 million inhabitants (about 30% of the total Norwegian population) and an adolescent population (aged 14–15 years) of approximately 37,000. Four counties were considered representative of the target population and selected: Agder west and Agder east from the southern part of Norway and Oslo and Akershus from the eastern part of Norway. Based on the main measures of the Start Young study, KIDSCREEN (HRQOL), and the Brief Pain Inventory (BPI, Pain), an affiliated statistician estimated that 800 adolescents divided equally among the four counties should be included in the study. Possible attrition in the Start Young study's four-year follow-up was considered in this estimation. We anticipated that an inclusion of 800 participants would provide enough statistical power to estimate proportions of participants with the desired level of precision and enable us to run multiple analyses to identify possible confounding variables.

In addition, we aimed to include one parent of each adolescent in the survey. We did not want both parents of the adolescents to participate because we assumed it is unlikely we would have been able to recruit both parents of each adolescent. This could have resulted in a skewed sample if certain groups of adolescents were represented by two parents and other groups were represented by only one. Thus, we chose to inform both parents/legal guardians about the study and invited them to participate, but it was emphasized that only one of them could sign up for their own participation.

During spring 2018, the Department of Statistics at the Norwegian Directorate for Education and Training provided us with a document containing a list of all public and private schools with ninth grade (lower secondary schools) in Agder west, Agder east, Oslo, and Akershus. A highly experienced statistician affiliated with the Start Young research group helped with planning and conducting the sampling. Schools from the selected geographical area were stratified according to region, urban and rural districts, and school size. Two schools were randomly selected from each stratum. Details regarding the recruitment procedure at Time 1 are provided in section 5.3.

A total of 59 schools were invited to participate, but 37 schools declined. The main reason for declining was that the schools did not have time to contribute to the Start Young study and/or they were already involved in other research projects. Schools that did not want to participate were replaced by other schools selected according to the same criteria. Among these, 22 schools agreed to participate. These 22 schools varied in size and localization (rural and urban districts), admitting adolescents with different economic and sociocultural backgrounds. Seven schools were Grade 1–10 schools, and 15 schools were lower secondary schools (Grades 8–10). Two schools were private schools, and the remaining 20 were public schools. Considering school size, nine schools had 100–299 pupils, and the remaining schools had 300 pupils or more. According to Statistics Norway, more than 90% of Norwegian schools are public schools. Further, about 30% of Norwegian schools have less than 100 pupils, about 40% have 100–299 pupils, and about 30% have 300 pupils or more [236]. Hence, the participating schools may be regarded as representative of schools in Norway regarding school ownership, but they are not representative of Norwegian schools regarding school size.

To minimize possible selection bias, all ninth-grade students at the participating schools and their respective parents were invited to participate. Thus, potential participants from the 22 participating schools in the Start Young study were 1663 adolescents in the 9th grade and 1663 parents of 9th graders. In addition to being a student in ninth grade at one of the participating schools, the inclusion criteria for *adolescents* in the Start Young study were being present at school by the time of data collection, having active informed consent to participate from one parent or a legal guardian, and providing own consent to participate. The inclusion criteria for *parents* were being a parent of a ninth-grade adolescent at one of the participating schools and providing own consent to participate.

A total of 967 adolescents were excluded because they were not present at school by the time of data collection (n = 77), did not have active informed consent from parents (n = 872), did not provide own consent to participate (n = 8) or because of technical problems at one school (n = 10). This resulted in a total of 696 adolescents aged 14–16 years taking part (response rate 41.8%) at Time 1. This sample of adolescents was used in Paper I (see Figure 5). The response rate

varied across schools from 8.6% to 92.1%; it was lowest in two schools in Oslo where many adolescents had a minority background and highest in the two public schools in Agder. Further, a total of 561 parents gave their consent to participate and answered the survey (response rate 33.7%) at Time 1. The adolescents and parents who participated at Time 1 became the cohorts this study followed for two years.

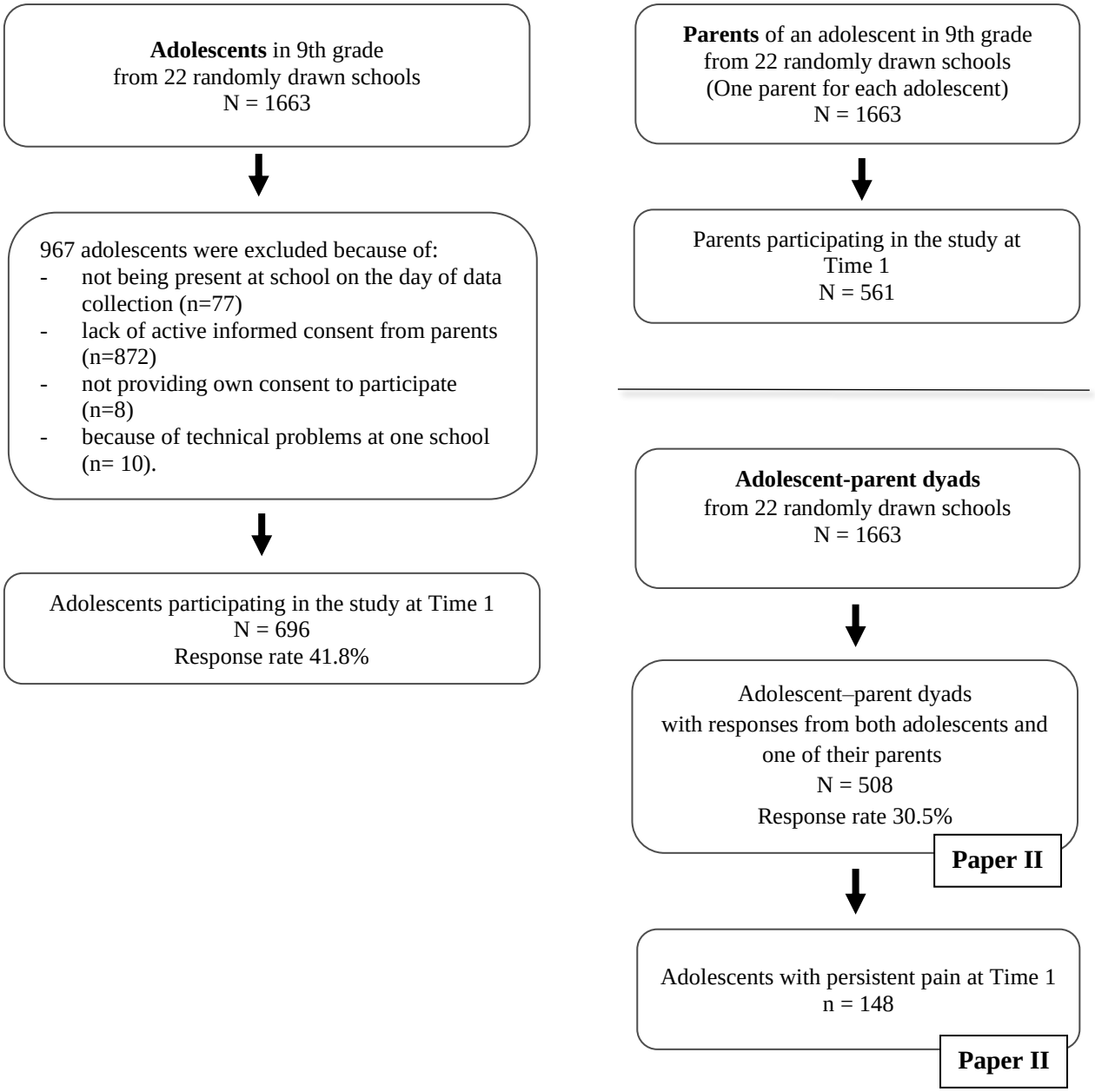

Figure 5. Samples at Time 1

To quantify the risk of bias, the common practice is to compare responders and nonresponders regarding selected background variables. However, due to the General Data Protection Regulation (GDPR), we were not allowed to ask nonresponders any questions, nor could we ask the schools to provide us with any such information. Therefore, we could not assess whether the participants and nonparticipants differed in any way. Nevertheless, descriptive characteristics in Papers I–IV show that more than two-thirds of the adolescent participants lived with both parents and had parents who were both born in Norway and were both employed. Further, the descriptive characteristics in Paper II (with only small differences in Paper III) show that about three-quarters of the participating parents had higher education, were working full time, and had a household income of more than 750,000 NOK/year. According to Statistics Norway, in 2021, about 77% of Norwegian children and adolescents aged 0–17 years lived together with both parents [237], a total of 72.5% of Norwegian men and 67% of women were employed [238], and 18.5% of the total Norwegian population were immigrants or Norwegian-born with immigrant parents [239]. In 2020, about 35% of Norwegian adults were educated at the university level [240], the median household net income for couples with children (where the youngest child was aged 7–17 years) was about 950,000 NOK/year, and the median household net income for single parents with children (children aged 0–17 years) was about 430,000 NOK/year [241]. These facts indicate that the sample may be representative of Norwegian families regarding who the adolescents live together with, the percentage of parents employed, the percentage of immigrants or Norwegian-born with immigrant parents, and household income. However, our sample had higher levels of education compared to the Norwegian population, indicating that the sample may not be representative of adolescents and parents within families of lower education levels. Further, it is important to note that the fact that we only included one of each adolescent's parents (Papers II and III) and that most were women/mothers may have affected the results. It is likely that the results would have been different if more fathers were included and/or if both parents were included. All these aspects should be taken into consideration when interpreting our results.

In Paper II, the target sample was adolescent–parent dyads, with responses from both adolescents and one of their parents at Time 1. This resulted in

508 adolescent–parent dyads (30.5% of the invited) (Figure 5). The response rate of adolescent–parent dyads varied across schools from 71.1% to 2.9%. Further, to explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and/or self-efficacy, we selected the 148 adolescents that reported having persistent pain for further analyses. As the descriptive characteristics in Paper II show, the pain intensities reported by the adolescents are not considered high. This indicates that the results of Paper II may not be representative of adolescents with higher levels of pain.

The cohorts of adolescents and parents who participated at Time 1 were asked to answer almost identical questions at a two-year follow-up study in 2021 (Time 2). The adolescents were aged 16–17 years at Time 2. Details regarding the recruitment procedure at Time 2 are provided in section 5.3. Of the 696 adolescents and 561 parents eligible for inclusion at Time 2, a total of 215 adolescents (response rate 30.9%) and 320 parents (response rate 57.0%) participated. This sample of adolescents and parents was used in Paper III. Due to a technical error, 4 adolescents were excluded from the sample in Paper IV, resulting in a total sample of 211 adolescents (see Figure 6).

A total of 486 adolescents dropped out from Time 1 to Time 2. We do not have any information about why they dropped out. However, dropout analyses were conducted to assess whether the participants at Time 2 differed from the adolescents who participated at Time 1, but then dropped out at Time 2. When comparing baseline scores between the participants at Time 2 and the adolescents who dropped out from Time 1 to Time 2 (nonparticipants), we found that the participants consisted of significantly more girls (68.2%) compared to the nonparticipants (52.8%). We found no statistically significant differences in the other sociodemographic factors, HRQOL, pain, self-esteem, self-efficacy, stress, or loneliness between the participants and nonparticipants. This indicates that, except for gender, the adolescents who participated at Time 2 were not very different from those who dropped out from Time 1 to Time 2.

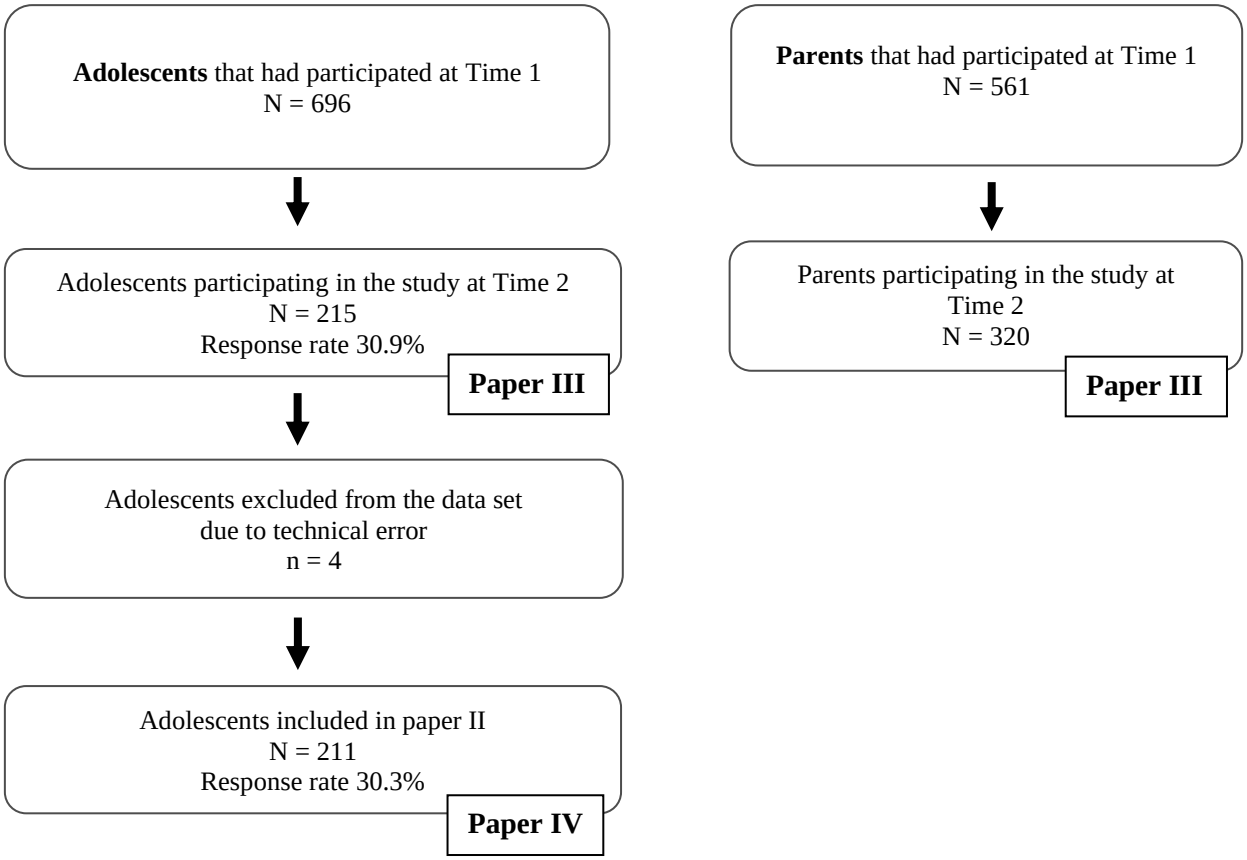

Figure 6. Samples at Time 2

5.3 Recruitment procedure and data collection

A website was built for the Start Young study to inform and invite adolescents and their parents to participate in the study [235]. The website contained information for adolescents, parents, and school staff about the project, the project members, relevant research, and practical information about participation, including information letters. On the website, there was also a link to a digital form in Nettskjema [242], where parents could register the adolescents and themselves to become participants in the study. This registration included a section for informed consent that required parents to use two-factor authentication. Through this registration, the adolescents' and parents' contact information was obtained.

A pilot study was carried out a few months before the main study to test the routines for recruitment and data collection and get feedback regarding completion of the questionnaire. The pilot study took place in a ninth-grade class at a local school. We received mostly positive feedback regarding routines and

the questionnaire. However, we experienced that the questionnaire was too lengthy, requiring the removal of some items/questions. Based on the pilot study, the Start Young research group adapted the questionnaire and the final implementation of the research project itself so that it became as feasible as possible for future participants.

In November 2018, we started contacting schools. The principals at the selected schools were contacted by the PhD student (see Appendix 1) and asked whether the school wanted to participate in the research project. If the school agreed to participate, project members visited the school approximately one week prior to data collection. During the visit, adolescents were given oral information about study participation and given two information letters, one for them and the other for their parents/legal guardians (see Appendices 2 and 3). If possible, the schools were also asked to post information about the Start Young study on their websites.

Data collection at Time 1 took place between November 2018 and April 2019. Adolescents and parents received a link to the digital survey on their registered email addresses. Adolescents completed the survey on their computers during school hours. Most adolescents used about 20–30 minutes to complete the survey, but the time varied between 10 minutes and 1 hour and 14 minutes. One or two project members and a teacher were present to provide assistance and answer questions when needed. Parents completed the survey in their spare time. Most parents used about 20–30 minutes to complete the survey, but the time varied between 10 minutes and 4 hours and 11 minutes.

Although steps were taken to attain as much control as possible over the external factors related to recruitment procedure and data collection, some problems occurred. The planned method of digital informed consent via two-factor authentication worked well in the pilot study. However, obtaining digital consent turned out to be more challenging at the first school we visited because several parents did not have two-factor authentication on their telephone/tablet/computer. Therefore, this way of obtaining consent may have led to a low response rate at this school. Thus, after attending this school, we chose to give future participants an opportunity to provide written consent as well. At the remaining participating schools, about 20%–40% of the parents chose to give their consent on paper.

Furthermore, we experienced the lowest response rates at the two largest participating schools (in terms of number of students). At these schools, many students had parents with an immigrant background, and the teachers informed us that it was a known challenge that several parents could not read Norwegian and that some parents were illiterate. Considering that parents only received written information about the study, it is likely that many of these parents were skeptical about giving consent to a study they could not understand its scope. This may explain the low response rate among adolescents having parents with an immigrant background. There were also some technical problems on the day of data collection at one school, causing some adolescents who had received digital informed consent from parents to not receive the link to the questionnaire. This technical problem was not solved before the school hour was over, and then the adolescents did not want to spend their spare time answering the survey. This may partly explain the low response rate at this school.

Data collection at Time 2 took place between January and February 2021. All adolescents and parents who participated at Time 1 were sent a text message with information about the follow-up study one week in advance. The message contained a link to the study's website – where information about the survey, including the information letters, was available (see Appendices 4 and 5). The survey itself was sent out one week later via a safe link distributed by text message to the adolescents and by email to parents via Nettskjema. The first part of the survey contained an informed consent section. Both adolescents and parents completed the survey in their spare time and used about 20–30 minutes. The time adolescents used varied between 7 minutes and 1 hour and 49 minutes. The time parents used varied between 10 minutes and 3 hours and 36 minutes. Information from the initial registration at Time 1 enabled us to link the questionnaires from Time 1 to the questionnaires at Time 2 by creating a mutual ID number.

The IT platform Services for Sensitive Data (TSD) was used to collect, store, and analyze data. TSD has an integrated solution for collecting and storing sensitive data, via Nettskjema, in a secure environment that follows the Norwegian privacy regulation and the GDPR [243]. The study was reviewed by the Regional Research Ethics Committee of Norway (REK), first, through a presentation assessment and, afterward, through a full application. However, REK concluded

that the study did not need their approval (see Appendix 6). The recruitment procedure and data collection were approved by the Faculty of Health and Sports Science's Research Ethics Committee at the University of Agder (FEK) (see Appendix 7) and the Norwegian Centre for Research Data (NSD) (see Appendices 8 and 9).

5.4 Ethical considerations

Research involving adolescents entails special ethical considerations. In this study, the Declaration of Helsinki was followed. This declaration was developed by the World Medical Association as a statement of ethical principles for medical research involving human subjects [244]. The declaration points out that special attention must be paid to vulnerable groups and individuals, such as adolescents, and highlights that vulnerable groups should stand to benefit from the knowledge that results from research [244]. The Start Young study explores important conditions for adolescents' living conditions. Thus, it is relevant and necessary to obtain information from the adolescents themselves. However, the survey contained some questions about conditions (e.g., loneliness, self-esteem, self-efficacy) that may be perceived as sensitive and that may arouse negative emotions. Further, participants had to spend some time answering the questionnaire. Nevertheless, based on a weighing of the pros and cons of the research project, we believe that the benefits clearly exceeded the disadvantages. The Norwegian Centre for Research Data and the Faculty of Health and Sports Science's Research Ethics Committee reviewed the ethical aspects of the study, and necessary approvals were obtained (see Appendices 7–9). REK also reviewed the study but concluded that the study did not need its approval (see Appendix 6).

The right to self-determination and the right to full disclosure are important ethical principles within research ethics. *Self-determination* refers to having the right to voluntarily decide whether to participate in a study without risking negative consequences, having the right to ask questions, and having the possibility to refuse giving information and to withdraw from the study. *Full disclosure* means that the nature of the study is fully described, including risk and benefits, the responsibilities of the researchers, and the person's right to refuse participation [245]. The Start Young study's information letters, containing subsequent informed consent (see Appendices 2–5), were based on

the participants' right to self-determination and full disclosure. We strived for consistent and clear language adapted for adolescents and parents. *Informed consent* refers to participants having adequate information about the research project, being capable of understanding and comprehending the information, and having the power to choose freely [245]. The information letters stated clearly that the participants could access, correct, or delete information about themselves by contacting project staff.

At Time 1, the adolescents participating in the study were aged 14–15 years and considered able to decide whether they wanted to participate. However, they were legally minors. Thus, their parents were required to consent to their participation. Written informed consent was obtained from the adolescents' parents or guardians either digitally through a form on the Start Young's web page or in paper form, which the adolescents delivered at school. Parents could give their consent for both adolescents and themselves to participate. The adolescents actively agreed to participate by choosing to answer the questionnaire. Further, the first part of the questionnaire contained the study's information letter. All participants had to tick that the information was read and understood and that they agreed to participate before they could proceed in the questionnaire.

Several steps were taken at Time 1 to protect participants in the research project and limit potential risk due to study participation: 1) A pilot study was conducted in autumn 2018. Based on this, the Start Young's project staff could customize the digital survey and the final implementation of the research project to finetune it as best as possible for the participants. 2) School health services/ public health nurses at the relevant schools were informed about the research project and agreed to help in case any of the participants needed further support. Adolescents and parents were informed about the possibility of contacting the public health nurses if they needed to talk to someone after they had filled out the questionnaire or if they had questions or concerns. 3) The adolescents were given oral and written information about the study. Parents were given written information digitally on the Start Young study's web page and in paper form. 4) We ensured that the adolescents were given the opportunity to make an independent choice of whether they wanted to answer the questionnaire, without influence from parents, other students in class, or school. We clarified in advance

that adolescents who did not want to participate or who had not received their parents' permission were offered digital assignments to work with on their computer inside the classroom while others completed the digital survey. 5) To minimize the possibility of others seeing what the adolescents answered on the digital questionnaire, we ensured that adolescents were placed separately, with some space between them, in the classrooms. 6) The study was conducted according to the GDPR. We used a safe data server to store the collected data [243].

At Time 2, the adolescents were aged 16–17 years and did not need parental consent to participate. Updated information letters were distributed digitally to adolescents and parents in advance and were also available on the study's web page. Adolescents and parents actively agreed to participate by choosing to answer the questionnaire and by ticking that the information was read and understood and that they agreed to participate in the first part of the questionnaire.

As an expression of gratitude, participants at Times 1 and 2 joined a draw to win a gift card. However, the amount was only 500 NOK, and the odds of winning were small. Thus, this incentive was not considered to place pressure on prospective participants.

5.5 Measures

Several questionnaires were used to measure the selected variables in Papers I–IV. Tables 2 and 3 give an overview of the questionnaires used for adolescents and parents, respectively. The internal consistency and, thus, reliability for multi-item scales was assessed using Cronbach's alpha [246]. All questionnaires showed satisfactory Cronbach's alpha values of above 0.7 (Tables 2 and 3).

Table 2: Overview of questionnaires completed by adolescents in Papers I–IV

Questionnaire	Paper	Number of items	Cronbach's alpha [a]
Gender	I, II, III, IV	1	
Age	I, II, III, IV	1	
Adult members of the household	I, II, III, IV	1	
Number of siblings	I	1	
Parents' birthplace	I, II, IV	1	
Parents' marital status	I	1	
Parent's work status	I, II, IV	1	
School absence	I, II	1	
Moved during the previous 5 years	I	1	
KIDSCREEN-27	I, II, IV	27	All 5 scales ≥ 0.77
KIDSCREEN-10	III	10	0.81
Brief Pain Inventory (BPI)	I, II, IV	1–10 [b]	2 interference indexes ≥ 0.77 [c]
Lübeck Pain-Screening Questionnaire (LPQ)	I, II, IV	2–3 [d]	
OTC analgesic questions (derived from SUS)	I, II	2	
Generalized Self-Efficacy Scale (GSE)	I, II, IV	10	≥ 0.87
Rosenberg Self-Esteem Scale (RSES)	I, II, IV	4	≥ 0.79
UCLA Loneliness Scale 8 item (ULS-8)	I, II, IV	8	≥ 0.80
Perceived Stress Questionnaire (PSQ)	I, II, IV	30	≥ 0.93
School Sleep Habits Survey	I, II	2	
Health Literacy in School-Aged Children questionnaire (HLSAC)	III	10	0.86
COVID-19-related worries	III	8	

[a] Cronbach's alpha in all relevant papers. The exact value for each paper is reported in tables within the respective papers.

[b] Paper I : 9 questions, Paper II : 10 questions, Paper IV : 1 question.

[c] The two Brief Pain Inventory interference indexes were used in Papers I and II.

[d] Papers I and IV: 2 questions, Paper II: 3 questions.

Table 3: Overview of questionnaires completed by parents in Papers II and III

Questionnaire	Paper	Number of items	Cronbach's alpha [a]
Gender	II, III	1	
Age	II, III	1	
Marital status	II, III	1	
Education level	II, III	1	
Work status	II, III	1	
Household income	II, III	1	
RAND-36	II, III	36	All 8 scales ≥ 0.84
Brief Pain Inventory (BPI)	II	10	Both interference indexes ≥ 0.77
Lübeck Pain-Screening Questionnaire (LPQ)	II	2	
OTC analgesic questions (derived from SUS)	II	2	
The Health Literacy Questionnaire (HLQ)	III	23	All 5 scales ≥ 0.75
COVID-19-related worries	III	8	

[a] Cronbach's alpha in all relevant papers. The exact value for each paper is reported in tables within the respective papers.

5.5.1 Sociodemographic variables

The first part of the questionnaires at Times 1 and 2 included self-reported data on selected sociodemographic variables. Tables 2 and 3 provide an overview of the sociodemographic variables assessed in adolescents and parents in Papers I–IV. Further details are provided in Papers I–IV.

5.5.2 HRQOL measures

HRQOL in adolescents is considered best assessed through age-appropriate self-reports [17, 82, 247]. Self-reports or subjective measures are often referred to as patient- or person-reported outcome measures (PROMs) [60]. Several PROMs have been developed for HRQOL assessments. Some instruments are intended for general use, irrespective of the illness or condition of the person. These instruments are often referred to as "generic questionnaires"; they focus on broad aspects of HRQOL and may also be applicable to healthy people. Other instruments focus on issues of particular concern to patients with a certain disease and are referred to as "disease-specific questionnaires" [60]. Considering

that the focus of my PhD study is adolescents from a general, nonclinical population, a generic instrument was considered appropriate.

Aspects of what characterizes the adolescent population and this particular life phase are relevant and important to consider when measuring HRQOL in adolescents [248]. Many generic HRQOL measures cover a wide set of dimensions related to physical, psychological, and social health. However, the number and names of dimensions vary [17, 247, 249]. Generic HRQOL in adolescents should include dimensions specifically related to the adolescents' environment and experiences, such as physical and psychological well-being, family life, peer relations, and school environment [250]. A recent systematic review of the most frequently used generic PROMs that measure HRQOL in children and adolescents evaluated six instruments: 1) KIDSCREEN, 2) KINDL, 3) the Pediatric Quality of Life Inventory 4.0, 4) the Child Health Questionnaire, 5) DISABKIDS, and 6) the Child Health and Illness Profile. Across these six instruments, dimensions of physical, emotional, social health, and school activities were common, while dimensions of parent relations, family activities, self-esteem, and independence or autonomy were not present in all. All instruments used Likert scales [249].

We chose to use KIDSCREEN to measure HRQOL in adolescents in our study. The KIDSCREEN questionnaires were developed to evaluate HRQOL in children and adolescents aged 8–18 years and can be used for both healthy and chronically ill children and adolescents [18, 82, 251]. Conceptually, the KIDSCREEN instruments are based on the same definition of HRQOL that is used within this thesis: "HRQOL is a multidimensional construct covering physical, emotional, mental, social, and behavioral components of well-being and functioning as perceived by patients and/or other individuals" [17, 18]. There are three different versions of the questionnaire: the KIDSCREEN-52 (52 items with 10 dimensions), KIDSCREEN-27 (27 items with five dimensions), and KIDSCREEN-10 (10 items that can provide a general HRQOL index score). The dimensions of the KIDSCREEN instruments and relationship between versions are depicted in Figure 7 [18]. The KIDSCREEN questionnaires assess several aspects of children's and adolescents' HRQOL. The questionnaires were developed based on a project involving 13 European countries and resulting in age-based norms for 8–18 year olds [82]. Research has shown that the

KIDSCREEN instruments offer valid, reliable, linguistically/conceptually appropriate, and sensitive HRQOL measures in 38 languages, including Norwegian, and KIDSCREEN is considered to be a cross-cultural comparable tool [18, 251]. In our study, all participating adolescents answered the 27 items from the KIDSCREEN-27 instruments.

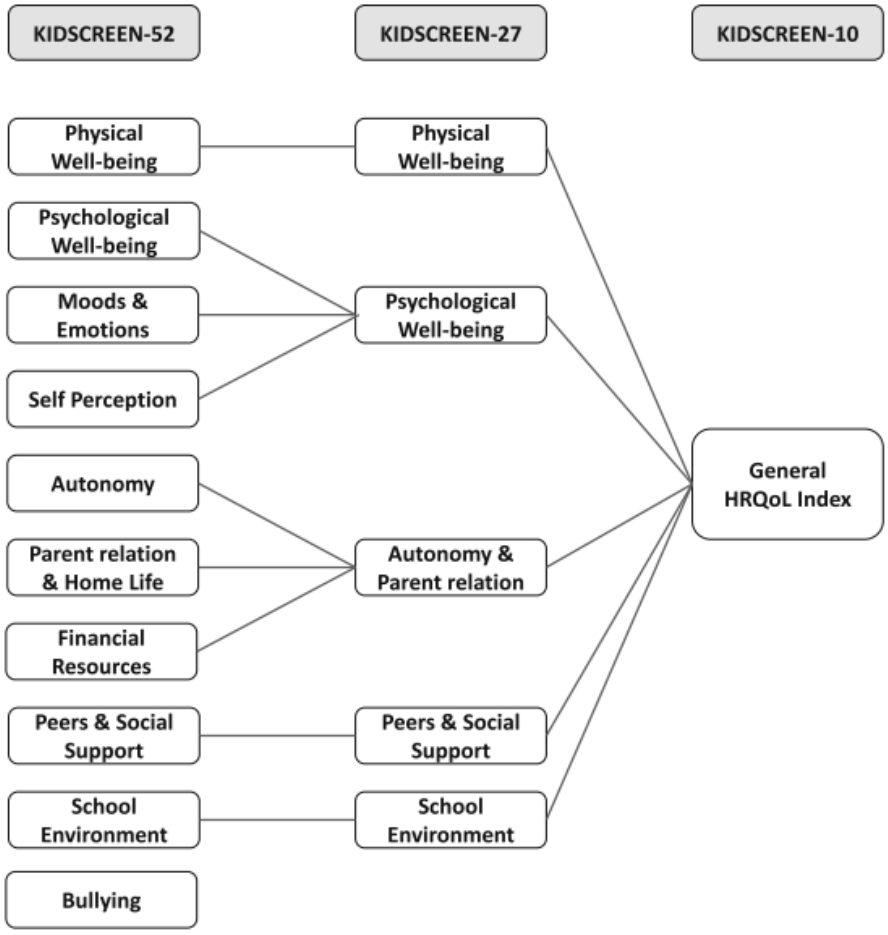

Figure 7. Dimensions of the KIDSCREEN instruments and relationship between versions [18]

In Papers I, II, and IV, HRQOL in adolescents was assessed using the KIDSCREEN-27 [252, 253]. This instrument was developed as a shorter version of the KIDSCREEN-52 with good psychometric properties and with a minimum of information loss. It represents the ten dimensions from KIDSCREEN-52 merged into 5 HRQOL dimensions/subscales, allowing detailed profile information for the dimensions: 1) physical well-being (5 items) which explores

the level of the respondent's physical activity, fitness, and energy; 2) psychological well-being (7 items) including items on positive emotions, satisfaction with life, and feeling emotionally balanced; 3) autonomy and parent relations (7 items) which examines the relationship with parents, the atmosphere at home, feelings of having enough age-appropriate freedom, and the degree of satisfaction with financial resources; 4) social support and peers (4 items) which examines the respondent' relationships with other adolescents; and 5) school environment (4 items) which explores the respondent's perceptions of their cognitive capacity, learning, concentration, and feelings about school [18, 82, 252, 254]. The items refer to the previous week and are rated on a 5-point scale ranging from 1 (never/not at all) to 5 (always/extremely), indicating either the frequency of certain behaviors or feelings or the intensity of an attitude. We computed Rasch scores for each subscale and transformed them into t-values in line with the KIDSCREEN handbook [82]. These t-values are normed to a mean (standard deviation [SD]) of 50 (10) and can be used to make comparisons with international t-values. For the interpretation of the subscale scores, the content of the subscales must be considered. The basic information about the subscales is given by their definitions. Higher scores indicate better HRQOL in the respective subscale/HRQOL dimension. The KIDSCREEN manual provides interpretations for very low or very high scores of each subscale/HRQOL dimension [82]. The internal consistency values of the KIDSCREEN-27 have been reported to be satisfactory across all five subscales, and the test-retest reliability ranges from 0.61 to 0.74 [82]. Cronbach's alpha values for the instrument in Papers I, II, and IV are given in Table 2.

In Paper III, HRQOL in adolescents was assessed using KIDSCREEN-10 [128, 255]. This instrument provides a singular index that represents a global HRQOL score for the dimensions of the longer KIDSCREEN versions [18, 82] as depicted in Figure 7. In our study, we derived ten items from the 27-item version to develop the KIDSCREEN-10 version in line with the KIDSCREEN handbook [82]. The ten items within KIDSCREEN-10 cover perceptions of physical well-being (2 items), psychological well-being (2 items), autonomy and parent relations (3 items), social support and peers (1 item), and school environment (2 items). We computed Rasch scores and transformed them into t-values in line with the KIDSCREEN handbook [82]. These t-values are normed to a mean (SD) of 50 (10) and can be used to make comparisons with international t-values. The

Norwegian KIDSCREEN-10 is considered valid and reliable [251]. Cronbach's alpha value for the instrument in Paper III is given in Table 2.

In Papers II and III, HRQOL in parents was assessed using the 36-item Medical Outcomes Study Short Form (RAND-36). This is a generic questionnaire consisting of 36 questions organized into 8 health concepts/domains: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health. These domains can be combined into a physical component sum score (PCS), reflecting physical health, and a mental component sum score (MCS), reflecting mental health [256, 257]. Recommended scoring procedures were followed. Sum scales were expressed in values from 0–100, with 100 representing excellent health [256, 257]. We reported the PCS and MCS results in Papers II and III only. Previous international studies have found RAND-36 to be a reliable, valid, and suitable instrument for HRQOL measurement in adults [258, 259]. The Norwegian RAND-36 version is also considered valid and reliable [260]. Cronbach's alpha values for the instrument in Papers II and III are given in Table 3.

5.5.3 Pain measures

In Papers I, II, and IV, pain was assessed using the BPI, which consists of four questions related to pain severity or intensity (pain now, at its worst, at the least, and on average) and seven questions related to pain interference on aspects of life related to activity and emotions [261, 262]. The items are presented as numeric rating scales, with 0 = no pain to 10 = pain as bad as you can imagine. The interference items can be combined into two indexes of interference: activity and emotions [261]. The instrument has been used among Norwegian adolescents and adults [262-266]. The Norwegian BPI version has shown satisfactory psychometric properties [262] and is considered a valid and reliable pain assessment tool [266].

Furthermore, in Papers I, II, and IV, pain frequency and duration were assessed using two selected questions from the Lübeck Pain-Screening Questionnaire (LPQ), which evaluates pain during the preceding three months [267]. Pain duration was measured in three categories: pain lasting more than 3 months,

more than 6 months, or more than 12 months. Pain frequency refers to how often pain is experienced and categorized as daily pain, pain several times a week, or pain once a week. In Paper II, the adolescents were also asked about self-perceived pain triggers. A list of possible triggers was given (anger/disputes, sadness, agitation, school situation, schoolwork, a lack of sleep, cold/illness, digital technology use, social media, screen time, loneliness, sport/physical activities, menstruation, change of weather, noise, family condition, a new situation, nutrition/sweets, nonspecific factors, other). This list was derived from the LPQ, with the addition of social media and screen time as possible triggers due to previous studies showing that these factors have an impact on adolescents' well-being and pain [7, 46-49, 268]. The adolescents were asked to tick all possible triggers. The original LPQ has demonstrated satisfactory content and face validity and has previously been validated in a German study that used qualitative research methods to examine the instrument's content [269]. The Norwegian LPQ version has demonstrated high internal consistency and satisfactory content validity [14].

OTC analgesic intake in adolescents and parents was assessed in Papers I and II using two questions derived from the Norwegian "Pain, Youth and Self-Medication study" (SUS) [105, 270]. During the SUS's questionnaire development, adolescents were involved through a three-step process [105, 270]. Respondents were asked about OTC analgesic intake during the last four weeks and the frequency of OTC analgesic intake.

5.5.4 Self-esteem

In Papers I, II, and IV, self-esteem in adolescents was assessed using the 4-item version of the Rosenberg Self-Esteem Scale (RSES) [271], which consists of four statements on self-perception related to attitude toward oneself, the feeling of uselessness, the state of having something to be proud of, and self-worth. The items are rated on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Items are recoded so that higher values always indicate higher levels of self-esteem. Scores on the four items are summed and divided by 4 to produce an RSES score ranging from 1 to 4. The four-item version is highly correlated (0.95) with the 10-item version [272]. The Norwegian version has previously been used among adolescents and has shown good internal

consistency [273-276]. Cronbach's alpha values for the instrument in Papers I, II, and IV are given in Table 2.

5.5.5 Self-efficacy

In Papers I, II, and IV, self-efficacy in adolescents was assessed using the Generalized Self-Efficacy Scale (GSE), which consists of 10 items that reflect optimistic self-beliefs in coping with the demands, challenges, and tasks of life in general [277, 278]. The items are rated on a scale ranging from 1 (completely wrong) to 4 (completely right). The scores on each item are summed and divided by 10 to produce a GSE score ranging from 1 to 4. Higher GSE scores indicate higher levels of generalized self-efficacy. The Norwegian GSE has been shown to be valid and reliable with satisfactory internal consistency [278, 279]. Cronbach's alpha values for the instrument in Papers I, II, and IV are given in Table 2.

5.5.6 Loneliness

In Papers I, II, and IV, loneliness in adolescents was assessed using the eight-item version of the revised UCLA Loneliness Scale (ULS-8) [280]. This instrument is a short version of the widely used 20-item revised UCLA Loneliness Scale (ULS-20) [281], which is considered to be an adequate and reliable measure of loneliness among adolescents [282]. ULS-8 is rated on a 4-point Likert scale ranging from 1 (never) to 4 (always). The total score ranges from 8–32, with higher scores indicating a higher degree of loneliness. ULS-8 has been recommended as a good substitute for the longer ULS-20 [280, 282, 283].

The ULS-8 questionnaire was translated into Norwegian using a standardized translation procedure according to an international cross-cultural translation manual. This procedure includes a forward–backward–forward translation technique, with pretesting and cognitive interviews during a pilot test [284]. The instrument developer was contacted in advance and gave permission to translate the questionnaire into Norwegian.

First, the questionnaire was translated into Norwegian by four independent researchers with Norwegian as their mother tongue. This group agreed upon the

first Norwegian version. Second, the questionnaire was backtranslated into English by two professional translators with English as their mother tongue. Third, the English and Norwegian versions were compared by the first group of researchers, and inadequate concepts and differences between the alternative versions were discussed. This resulted in a preliminary Norwegian version. Three adolescents (two girls and one boy aged 14–17 years) and three parents (one mother and two fathers) participated in the pilot study with a pretest, followed by cognitive interviews. Adolescents and parents reported that the questionnaire was easy to understand and self-administer, except for one item (I am an outgoing person) that two of the adolescents found difficult to understand. Considering this specific item, changes were made to the questionnaire after the pilot test. Finally, an agreement on the final Norwegian ULS-8 version was reached by the first group of researchers. The reliability of this Norwegian ULS-8 version was assessed in Papers I, II, and IV using the Cronbach's alpha coefficient – which was above 0.80 (see Table 2) in all papers, suggesting good internal consistency for the instrument [246].

5.5.7 Stress

In Papers I, II, and IV, stress in adolescents was assessed using the Perceived Stress Questionnaire (PSQ) [285-287]. The PSQ consists of 30 items both negatively and positively formulated to reduce acquiescent bias. The items are rated on a 4-point rating scale ranging from 1 (almost never) to 4 (almost always) and referring to the last 4 weeks. Answers are recoded so that higher scores always indicate higher levels of perceived stress. The PSQ total score is linearly transformed between 0 and 1: PSQ = (raw value − 30) / 90. The recommended cutoff levels of perceived stress within the PSQ are low: < 0.33, medium: 0.33–0.45, moderate: 0.45–0.60, and severe: > 0.60 [285]. The Norwegian PSQ is considered valid and reliable [287]. Cronbach's alpha values for the instrument in Papers I, II, and IV are given in Table 2.

5.5.8 Sleep

In Papers I and II, sleep in adolescents was assessed using two selected questions derived from the School Sleep Habits Survey [168]. We used one question regarding problems with sleepiness during daily activities and one question regarding the frequency of enough sleep. The School Sleep Habits Survey has been widely used among adolescents and has an established validity compared to

actigraphy and sleep diaries [288]. The questionnaire has previously been used among Norwegian adolescents [289].

5.5.9 COVID-19-related worries

In Paper III, COVID-19-related worries in adolescents and parents were assessed using selected questions derived from the Norwegian study "Adolescents in Oslo in the Time of the COVID-19 Pandemic" [188, 290]. Two questions were used concerning whether the COVID-19 pandemic had changed the participants' lives positively and/or negatively. Further, six questions related to COVID-19-related worries were used, focusing on becoming sick and infecting others, as well as on being worried about family/friends becoming sick, school grades (for adolescents), work (for parents), the family's economy, and the Norwegian economy.

5.5.10 Health Literacy

In Paper III, HL in adolescents was assessed using the Health Literacy in School-Aged Children (HLSAC) questionnaire [291]. HLSAC consists of two items from each of the following theoretical components: theoretical knowledge, practical knowledge, critical thinking, self-awareness, and citizenship – in total, 10 items. Five of these items were informed by the Health Literacy Questionnaire (HLQ) [292]. Respondents are asked to rate whether items represent their opinion on a scale ranging from 1 (not at all true) to 4 (absolutely true). Based on the sum score, HL levels can be defined as low: score 10–25, moderate: score 26–35, or high: score 36–40 [293, 294]. Because of its satisfactory reliability, one-factor validity, and quick administration, the HLSAC instrument is considered appropriate for use in schools [295]. It was originally validated for adolescents in seventh and ninth grades [291], but it has also been applied among older adolescents [31, 296, 297]. The Norwegian HLSAC has been used among adolescents and has shown a dominant first factor, with eigenvalue = 3.88 and good internal consistency [31]. Cronbach's alpha value for the instrument in Paper III is given in Table 2.

HL in parents was assessed in Paper III using the HLQ, a generic, multidimensional instrument consisting of 44 questions that represent 9 independent HL domains [292]. We selected and used five of these domains that we considered to be most relevant to the paper's study purpose: having

sufficient information to manage my health (4 items), actively managing my health (4 items), appraisal of health information (5 items), ability to find good health information (5 items) and understanding health information well enough to know what to do (5 items). The first three of these selected domains are scored using response options ranging from 1 (strongly disagree) to 4 (strongly agree). The last two domains are scored using response options ranging from 1 (cannot do or usually difficult) to 5 (very easy). Domain scores are calculated as the average of the item scores. Higher scores indicate higher HL levels [292]. The Norwegian HLQ is considered valid and reliable [298]. Cronbach's alpha values for the instrument in Paper III are given in Table 3.

5.6 Data analyses and statistical methods

Different statistical methods were used, depending on the research questions addressed in the papers. The analyses were conducted with SPSS (versions 26 and 27) and Stata (version 16). For each analysis, the assumptions for the applied method (statistical test or model) were checked and fulfilled. After thorough discussions with the affiliated statistician and based on whether the analyses were considered exploratory (implying a need to adjust for multiple testing) or not, p-values< 0.05 or < 0.01 were considered statistically significant. More details regarding the analyses used are presented below and in Papers I–IV.

5.6.1 Descriptive statistics

In all papers, descriptive statistics were used to present the characteristics of the sample. The selected variables were presented as counts and percentages for categorical variables and as means and SD or medians and min/max for continuous variables, as appropriate. Details are provided in Papers I–IV.

5.6.2 Bivariate analyses

In Papers I–III, associations between pairs of variables were assessed using the chi-square test for categorical variables. Independent samples t-tests were used for normally distributed continuous variables, and the Mann–Whitney U test was used for continuous data where normal distribution could not be assumed [246]. Furthermore, in Paper II, associations between pairs of variables according to three pain groups were assessed using ANOVA, with Tukey's HSD post hoc test

for normally distributed continuous data and the Kruskal–Wallis test for variables that did not follow normal distribution [246].

In Paper IV, crude differences in HRQOL between Time 1 (adolescents aged 14–15 years) and Time 2 (adolescents aged 16–17 years) were analyzed using paired samples t-test [246]. The assumptions for this test were fulfilled, as all the HRQOL variables were considered normally distributed.

The empirical and theoretical rationale for assessing HRQOL stratified by gender in Papers I, III and IV was based on previous research demonstrating gender differences in HRQOL during adolescence [24, 25, 128, 198, 204, 205] and a need for more detailed studies of the specific HRQOL dimensions affected by gender [198, 201]. Through our research we wanted to increase the knowledge of gender differences related to adolescents' HRQOL in a Norwegian setting and gain more knowledge on whether and how specific HRQOL dimensions were different between genders.

5.6.3 Regression

In Paper I, linear regression analyses [246] were used to assess the strength of possible associations between HRQOL and selected covariates grouped into seven blocks (B1–B7): B1: Sociodemographic variables, B2: Self-efficacy, B3: Self-esteem, B4: Pain on average, B5: Frequency of enough sleep, B6: Loneliness, and B7: Stress. To assess possible associations between the covariates in each block and HRQOL, linear regression models were fitted separately for each of the five KIDSCREEN-27 subscales as the dependent variables. Moreover, hierarchical regression analyses [246] were used (method enter) to further assess the strength of adjusted associations between HRQOL and the seven blocks. The covariates were entered into the regression in seven steps by adding covariates from a previous block consecutively, leading to seven linear regression models (M1–M7) fitted for each of the KIDSCREEN-27 subscales. The strength of the associations between the covariates in each block and the dependent variables was expressed using standardized regressions coefficients (effect sizes) and explained variance (adjusted R^2). Because our independent variables were measured with different units and scales, and because of the article's aim, presenting standardized regression coefficients was considered

most appropriate. An unstandardized regression coefficient would represent the amount of change in the dependent variable due to a change of one unit of the independent variable. Standardized regression coefficients are values that have been converted to the same scale, which makes it possible to compare the impact of any independent variable on the dependent variable in the model regardless by what scale the variable is measured. Standardized regression coefficients indicate the number of SDs that scores in the dependent variable will change per one SD unit change of the predictor variable [246]. Per definition, the more variables included in a model, the higher the R^2. Thus, we reported the adjusted R^2 that compensates for this by "penalizing" for adding variables that do not improve the existing model. Adjusted R^2 informs of the variation explained by only the independent variables that actually affect the dependent variable [299]. Furthermore, a multiple testing problem may occur when one considers a set of statistical inferences simultaneously, as done in Paper I. The more inferences are made, the more likely erroneous inferences become (the risk of making a type I error) [300]. Thus, to adjust for multiple testing using a pragmatic approach, p-values ≤ 0.01 were considered statistically significant in Paper I.

The interpretation of our hierarchical model in Paper I can be different based on which findings are considered more or less clinically relevant. However, the statistical interpretation is as follows; given the large amount of data, the order in which we entered our variables (or more precisely blocks of variables; B1 -B7) did not influence the significance level of entered variables. In small datasets the order in which variables are entered into a model might change the significance of a given variable; if variable 1 is strongly correlated to variable 2, and variable 2 is entered first, variable 2 will be statistically significant and variable 1 will not and vice versa. However, this is not the case for our large data. Moreover, we chose to group possible explanatory variables into seven blocks (B1–B7) to illustrate how these groups were associated with the outcome.

In Paper III, multiple linear regression analyses [246] were used to explore possible associations between the selected covariates and HRQOL in adolescents. KIDSCREEN-10 was used as the dependent variable. For data on parents, the two RAND-36 sum scores (PCS and MCS) were used as the dependent variables. The assumptions for multiple linear regression were not fulfilled because of outliers. Thus, robust regression analyses (as implemented in

Stata) were used to explore associations between HRQOL in parents and the selected covariates. Robust regression is a form of weighted and reweighted least squares regression that compromises between excluding outliers entirely from the analysis and including all the data points and treating them all equally. The idea of robust regression is to weigh the observations differently based on how well behaved these observations are [301]. Age and education level were entered as covariates in the regression model. Results were presented as unstandardized regression coefficients with 95% confidence intervals (CIs) and p-values. Using unstandardized regression coefficients was considered most appropriate, as they are more intuitive to interpret and understand, given we aimed to build an association model and we did not aim to compare the impact of the included independent variables on the dependent variable.

5.6.4 Mediation

In Paper II, we aimed to explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and/or self-efficacy. The rationale for investigating the mediating role of self-esteem and self-efficacy was based on previous research demonstrating that these factors are associated to higher levels of HRQOL and lower levels of pain and that they might function as protective factors [23, 26, 86, 87, 150, 151, 302]. Furthermore, we considered self-esteem and self-efficacy to be intervening variables within the multidimensional biobehavioral model of pediatric pain by Varni and colleagues [34, 35]. The research group created direct acyclic graph (DAG) to observe if our data would confirm or deny the DAG. We proceeded with using the parallel multiple mediation model depicted in Figure 8. The mediation analyses were conducted using the PROCESS macro method developed for SPSS by Hayes [303]. Hayes has implemented a large number of possible statistical model for mediation analyses based on the original idea of Byron and Kenny [304]. We chose Hayes' model 4 as it was the one that was the closest to our hypotheses. Our hypotheses were based on our clinical knowledge and the available literature. Mediation analyses were fitted separately for the five KIDSCREEN-27 subscales. We used gender, adult members of the household, parental education, and household income as covariates in the mediation analyses. The mediation analyses did not provide p-values. Hence, the effect was regarded as statistically significant if the 95% CI for the effect did not include

zero. Results were presented as unstandardized regression coefficients. Further, it is common to present the mediation effects as percentages, thus the indirect and direct effects were separately divided by the total effect and multiplied by 100.

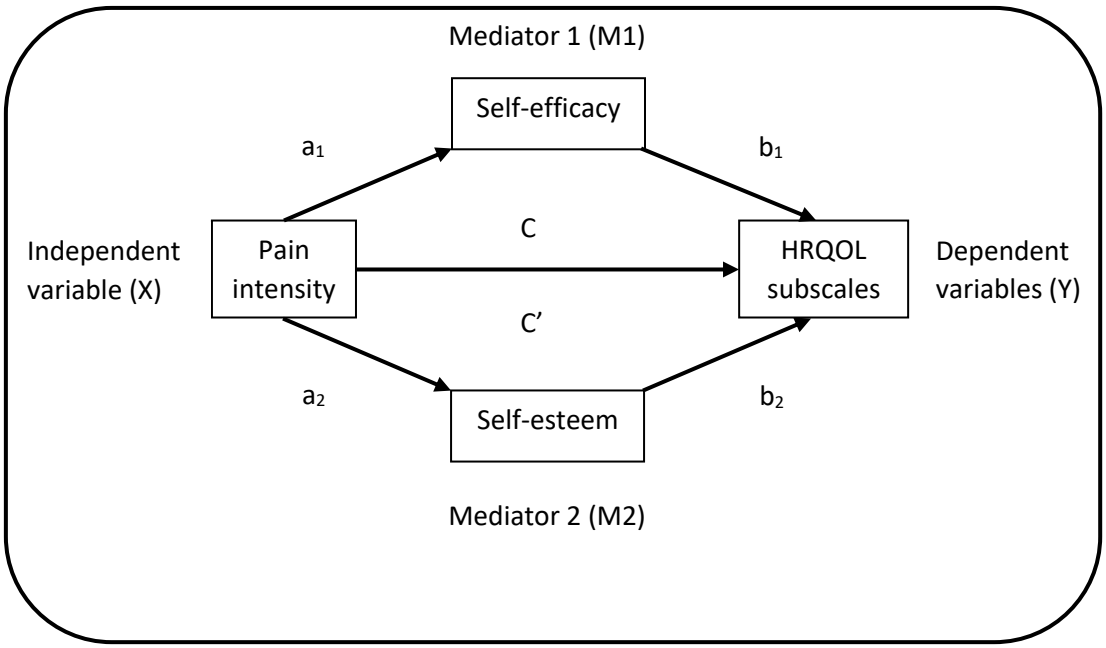

Figure 8. Schematic of our final parallel multiple mediation model

5.6.5 Linear mixed model for repeated measures

In Paper IV, to assess the impact of selected possible predictive factors on HRQOL changes over time, we used linear mixed models for repeated measures (LMM) [305]. Because our longitudinal data consisted of repeated observations of participants in different schools and counties, controlling for this is recommended. Thus, using the LMM approach was considered more suitable than using ANOVA models that allow for repeated measures. A repeated measures ANOVA does not offer the possibility of incorporating the clustering of participants, but LMM does. Furthermore, LMM handles missing data better than ANOVA and does not need complete sets of data while ANOVA requires complete data on all included variables. Although we did not have any missing data in our study, this is considered a strength of LMM. LMMs were fitted separately for the five KIDSCREEN-27 subscales as the dependent variables.

Selected factors (collected at Time 1 when the adolescents were 14–15 years) were entered into each of the models as fixed effects. We originally planned on using the same factors that we used as independent variables in Paper I in Paper IV (entered as fixed effects), but we chose to remove the variables school absence and sleep in Paper IV's analyses. This was done to save statistical power and because these variables were not strongly associated with HRQOL in Paper I. As the same individuals were measured several times, this introduced statistical dependencies which were handled within the LMM framework using an unstructured covariance matrix with no specific parametric form. To accommodate for the design, we entered the variables school (N = 22) and county (N = 4) into the models as random factors in our preliminary analyses, but this did not affect the estimates of the fixed effects (our estimates of interest) and the overall performance of the models. Thus, we removed the random effects from the models to save statistical power. Results were presented as unstandardized regression coefficients (B) with 95% CIs and p-values. A negative/reduced change score would imply lower HRQOL scores at age 16 compared to at age 14 as change was computed from Time 1 to Time 2, while a positive/increased change score would imply higher HRQOL scores at age 16 compared to at age 14.

6 Summary of results

This section presents the main results of Papers I–IV which have all been published [306-309].

6.1 Paper I: Health-related quality of life is strongly associated with self-efficacy, self-esteem, loneliness, and stress in 14–15-year-old adolescents: A cross-sectional study

Paper I aimed to assess possible associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL in 14- to 15-year-old adolescents. A total of 696 adolescents in a school-based setting participated in this cross-sectional study.

Our results showed that the adolescents reported high HRQOL. However, girls scored significantly worse on HRQOL, self-efficacy, self-esteem, pain, sleep, loneliness, and stress compared to boys. Using hierarchical regression analyses, we found that self-efficacy, self-esteem, loneliness, and stress had the strongest associations with the HRQOL dimensions. Sociodemographic-, pain-, and sleep-related covariates were all significantly associated with some of the KIDSCREEN dimensions; however, their effect on the outcome was smaller than for the psychosocial variables listed above. Being a girl, not living with both parents, not having both parents working, being absent from school for more than four days, having pain, and not having enough sleep were all independently negatively associated with HRQOL.

The results from the study indicate that positive psychosocial factors such as self-efficacy and self-esteem might play a buffer role for negative psychosocial factors (e.g., stress) in adolescents. To improve HRQOL in school-based populations of adolescents, we suggest that future interventions should aim to strengthen self-efficacy and self-esteem. We recommend gender-specific interventions.

6.2 Paper II: Pain and health-related quality of life in adolescents and the mediating role of self-esteem and self-efficacy: A cross-sectional study including adolescents and parents

Paper II aimed to describe selected factors and pain in 14- to 15-year-old adolescents and their parents, assess how these factors are associated with adolescent pain groups, and explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and self-efficacy. A total of 508 adolescent–parent dyads from a school-based setting participated in this cross-sectional study. Among these, 148 adolescents had persistent pain.

Our results showed that adolescents with pain reported significantly more stress, loneliness, and a lack of sleep and lower self-efficacy, self-esteem, and HRQOL compared to adolescents without pain. More girls than boys reported pain. Adolescents with persistent pain scored significantly worse on self-esteem, stress, loneliness, a lack of sleep, school absence, pain, and on three HRQOL dimensions compared to adolescents with a shorter pain duration. Considering parental factors, adolescent pain groups did not differ significantly. However, more adolescents with persistent pain reported that someone in their family had pain. In adolescents with persistent pain, the associations between pain intensity and the HRQOL dimensions physical well-being, psychological well-being and school environment were completely mediated by self-esteem but not by self-efficacy. The highest degree of mediation was estimated for the HRQOL dimension school environment (indirect effect = 73.5%).

The results highlight the complexity within adolescent pain, demonstrating that adolescents with pain differ from adolescents without pain with respect to gender, school absence, and within-person and between-person factors. Particularly, adolescents with persistent pain seem to constitute a vulnerable group. We confirm the importance of resilience factors for HRQOL but indicate that self-esteem might be more important than self-efficacy. Still, to promote HRQOL in adolescents with persistent pain, a strengthening of both their self-esteem and self-efficacy is recommended. We highlight the need for an individual, holistic approach to adolescent pain.

6.3 Paper III: Health-related quality of life, health literacy and COVID-19-related worries of 16- to 17-year-old adolescents and parents one year into the pandemic: A cross-sectional study

Paper III aimed to describe HRQOL, HL, and COVID-19-related worries of 16- to 17-year-old adolescents and parents of adolescents one year into the pandemic and to assess the strength of associations between gender, HL, COVID-19-related worries, and HRQOL. A total of 215 adolescents and 320 parents participated in this cross-sectional study.

Our results showed that adolescents' HRQOL was notably lower compared to that of previous Norwegian studies and European norms. Parents' HRQOL was comparable to Norwegian norms. Adolescents and parents reported moderate-to-high HL and high degrees of COVID-19-related worries. Girls and mothers reported significantly lower HRQOL and more worries compared to boys and men, respectively. In adolescents, higher HL was significantly associated with higher HRQOL. COVID-19-related worries were not significantly associated with HRQOL. In parents, higher HL in the "understand health information" domain was significantly associated with higher HRQOL for mental well-being (MCS) and with lower HRQOL for physical well-being (PCS). Being worried a lot about infecting others and about family/friends becoming sick was significantly associated with higher MCS and lower MCS, respectively. COVID-19-related worries were not significantly associated with PCS.

The results indicate that the pandemic has a major negative impact on adolescents' HRQOL. Parents' HRQOL remained unchanged and comparable to previous studies. We demonstrate that gender, HL, and COVID-19-related worries are significantly associated with adolescents' and parents' HRQOL.

6.4 Paper IV: Changes in health-related quality of life in adolescents and the impact of gender and selected variables: A two-year longitudinal study

The primary aims of Paper IV were to investigate possible HRQOL changes in adolescents aged 14 and 16 years and to assess the impact of sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL changes over time. Our secondary aim was to assess HRQOL stratified by gender. A total of 211 adolescents participated in this longitudinal study.

At age 16, the adolescents reported statistically significantly lower HRQOL scores for physical well-being, psychological well-being, and school environment compared to their scores at age 14. Girls reported statistically significantly lower HRQOL scores for three of the KIDSCREEN subscales at ages 14 and 16 compared to boys. The results of the linear mixed models for repeated measures demonstrated that time was significantly associated with a reduction in physical well-being and psychological well-being, meaning that the HRQOL scores for these dimensions would be lower at age 16 compared to when assessed two years earlier (at age 14). Pain, loneliness, and stress were significantly and independently associated with reduced HRQOL change scores for four of the five KIDSCREEN dimensions, meaning that these variables contribute to lower HRQOL scores at age 16 compared to age 14. Pain had its highest negative effect on school environment, loneliness had its highest negative effect on social support and peers, and stress had its highest negative effect on autonomy and parent relations. Further, male gender was significantly associated with a reduction over time in social support and peers compared to female gender. In contrast, self-efficacy and self-esteem were significantly positively associated with higher HRQOL change scores for four and two dimensions, respectively, meaning that these variables contribute to higher HRQOL scores at age 16 compared to age 14. Self-efficacy was significantly associated with an increase in HRQOL for four of the five KIDSCREEN dimensions, with the highest positive effect on school environment. Self-esteem was significantly associated with an increase in physical well-being and psychological well-being. When both parents were employed, this was significantly associated with an

increase in the adolescents' physical well-being, compared to when only one parent was employed.

This study provides important insight into changes in adolescents' HRQOL at two time points, when they are 14 and 16 years old, and into factors associated with these changes. The results highlight the importance of increased understanding regarding factors associated with changes in adolescents' HRQOL to enable accurate and strategic interventions.

7 Discussion

In this section, I will start by discussing methodological considerations. Further, I will discuss the main results of the thesis, divided into three subsections: HRQOL in adolescents, the importance of resilience, and pain in adolescents.

7.1 Methodological considerations

Before discussing the methodological considerations of this study, I will briefly define reliability and validity, as these are important criteria to consider. *Reliability* refers to the consistency and accuracy of a study's obtained information, as well as the accuracy and consistency when an instrument measures an attribute. *Validity* refers to the degree to which the inferences made in a study are well founded and accurate. External validity concerns the degree to which findings can be generalized to other people, settings, and situations. Internal validity concerns the degree to which it is possible to make an inference that the independent variable is truly influencing or causing the dependent variable. Regarding measurement, validity refers to the degree to which an instrument measures what it is supposed to measure [245]. Further in this section, I will discuss methodological considerations related to the study design, study samples, recruitment procedure and data collection, outcome measures, and choice of data analyses. Aspects related to reliability and validity and regarding possible sources of errors or threats will be discussed, as these aspects are of vital importance to consider in order to draw appropriate conclusions [245].

7.1.1 Study design

This thesis used a combination of designs to provide a greater understanding of HRQOL in adolescents and associated factors. A cross-sectional design is appropriate for describing the status or prevalence of a phenomenon and for outlining relationships among phenomena at a specific time point [245]. Hence, considering the main aims of Papers I–III, the cross-sectional design is considered appropriate. A strength of using a cross-sectional design is that it provides information about the prevalence of outcomes (e.g., HRQOL) and/or exposures (e.g., factors associated with HRQOL). Further, it makes it possible to examine associations between the outcome and other factors and to explore underlying mechanisms at a certain time point. However, a limitation of cross-

sectional study designs is that no causal relationships can be identified. As a famous research dictum says, *correlation does not prove causation* [245]. This is because the outcomes and exposures are measured at the same time. Thus, one cannot determine whether the exposures are really exposures for the outcomes. They might be consequences of the perceived outcomes instead. Therefore, our results cannot ascertain causation, only associations.

In Paper IV, we used a longitudinal design. This design is useful for studying changes over time [245], and related to HRQOL in adolescents, longitudinal studies can provide a broader understanding of the direction and magnitude of HRQOL changes, confirm or disconfirm results from cross-sectional data, and help identify factors associated with HRQOL changes [123, 221]. Considering the aims of Paper IV, the longitudinal design is considered appropriate. Few studies have investigated HRQOL changes in general adolescent populations, including a wide range of factors associated with HRQOL changes. Furthermore, longitudinal HRQOL studies in general adolescent populations within the transition period from lower to upper secondary school are scarce. This indicates that the longitudinal design and the inclusion of several factors associated with adolescents' HRQOL in Paper IV can be considered a strength of the PhD study.

7.1.2 Study samples

To minimize possible selection bias, all adolescents and their respective parents at the 22 participating schools were invited to participate, which should be considered a strength. Nevertheless, the response rate across the schools varied from 8.6% to 92.1% at Time 1. It is a very important issue to consider for whom our findings are representative. Especially given large data, one can often derive very biased estimates with large precision. However, due to strict GDPR laws concerning data protection, we were not able to collect any data on those who chose not to participate. Thus, we were not able to compare those who could have been included (nonparticipants) with participants and can only speculate on direction of possible biases in our sample. Based on characteristics of the participants in Papers I and II, we may only speculate that parents with high SES (especially regarding high education level) and of native origin were more likely to give their informed consent. Previous studies have also found that, compared to those who participate, non-participants often have lower SES levels [310, 311]. Only a small percentage of the samples in Papers I–IV were adolescents

within families of low parental education, low income, unemployed parents, immigrant background, and adolescents who lived together with only one parent. Thus, the findings in Papers I–IV may not be generalizable for these subgroups. It is important to consider that socioeconomic inequalities can have a negative impact on adolescents' lives; adolescents with low SES may have worse access to social participation and education than their peers with high SES, families with low SES often report lower HRQOL scores, reduced physical and mental health, and report pain more frequently [12, 13, 26, 97, 121, 124-130, 135-137]. Furthermore, living with two parents is associated to higher HRQOL and better physical and mental health outcomes, and studies have shown that racial/ethnic disparities in adolescent HRQOL and health are substantial, favoring white ethnicity [13, 139-141]. Hence, we encourage future studies to include a higher percentage of participants with low SES, an immigrant background, and adolescents who live together with only one parent to explore our findings more thoroughly given a more representative sample.

Our results from Papers I, III and IV give insight into important gender differences related to adolescents' HRQOL at age 14 and 16. However, as previously mentioned, our sample (especially at Time 2) consisted of a high percentage of girls. Hence, a selection bias may exist in our findings. Knowing that gender differences related to biology and physiology, the onset of puberty, and cognitive, emotional, and social development exist from birth and through life [3, 38, 123], and knowing the important association between gender and HRQOL [24, 25, 128, 198, 204, 205], the high percentage of girls in our sample may have influenced the results and should thus be considered when interpreting our results. We encourage future studies to include a higher percentage of male gender to explore our findings more thoroughly given a more representative sample.

In school studies, there is an assumption that pupils attending the same school are in some respects more alike than pupils from two different schools [245]. Hence, it is a limitation of this study that we did not explore possible cluster effects in Papers I–III. However, in Paper IV, we estimated the random effects of school (N = 22) and county (N = 4), but this did not affect the overall performance of the models or the estimates of fixed effects. The estimation of random effects in Paper IV was also considered important because the severity of the pandemic and

mitigating strategies has varied across Norwegian counties, and the counties Oslo and Viken (former Akershus) experienced more COVID-19-related restrictions, such as social distancing instructions, closed or limited leisure activities, lockdowns, and homeschooling, than Agder during the first year of the pandemic.

Attrition of participants over time can be a major methodological problem in longitudinal studies because the participants who drop out often differ in important respects from the ones who continue participating. This may result in potential biases, concerns about the generalizability of the findings, and the risk of faulty inferences [245, 312]. It is important to note that only around 13% (N=215) of the initial study population from the first data collection (N=1663) participated at Time 2. This calls for caution, but as previously mentioned, we were not able to collect any data on those who chose not to participate at Time 1, making it impossible to compare the nonparticipants at Time 1 with the participants. However, dropout analyses of participants at Time 2 and adolescents who dropped out from Time 1 to Time 2, indicate that the adolescents who participated at Time 2 were not very different from those who dropped out considering HRQOL and the other variables measured, except for the factor gender. The participants at Time 2 comprised significantly more girls. Hence, as previously mentioned, a selection bias may exist in our findings.

The sample of adolescents with persistent pain included in the mediation analyses in Paper II (N = 148) and the study sample size at Time 2 (N = 215) could be considered small, which is a limitation of this thesis and may indicate a threat to its validity because of the risk of bias. Moreover, only one of each adolescent's parents was included in this study. Knowing the importance of gender regarding adults, and the fact that mothers and fathers may have different roles in relation to their children, this may have affected the results and is thus a limitation of this study. Hence, I recommend the inclusion of both parents in future studies.

7.1.3 Recruitment procedure and data collection

Most schools that declined to participate in the Start Young study said that they did not have time to contribute and/or that they were already involved in other research projects. Similar findings were also reported in the latest HEVAS report

[7], where more than 60% of principals at the nonparticipating schools said that they declined to participate because they did not have the time or capacity to complete. The principals also pointed out that schools participate in too many surveys and that several schools therefore choose to concentrate on surveys that are compulsory or school owner–initiated [7]. This indicates a challenge with recruiting schools to participate in research surveys, especially for smaller research projects.

That parents had to explicitly give their consent for the adolescents to participate in the study may have led to a low response at Time 1. At each school, we experienced that on the day of data collection, several adolescents told the researchers that they wanted to participate in the study, but they had forgotten to bring their parents' consent form or ask their parents to give their consent. However, it should be considered a strength that we altered the recruitment procedure by also giving parents an opportunity to provide written consent as soon as we were made aware of the challenge regarding two-factor authentication to give informed consent. Further, that parents were only given written information about study participation may have resulted in more nonresponders among adolescents and parents with an immigrant background. We did inform all schools about the possibility of joining, for example, parent meetings to inform parents orally as well (see Appendix 1); however, it was impossible to facilitate this for any of the participating schools. There were also some technical problems on the day of data collection at one school. Together, these may partly explain the low response rate in this study.

Knowing adolescents are a difficult population to recruit [313], we could have provided reminders using multiple platforms, as recommended for online trials [314]. That we only used email and SMS as communication platforms at Time 2 could be considered a limitation. Given the rapid development of technology, there were probably other appropriate platforms for communicating with adolescents during the follow-up recruitment procedure at Time 2 that we could have used as well.

Differences in procedures regarding recruitment and data collection may have influenced the validity of the study's findings [60, 245]. Steps were taken to attain as much control as possible over the external factors/the research

environment. An advantage of the study recruitment procedure at Time 1 is that the researchers provided information to adolescents during school hours, ensuring that adolescents in each classroom and at each school received the same oral and written information before study enrollment. Further, all questionnaires were answered during school hours while researchers were present and could offer help, if necessary. Together, these may have reduced possible bias in the enrollment and data collection process.

About 90% of adolescents and parents used about 20–30 minutes to complete the survey, but the time varied significantly. Although we removed several questions after the pilot study, it is possible that our electronic survey still entailed too many questions, at least for those with a slow reading capacity. This may have reduced participants' motivation and concentration at the end of the survey, causing some participants to not answer the last part of the survey precisely. Further, participants who completed the survey in their spare time (adolescents at Time 2 and parents at both times) may have been distracted by other things happening around them, which may have negatively affected their concentration. Also, it is possible that participants who rapidly completed the survey did not use enough time to answer all the questions precisely. Together, these may have led to errors in the data collection that may threaten validity.

7.1.4 Outcome measures and data analyses

The description of HRQOL presented in Papers I-IV is differently worded from the HRQOL definition presented in this thesis, which may lead to unclarity. Although I refer to the same article [17] as reference in the papers and in the thesis, we chose to rewrite the description of HRQOL in the papers to emphasize the subjectivity related to HRQOL and also describe aspects of health that are included in HRQOL. Retrospectively, I do think that providing the same HRQOL definition in the papers that I present in the thesis, would have been better. Still, it is considered a strength that the KIDSCREEN instruments used to measure HRQOL in the four papers are conceptually based on the same definition of HRQOL that is used within this thesis [17, 18].

Self-report is the "gold standard" in HRQOL research [17, 60, 315]. Thus, it is a strength of this study that the adolescents described their HRQOL by PROMs.

We also used PROMs to measure the other selected variables in this study. Most of these factors were assessed with validated instruments, and all multi-item scales showed satisfactory Cronbach's alpha values of above 0.7 (Tables 2 and 3) – which indicates internal consistency and, thus, reliability for multi-item scales [246]. Together, this should be considered a strength of this study. Nevertheless, although the selected instruments in this study have been validated in adolescent samples, not all of them have been validated for Norwegian adolescents. The BPI and HLSAC instruments have previously been used among Norwegian adolescents but have not been properly validated among Norwegian adolescents. Further, although the ULS-8 instrument was translated into Norwegian using a rigorous translation procedure and the instrument showed satisfactory Cronbach's alpha scores above 0.80, indicating high internal consistency reliability, this new Norwegian version has not been properly validated among Norwegian adolescents. Together, this is considered a limitation of our study, and validity testing of the BPI, HLSAC, and ULS-8 in a general Norwegian adolescent sample is highly recommended for further research.

It is recommended that the recall period of PROMs for children and adolescents should be kept short to prevent recall bias [315]. Hence, it is a strength that most of the selected instruments, including KIDSCREEN, use a recall period of one week or less. However, the PSQ instrument uses a four-week recall period, but previous research has suggested that a recall period of four weeks to one month is manageable for adolescents [315, 316]. The pain frequency question from LPQ refers to a three-month recall period, which might be a long period to remember for the adolescents and may thus have reduced the validity of the data. A study reporting on recall periods related to pain measurement has shown that when compared to daily pain diary entries, recall accuracy of pain frequency improves at 30 days compared to 90 days [317].

We included some potential confounders in the analyses of Papers I–IV. Nevertheless, possible confounding by other relevant variables not included that may have contributed to the associations, such as depression, anxiety, bullying, and physical activity, cannot be ruled out. Our results could have been different if this had been done. As the results presented in Tables 4 and 5 of Paper I show, the selected variables may explain some of the variation in the HRQOL dimensions but not all. Given the analyzed variables, the explained variance in

Paper I was the highest for the psychological well-being dimension (65.8%). For the other four HRQOL dimensions, the explained variance varied between 30.8% (physical well-being) and 40.4% (school environment). This indicates that the selected variables in this thesis may be more suitable to explain the dimension psychological well-being than the other four HRQOL dimensions. The psychosocial variables (self-efficacy, self-esteem, loneliness, and stress) had the largest effects in terms of standardized beta on the HRQOL dimensions. However, none of these four psychosocial variables had a unique statically significant association with every HRQOL dimension. It should also be noted that the level of covariance between each of these variables and the outcome was higher for the psychological well-being dimension. Furthermore, some items in the instruments related to loneliness (ULS-8) and self-esteem (RSES) are fairly similar to items in the psychological well-being dimension. Thus, it was unsurprising that the explained variance was highest for the psychological well-being dimension. However, preliminary analyses in Paper I showed that the level of collinearity between each of the selected variables and the psychological well-being dimension was acceptable. Thus, we were able to estimate the effect of all covariates. Nevertheless, more knowledge about the associations between HRQOL and other variables not included in our analyses is needed to fully explain the variation within different HRQOL dimensions. I recommend that other relevant factors should be addressed and controlled for in further HRQOL research.

We chose to focus on the psychosocial factors in our interpretation of the hierarchical model in Paper I as these are variables which might be targeted in an intervention. However, the statistical interpretation is always in terms of statistical association and never in terms of possible causal influence which cannot be proven using traditional statistical methodology. Statistical models only reveal statistical associations, the strength of a modelled association. However, the clinical interpretation is based on our beliefs, knowledge, and existing literature. We chose to interpret our findings as a possible “buffering effect” of positive psychosocial factors (self-efficacy, self-esteem) on negative factors (stress), but it can be viewed differently. Traditional statistical models never imply any causality; however, it is up to the researcher to interpret the findings.

The main idea behind mediation analysis is to draw a graph depicting our perception of possible associations between selected variables and in step 2 use the data to confirm (or not) our hypotheses. The mediation models in Paper II aimed to explore possible underlying mechanisms of the relationship between pain intensity and HRQOL in adolescents with persistent pain. The research group created the DAG (see Figure 8) to observe if our data would confirm or deny the DAG. Hence, the mediation models were of an exploratory nature and were based on our assumptions and understanding of the current research area. Thus, we can only assume the direction of the indirect and direct effects.

The use of a generic instrument to measure self-efficacy may have led to self-efficacy not being significant in our mediation analyses in Paper II. It is possible that the results would be different if we had used a specific instrument measuring pain self-efficacy instead of using the GSE. Therefore, it cannot be excluded that self-efficacy is a mediator in the relationship between pain and HRQOL, even if we were unable to demonstrate it in our study. Pain self-efficacy can be defined as "one's confidence in successfully dealing with pain, which arises from feeling capable of implementing appropriate pain coping strategies" [318]. Previous studies on children and adolescents with chronic pain have found that pain self-efficacy is associated with higher HRQOL, fewer depressive symptoms, less disability, and better school functioning [151, 302]. The reason for why we chose to use the GSE in the Start Young study was to explore the associations between self-efficacy and various factors, such as HRQOL and stress, and not solely focus on pain. As the survey already included many questions, it was not possible to include more than one self-efficacy instrument. Furthermore, the pain intensity reported by the adolescents in Paper II is not considered high, which indicates that the results of Paper II may not be generalizable to adolescents with higher levels of pain. I recommend that our results should be replicated and verified in future and larger studies and among adolescents with higher pain intensity. Further, I recommend that future studies test our hypothesis using a specific pain self-efficacy instrument.

More knowledge of family patterns related to HRQOL, HL, and COVID-19-related worries one year into the pandemic would be valuable and interesting to analyze. Nevertheless, adolescents and parents included in Paper III were not paired into adolescent–parent dyads – as there was a mismatch between the

adolescents and parents participating in the study at Time 2, which would have led to a small sample of adolescent–parent dyads in Paper III. Furthermore, we considered it important to provide knowledge of both adolescents' and parents' HRQOL, HL, and COVID-19-related worries, and because the pandemic was still ongoing, it was considered important to publish our results as soon as possible. However, we realized that we did not have enough time and resources to write one paper focusing on adolescents and another paper focusing on parents. Thus, we chose to focus on both adolescents and parents in Paper III.

In Paper IV, factors collected at Time 1 when the adolescents were 14–15 years old were entered into each of the models as fixed effects. Using data from Time 1 as fixed effects gives an opportunity to gain increased knowledge of whether and how the selected factors at age 14–15 are associated with HRQOL changes over time. This provides insight into whether it is important to intervene in selected factors during early adolescence to promote adolescents' future HRQOL. Another possibility was to use change scores as fixed effects. This could, among other things, have made it easier to view the results in light of the pandemic. Hence, such analyses are recommended for future studies to conduct.

7.2 Discussion of main results

The overall aim of this thesis was to expand our knowledge of HRQOL and pain by investigating sociodemographic, psychosocial-, pain-, sleep, HL- and COVID-19-related factors associated with HRQOL in a school-based sample of Norwegian adolescents and in their parents during two years of youth. This section will discuss the main findings of this thesis in relation to current research evidence and theory, including the revised Wilson and Cleary model by Ferrans and colleagues [22]. Moreover, when discussing pain, findings will also be related to the multidimensional biobehavioral model of pediatric pain by Varni and colleagues [34, 35].

7.2.1 HRQOL in adolescents

The results of this thesis and the four related papers indicate that HRQOL in adolescents should be viewed as a complex picture. Our results demonstrate that several factors are associated with adolescents' HRQOL and changes in their

HRQOL. Hence, we highlight the importance of understanding the underlying mechanisms related to HRQOL.

Ferrans and colleagues' [22] revised model provides an understanding of the relationships among different HRQOL components that is useful to provide a theoretical understanding of HRQOL in adolescents and how the variables included in this PhD study may be related to HRQOL. The four papers provide different views into the HRQOL of adolescents, by exploring characteristics of the individual (age, gender, ethnicity, self-esteem, self-efficacy, sleep, and HL) and of the environment (loneliness, who the adolescents live with, parental factors, and (indirectly) the COVID-19 pandemic) that are associated to and may influence both symptoms and the HRQOL of adolescents. Furthermore, we explore how the symptoms pain, stress and COVID-19-related worries are associated to and may influence adolescents' HRQOL (see Figure 3). The results contribute to HRQOL research by exploring adolescents' HRQOL using different analyses and both cross-sectional and longitudinal designs. The results provide support for the revised Wilson and Cleary model, by demonstrating how the above-mentioned factors influence and are associated to adolescents' HRQOL dimensions.

The results of Papers I, III and IV demonstrate significant gender differences in HRQOL insofar as boys reporting higher HRQOL compared to girls for several dimensions, but not all. Our findings are in accordance with previous research among adolescents [24, 25, 128, 198, 200, 204, 205]. Moreover, our results add to existing knowledge by assessing several other factors simultaneously. In Paper I, when the adolescents were aged 14–15 years, adjusted associations showed that gender was statistically significantly associated only with the dimension autonomy and parent relations. Being a girl was associated with higher HRQOL in this dimension. In Paper IV, when the adolescents were aged 16–17 years, the results showed that when all the selected variables were added into the linear mixed models, gender was statistically significantly associated only with changes in social support and peers. Being a boy was associated with reduced HRQOL in this dimension. The findings of no significant association between gender and changes in HRQOL in four of the HRQOL dimensions in Paper IV are similar to that of Langeland and colleagues' study, which found no significant difference between the decline in HRQOL (assessed with KIDSCREEN-10) for Norwegian

boys and girls from the first to the third year of upper secondary school [200]. The results in Paper IV may indicate that gender-related differences in HRQOL remained unchanged from 14 to 16 years, and Langeland and colleagues' [200] results indicate that this may also be the case for adolescents aged 16–18 years as well. Considering that the decline for most HRQOL dimensions in these studies was comparable between genders in late adolescence, this might imply that the gender-related differences increase most rapidly from early adolescence. Thus, further understanding of factors associated with HRQOL and possible underlying mechanisms in this population is important. Possible explanations for why gender was not significantly associated with four of the HRQOL dimensions in Papers I and IV might be that gender is important to adolescents' HRQOL, but that part of the differences in HRQOL scores between boys and girls can be explained through gender-related differences in the other factors associated with HRQOL, such as self-esteem, self-efficacy, loneliness, stress, pain, and sleep. Similar differences between genders have also been reported in previous studies [7, 23, 150, 159, 319].

Based on previous research [13, 26, 97, 124-130], one would assume that low SES would be negatively associated with HRQOL in adolescents. However, the results of Papers I and IV showed that the selected sociodemographic factors were not strongly associated with the adolescents' HRQOL. In Paper I, sociodemographic factors were significantly associated with the HRQOL dimensions physical well-being, psychological well-being, and autonomy and parent relation (unadjusted associations). Not living with both parents and not having both parents employed was significantly associated with lower HRQOL, but when we adjusted for other factors, such as stress, pain, loneliness, self-efficacy, and self-esteem, these associations were no longer significant. It is possible that these factors outweighed the influence of SES on HRQOL in Paper IV as well – except for the factor parents' work status, which was associated with physical well-being. When both parents were employed, this was significantly positively associated with changes in HRQOL scores compared to when only one parent was employed. Interestingly, a recent article from Start Young among the adolescents' parents found that work affiliation is strongly associated with parents' HRQOL [320]. Hence, it is plausible to think that parents' work affiliation may also influence adolescents' well-being. Another possible explanation is that the results regarding the association between the selected

sociodemographic factors and HRQOL in all four papers may have been influenced by a high SES in our sample. We did not assess parental education in Papers I and II. It is possible that this factor could have changed our results, as high parental education is positively associated with adolescents' HRQOL [26, 126, 129, 321]. Furthermore, results from a recent longitudinal study suggest that family education and income may influence HRQOL at the start of adolescence but that its effect fades as adolescents mature [129].

The results of Papers I and IV show that loneliness is negatively associated with two HRQOL dimensions of 14- to 15-year-old adolescents and changes in four of their HRQOL dimensions, meaning that loneliness contribute to lower HRQOL scores for these dimensions at age 16 compared to age 14. Loneliness was most strongly associated with the HRQOL dimension social support and peers (Paper I) and changes in the dimension (Paper IV). This was unsurprising, considering that some of the items in ULS-8 and this KIDSCREEN dimension are fairly similar. However, preliminary analyses in the papers showed that the level of collinearity between loneliness and social support and peers was acceptable. Thus, we were able to estimate the effect of both covariates. Moreover, the results of Paper II highlight that loneliness is a significant problem among adolescents with persistent pain. Based on previous research [3, 40, 88, 89, 102, 153-156], our results, and that the COVID-19 pandemic is associated with increased rates of loneliness among adolescents [10, 179], continued efforts to prevent and reduce loneliness during adolescence seems highly important. Previous research highlights that failure to resolve loneliness during adolescence may pose significant concerns for future mental health, physical health, and social relationships, as well as later midlife outcomes related to education and employment [153, 155].

The stress levels reported by our sample of adolescents aged 14–15 years are a little lower compared to previous findings among Norwegian adolescents [9, 159]. Although the stress scores in our sample indicate low stress levels, the results of the final models in Papers I and IV show that stress is negatively associated with three HRQOL dimensions of 14- to 15-year-old adolescents and changes in four of their HRQOL dimensions, meaning that stress contribute to lower HRQOL scores for these dimensions at age 16 compared to age 14. Furthermore, although our study did not provide large effect sizes for the strength

of association between stress and HRQOL in the final analyses, our findings suggest that stress is a risk factor for adolescents' HRQOL, even with low stress levels, and our results give insight into which HRQOL dimensions are most strongly associated with stress. Results from Papers I and IV show that stress was most strongly associated with the HRQOL dimension autonomy and parent relations (Paper I) and changes in autonomy and parent relations (Paper IV). The results are in line with Freire and Ferreira's [23] study and highlight the need to be especially aware of the negative influence stress may have on this HRQOL dimension that reflects the feeling of love and support by family and the quality of adolescent and parent interactions, as well as on adolescents' perceived autonomy [82]. The results of Paper II indicate that this may be especially important to consider among adolescents with persistent pain, as they reported significantly higher stress levels and lower HRQOL levels in the autonomy and parent relations dimension than adolescents without pain or with a shorter pain duration (Paper II). An important premise in the understanding of stress is that the experience of stress can be changed by adjusting either a person's experience of their own resources or the demands and expectations of the environment [157, 158]. A Norwegian qualitative study among 53 adolescents emphasizes that parents have an opportunity to alleviate the stress and pressure that adolescents experience [165], indicating this is important to acknowledge. The importance of adolescents' resilience in relation to stress is further discussed in section 7.2.2 of this thesis.

About one-third of the adolescents in Paper I reported they only sometimes or rarely/never got enough sleep, and more than half reported having problems with sleepiness. Significantly more girls reported less frequently getting enough sleep and having problems with sleepiness compared to boys. Further, the results of Paper II show that adolescents with pain reported significantly more problems with sleepiness and not getting enough sleep compared to adolescents without any pain. Together, this underpin the need for continued efforts to help adolescents improve their sleep and indicate this may be especially important to consider regarding girls and adolescents suffering from pain. Paper I confirm that sleep is associated with adolescents' HRQOL [28, 170-174, 322], but indicate that sleep in 14- to 15-year-old adolescents may first of all be important for the HRQOL dimension physical well-being, which explores the level of physical

activity, fitness, and energy and the extent to which adolescents feel unwell and complain of poor health [82].

The Ottawa Charter for Health Promotion, adopted in 1986, was a milestone in the development of a positive and holistic understanding of health and the importance of health promotion [323, 324]. According to the Ottawa Charter, health promotion is "the process of enabling people to increase control over, and to improve, their health" [323]. HL is highly relevant, considering health promotion in adolescents. HL level may likely affect one's health behavior and how one chooses health-promoting activities [325], such as complying with preventive measures during a pandemic [326]. Paper III demonstrated that the adolescents had moderate-to-high levels of HL one year into the pandemic, which corresponds with previous findings among Norwegian adolescents [31]. This indicates that the adolescents in our sample may have had the necessary skills to understand and act upon COVID-19-related information. However, it should be noted that the reported HL scores were higher compared to the scores of Norwegian adolescents in a previous study before the pandemic [296]. The HL scores reported by parents in Paper III also indicate higher HL levels compared to adults in the Norwegian national HL survey [327]. The high HL scores for both adolescents and parents may be explained by a higher education level reported by parents in our study compared to the general Norwegian population. It is important to consider the relationship between parental education and HL because a high parental education level is positively related to parents' HL, and parents with high HL are considered to be better equipped to teach their children HL skills and are more likely to engage in preventive health behaviors for their children [325]. This indicates that our results may not be representative of adolescents coming from families with lower education levels. One may speculate that adolescents coming from families with lower education levels could be having lower HL levels, which is important to consider, especially during a pandemic. HL provides important tools for translating knowledge into behavior, and may empower adolescents' health decision-making [325], e.g., enabling them to cope efficiently with health threats such as the COVID-19 [328]. Thus, one may further speculate that adolescents with lower HL levels might find it more difficult to understand and act upon COVID-19-related information. Hence, more knowledge of HL in adolescents coming from families with low education levels is warranted, especially during the pandemic.

Furthermore, the results of Paper III confirmed that higher HL is significantly associated with increased HRQOL in adolescents [31, 191]. From a health promotion view, and considering the revised Wilson and Cleary model, our findings suggest that HL is an important individual characteristic that may positively influence adolescents' HRQOL. However, it should be noted that the associations between HL and HRQOL in adolescents reported in Paper III were small, which corresponds to a previous Norwegian study [31], and this indicates that the results should be viewed more as a tendency.

The findings of Paper III contribute to an increased understanding of the COVID-19 pandemic's influence on adolescents' and parents' health and well-being. The pandemic had changed the participants' lives both positively and negatively; however, the proportion of adolescents and parents who reported a considerably negative change was higher than the proportion who reported a positive change. The adolescents reported a high degree of COVID-19-related worries. Interestingly, they were a lot more worried about infecting others with COVID-19 and about family/friends becoming sick than being worried about own sickness. Our findings are in line with a previous Norwegian study during the pandemic that suggested that this finding could be explained by the fact that the mortality of the COVID-19 virus is primarily linked to older people and people with underlying diseases [188]. Furthermore, Paper III demonstrated gender-related differences regarding COVID-19-related worries, which confirm previous findings during the pandemic [188, 329]. Nevertheless, more girls and women reported a positive change in life due to the pandemic compared to boys and men. This would be interesting for future studies to explore further.

No statistically significant associations were found between the selected COVID-19-related worries and HRQOL in adolescents (Paper III) – indicating that these COVID-19-related worries may not function as symptoms that are related to HRQOL within the revised Wilson and Cleary model, at least not for the participants in our study. Previous research during the pandemic shows that HRQOL and factors among adolescents and parents, such as worries related to the pandemic, mental and physical consequences of the pandemic, and HL levels, vary across sociodemographic groups [29, 183, 188, 192, 330, 331]. Hence, because most participants in our study consisted of persons from families with a high SES, this should be considered when interpreting our results. The results

may have looked different if our sample was less selected in terms of e.g., socioeconomic factors. One may for instance speculate that the adolescents could have been more worried during the pandemic if their parents were unemployed and/or had economic problems, which again could have resulted in a significant reduction of HRQOL among these adolescents.

Paper IV demonstrated a decline in adolescents' HRQOL from the age of approximately 14 to 16 years, supporting previous findings of HRQOL deteriorating with age [140, 198, 200-202]. However, it should be noted that the difference between HRQOL scores from Time 1 to Time 2 is considered small [252, 332]. When all variables were entered into the final model in Paper IV, the negative association between time and HRQOL was only statistically significant for the physical and psychological well-being dimensions. The adolescents' HRQOL scores at age 14 (reported in Papers I, II, and IV) were comparable to European KIDSCREEN norms [82] and the HRQOL scores of other studies among Norwegian adolescents [122, 200]. In contrast, one year into the pandemic, our results showed that the adolescents' HRQOL scores for the dimensions physical and psychological well-being were notably lower compared to European KIDSCREEN norms and HRQOL scores among Norwegian adolescents before the pandemic [122, 200]. Our findings correspond with other studies on adolescents' HRQOL and well-being during the pandemic [29, 31, 181, 182, 333, 334], indicating that the pandemic has a negative influence on adolescents' HRQOL. This suggests that the pandemic may be viewed as an environmental characteristic within the revised Wilson and Cleary model that negatively influences adolescents' HRQOL. However, it seems important to consider the degree and duration of pandemic infection control measures, as the Norwegian Public Health Report states that the population who experiences poor QOL during the pandemic appears to vary with the degree and/or duration of infection control measures [212]. Furthermore, it is important to consider that the norm data provided by KIDSCREEN manual is for the age group of 12-18 years [82]. Also, it is important to consider that numerous studies have documented an age trend involving reduced HRQOL over the specific age span investigated. Longitudinal studies in general adolescent populations have shown a decline in HRQOL during adolescence, with a more pronounced decrease in girls' HRQOL over time compared to boys' [200-202]. Thus, we do not know for certain

whether our results would have looked different without the pandemic happening.

7.2.2 The importance of resilience

What is it that makes some people cope well through strain, while others succumb? Resilience may be one of the answers. Self-esteem and self-efficacy are both considered resilience factors [121, 144, 148]. The levels of self-esteem and self-efficacy reported by the adolescents in our study correspond to previous findings among Norwegian adolescents [273, 274, 335, 336]. The results of Papers I, II, and IV emphasize the importance of considering self-esteem and self-efficacy as important protective or resilience factors for adolescents' HRQOL because these factors were positively associated with higher HRQOL for several HRQOL dimensions. Our results are in line with previous HRQOL research among adolescents [23, 25-27, 87, 150, 174]. However, this thesis adds to existing literature by additionally including a wide range of other potential predictive factors associated with HRQOL (Papers I and IV). The results of this thesis indicate that self-esteem and self-efficacy (individual characteristics) should be viewed as important intervening characteristics within the revised Wilson and Cleary model. Our findings show that while considering risk factors such as loneliness (environmental characteristic) or stress and pain (symptoms), self-esteem and self-efficacy are still significantly positively associated with several of the adolescents' HRQOL dimensions. The revised Wilson and Cleary model depicts that the health continuum is influenced by characteristics of the individual and their environment but emphasizes that the associations are complex [22]. This way of thinking coincides with resilience theory [337], which focuses on understanding healthy development despite risk exposure. Within resilience theory, resilience factors are considered to be either assets or resources, where assets are positive factors within the individual (such as self-efficacy or self-esteem) and resources are positive factors external to the individual (such as parental support or positive factors within the individual's social environment) [337]. Further in this section, the main focus related to resilience will be on self-esteem and self-efficacy and their role as positive assets for adolescents' health and well-being.

The results of Papers I, II, and IV indicate that self-efficacy and self-esteem are associated with the physical, psychological, social, and functional aspects of

adolescents' lives in different ways. When all variables were added to the models in Paper I, the results showed that at age 14–15 years, self-efficacy was most strongly associated with the dimension school environment, whereas self-esteem was most strongly associated with psychological well-being. Further, the results of Paper IV indicate this was also the case two years later; self-efficacy was most strongly associated with changes in school environment, whereas self-esteem was most strongly associated with changes in psychological well-being. For adolescents with persistent pain, the results of Paper II suggest that self-esteem and self-efficacy may especially play an important role in their well-being at school, as the highest degree of mediation was estimated for the HRQOL dimension school environment.

In the presence of self-efficacy and self-esteem, the results of Paper I indicate that the strength of the negative association between stress and HRQOL might possibly be reduced. The results correspond to Freire and Ferreira's [22] findings and indicate that higher levels of self-esteem and self-efficacy might play a buffer role for the negative influence that stress has on adolescents' HRQOL. We know that adolescence can be challenging and cause stress and that it may be difficult to address a great deal of this stress. However, interventions aimed at increasing the modifiable factors self-esteem and self-efficacy are promising and possible to carry out [144, 337-339] in, for instance, a school setting. A key idea within resilience thinking is that instead of focusing on risk amelioration, interventions should focus on developing assets and resources for adolescents exposed to risk to increase their resilience [337]. Thus, I recommend that resilience-enhancing interventions should be a high priority in schools to promote adolescents' well-being.

Shifting the focus of adolescent pain research into protective and resilience factors has been recommended [96, 230, 231]. Paper II contributes to this by exploring whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and self-efficacy. The results of Paper II indicate that self-efficacy and self-esteem should be viewed as important intervening variables within the multidimensional biobehavioral model of pediatric pain by Varni and colleagues [34, 35], as the variables influenced both pain and several of the HRQOL dimensions in adolescents. Results show that self-esteem and self-efficacy are associated to the HRQOL dimensions in

different ways, suggesting that both resilience factors are important for the well-being of adolescents with persistent pain. However, our results indicate that self-esteem has a stronger influence on the relationship between pain and HRQOL than self-efficacy. The results showing that self-efficacy is not a mediator in the relationship between pain and HRQOL contrast with the findings of a previous study among adolescents with persistent pain by Grasaas and colleagues [150]. Their study showed that the associations between pain intensity and several HRQOL subscales within the KIDSCREEN-52 questionnaire were mediated by self-efficacy. However, contrary to Grasaas and colleagues' study, ours included self-esteem as a parallel mediator and gender as a possible confounder. Further, the participants in Grasaas and colleagues' study were aged 16–19 years, and they reported a mean (SD) pain intensity of 5.4 (1.9) [150], while the adolescents with persistent pain in Paper II were aged 14–15 years and reported a median (min, max) pain intensity of 3 (1.0, 9.0). Papers I, II, and IV, together with previous studies [7, 8, 14, 23, 33, 86, 319], have demonstrated statistically significant gender and age differences in adolescents regarding pain, HRQOL, self-efficacy, and self-esteem. Together, this may explain the different results. Considering the complexity of pain, and in line with previous studies [96, 150, 230, 231], our findings emphasize that the approach to adolescent pain management should include resilience strategies and resources and not only focus on risk factors and pain in itself. An enhancement of adolescents' resilience factors may empower adolescents to foster the necessary strengths and skills to positively adapt and live successfully with their pain [96].

7.2.3 Pain in adolescents

Paper I showed that the prevalence of pain is high in 14- to 15-year-old adolescents: about three in four reported a pain average of one or more, indicating pain. This confirms the findings of other studies showing that pain is a common problem in adolescence [9, 11, 12, 14, 93]. Our results are worrying, especially because the results of Paper II show that 14- to 15-year-old adolescents with pain reported significantly more stress, loneliness and a lack of sleep, and lower self-efficacy, self-esteem, and HRQOL compared to adolescents without pain. Furthermore, Paper II provides important knowledge of how factors in adolescents with persistent pain differ from those in adolescents with a shorter pain duration, indicating that adolescents with a longer pain duration

seem to constitute a more vulnerable group. We do not know what the likely mechanisms underpinning the observed relationships are. However, studies have shown that adolescents with persistent pain are more absent from school and leisure activities and thus miss out on important social and theoretical experiences during adolescence [101, 106, 111]. The review of Forgeron et al. [102] found that across studies, adolescents with persistent pain were reported to have fewer friends, were viewed as more isolated than healthy peers, and may be subjected to more peer victimization. Thus, one may speculate that such aspects may reduce the HRQOL and self-esteem in adolescents with persistent pain and increase their feelings of loneliness. Furthermore, studies have shown that pain negatively affects adolescents' sleep quality and their concentration at school [101, 111]. School seems to be the area that most adolescents find stressful [6, 7, 49, 166], and reduced sleep and concentration may reduce school performance and increase school related stress [168, 340, 341]. This may partly explain our findings of more stress and a lack of sleep among adolescents with persistent pain compared to adolescents without pain or with a shorter pain duration. In Paper II, we also explored pain triggers from the adolescents' own perspectives and found a wide variety related to the triggers reported, highlighting the subjectivity within pain experiences. Loneliness, a lack of sleep, and school were the most prevalent reported triggers. In addition, menstruation was a prevalent trigger in girls. When comparing adolescents with different pain durations, results showed that more adolescents with persistent pain reported loneliness as a trigger compared to adolescents with a shorter pain duration. Negative aspects related to experiencing pain and having persistent pain during youth have also been found in other studies [33, 100-104, 121]. Our findings add to this and emphasize that an individual, holistic perspective and approach is needed to better understand pain problems- and pain triggers in adolescents that are experiencing pain.

A holistic perspective, such as that provided through Varni and colleagues' multidimensional biobehavioral model of pediatric pain [34, 35], may help to better comprehend the association between pain and HRQOL in adolescence and understand the intervening variables that may be altered to optimize the approach to pain management. As an example, the biobehavioral model (Figure 2) depicts a direct connection between stress and pain and between stress and HRQOL [34, 35], indicating stress may influence pain and have a direct influence on HRQOL.

Previous studies have suggested stress to be a possible cause of pain [98, 159, 162], and the results in Paper II support this by demonstrating more stress among adolescents with pain, and school being one of the most prevalent self-perceived pain triggers. As previously mentioned, studies have shown that school is an area that many adolescents find stressful [6, 7, 49, 166]. Further, the results of Papers I and IV demonstrate that stress is negatively associated with adolescents' HRQOL and changes in HRQOL. This is also supported by other studies [23, 233]. Moreover, the biobehavioral model depicts arrows going both ways between pain and HRQOL, indicating pain may influence HRQOL and vice versa. Results of Papers I, II, and IV confirm there is an association between pain and HRQOL in adolescents, and this has also been confirmed in other studies [14, 24, 150, 223]. Furthermore, the biobehavioral model depicts that intervening variables can influence pain and HRQOL [34, 35]. This was confirmed by the mediation analyses in Paper II, where we explored whether the relationship between pain and HRQOL is mediated by self-esteem and/or self-efficacy in adolescents with persistent pain. Further, the results of Papers I–IV indicate that intervening variables such as sociodemographic factors, self-esteem, self-efficacy, loneliness, sleep, and HL can influence pain and/or HRQOL. Previous studies have also identified these selected factors as being associated with pain and HRQOL in adolescents [12, 14, 23, 25, 28, 33, 84, 94-98, 113, 118-122]. It is important to note that opposite directions related to the arrows in the biobehavioral model should also be considered, as most studies, including our study in Paper II, are based on associations and/or descriptive data.

The descriptive data in Papers I and II revealed low pain intensity levels of approximately 2.0 in the adolescent sample. Still, results from the final analyses in Paper I show that pain was significantly associated with reduced HRQOL for four HRQOL dimensions, with the strongest negative associations reported for the dimension school environment (Paper I). This dimension explores the adolescents' feelings about school and their concentration, learning, perception of cognitive capacity, and views of their relationship with their teachers [82]. Furthermore, Paper IV found that pain was significantly associated with a reduction in HRQOL change scores in four dimensions. Hence, although our study did not provide large effect sizes for the strength of association between pain and HRQOL in the final analyses, the results of Papers I, II, and IV confirm the negative association between pain and HRQOL in adolescents [14, 24, 84,

85, 150, 223] and indicate this is evident even with low pain levels. Moreover, Paper IV showed that the strongest negative association between pain and changes in HRQOL scores was on the dimension school environment. Hence, our findings indicate that pain at age 14–15 years (during lower secondary school) may negatively influence HRQOL related to the school environment two years later (during upper secondary school). Together, our findings highlight that adolescent pain is negatively associated with this HRQOL dimension.

The results in Papers I and II revealed that despite reporting low levels of pain, the use of OTC analgesics among adolescents and parents in our sample was high. This may indicate that both adolescents and parents use OTC analgesics for reasons other than only pain relief, which is in accordance with previous studies suggesting that OTC analgesic use is common among adolescents to treat pain and other conditions (such as anxiety and stress) [161, 224-226]. Self-medication of OTC analgesics gives the consumer the ability to assume an active role in own health through symptomatic management of common conditions, such as pain management. However, the benefits of self-mediation are dependent upon the consumer taking the analgesics responsibly and appropriately [342]. It is important to consider the parental role related to adolescents' OTC analgesic consumption. Previous research has stated that parents are the most important information source regarding the use of OTC analgesics and constitute the main supplier of the analgesics [227]. However, the results of Paper II indicate that parents do not always use OTC analgesics appropriately – which is a concern, considering their influence as parents. A recent meta-synthesis of pain management in adolescents identified four themes that described adolescents' reasons for using OTC analgesics: 1) survival instinct (related to own pain management), 2) placebo for anxiety and stress control, 3) accessibility, and 4) consumer socialization (related to OTC analgesic use being a learned behavior) [224]. All this considered, the intake of OTC analgesics among adolescents and parents should be regarded as a significant health concern, especially because frequent consumption of OTC analgesics may lead to health problems such as liver failure or drug-induced headaches [227-229].

Paper II also explored whether parental factors are linked to adolescents' pain. Based on previous research [95, 118, 119, 207], we expected the three pain groups to differ regarding parental pain factors insofar as parental pain factors

being more present in the two groups of adolescents experiencing pain. Surprisingly, the results showed no differences between the three adolescent pain groups, considering parental pain factors. This may be explained by the fact that only one parent per adolescent was included in the study. Considering that about 44% of adolescents with persistent pain reported that someone in their family (such as the other parent) was having pain, our results may have been different if both parents were included. Hence, this may indicate that a family history of pain still plays a significant role. Furthermore, based on previous research [12, 97, 124], we also expected the three pain groups to differ regarding parental sociodemographic factors insofar as low SES being more present in the two groups of adolescents experiencing pain. However, the results showed that the three adolescent pain groups were similar regarding the selected SES factors: parental members of the household, parental work status, education level, and household income. Our findings may be explained by the high SES of the participants' families, indicating that the results may not be representative of adolescents coming from families with lower SES. Previous studies have shown that socioeconomic variables such as education and income are related to pain in adolescents and adults, e.g., families with low SES report more pain problems and lower HRQOL scores [12, 95, 97, 124-127, 130]. Thus, the results may have been different if we had been able to include more participants coming from families with a low SES in our study. Nevertheless, it is important to highlight that although family environment and parental factors may influence pain outcomes, most explanations for persistent pain are still at the individual level [343]. The last parental factor we explored was the parents' HRQOL – which we, based on previous findings [116], expected to be lower among parents in the two groups of adolescents with pain. However, Paper II found no statistically significant differences in parents' HRQOL between the three adolescent pain groups. This may be explained by the inclusion of only one parent and both mothers and fathers in our analyses. Skarstein and colleagues [116] only investigated HRQOL in mothers. Thus, the results may have been different if only mothers or both parents were included. Further, the adolescents reported low pain intensity levels, indicating that the results may not be representative of parents to adolescents with higher levels of pain. Hence, more research into HRQOL in parents of adolescents experiencing pain is still needed.

8. Possible implications for practice and further research

8.1 Health promotion

This thesis provides insight into factors that are associated to adolescents' HRQOL dimensions related to their present HRQOL and changes in their HRQOL. Increased understanding of factors associated with HRQOL can improve the ability to develop evidence-based health promotion and intervention programs and help to identify adolescents who need support and help. The results of this thesis indicate that it is important to consider adolescents' levels of stress, pain, loneliness and sleep when aiming to promote their HRQOL. More specifically, it seems important to facilitate strategies that may reduce adolescents' feeling of stress, pain and loneliness, and strategies that may improve adolescents' sleep. Furthermore, this thesis emphasizes that within a health promotion perspective, it may be especially important to consider adolescents' levels of protective and resilience factors, such as self-esteem and self-efficacy, as these factors may have the potential to increase adolescents' HRQOL. Moreover, it is important to consider adolescents' levels of HL, because higher HL is positively associated with adolescents HRQOL, indicating that increasing adolescents' HL may have the potential to improve their HRQOL as well. Hence, I recommend health promoting interventions focusing on increasing adolescents' resilience and HL. Health promoting interventions focusing on these aspects are needed at both an individual- and a community level. This is relevant to consider for public health nurses, other health-care professionals, parents, teachers, politicians, and researchers who aim to promote adolescents' HRQOL.

The school setting is considered as a promising arena for health-promoting interventions [296, 344-347]. Thus, I recommend that interventions aiming to increase factors such as self-esteem, self-efficacy, and HL should be a priority in schools from both public health nurses' and teachers' perspectives. Furthermore, I recommend involving parents in resilience and HL promotion, as they are considered to be important role models and influencers and may function as external resources for adolescents' resilience and HL [325, 337, 347, 348]. I believe this is relevant for public health nurses and teachers to consider, as they

have established communication with parents through school and school health services.

8.2 Knowledge about adolescents' HRQOL

The goal of ensuring healthy lives and promoting well-being for all at all ages [1] is highly important for public health work. However, to facilitate this among adolescents, more information about how they are doing is needed. Systematic knowledge about adolescents' health and well-being can lead to more knowledge-based practice and is needed to make good political and clinical decisions, find suitable health-promoting strategies according to the adolescents' needs and preferences, enable sustainable health through adolescence and into adulthood, and facilitate a healthier and fairer society. Including valid and reliable HRQOL instruments in national surveys among adolescents may help facilitate such knowledge. In Norway, including adolescents in the national QOL surveys is considered highly important, as this will provide valuable insight into Norwegian adolescents' health and well-being that is warranted. Furthermore, structured screening of children's and adolescents' HRQOL in Norwegian public health services, such as in school health centers, is recommended, as this may facilitate communication with families, add valuable decision support, improve earlier identification of child problems, facilitate interdisciplinary collaboration, and give opportunities for evaluation of preventive services and early interventions [349].

More research involving healthy and clinical samples of adolescents is still needed to better understand HRQOL in adolescents. To explore the findings of this study more thoroughly, future studies should strive for the inclusion of adolescents coming from families with a low SES or an immigrant background and adolescents who live together with only one parent. Future longitudinal studies should explore the development of adolescents' HRQOL over a longer period. I also recommend including possible confounders not included in this study, such as anxiety, depression, physical activity, pubertal development, social media use, body image and bullying. Furthermore, to gain more in-depth knowledge of adolescents' HRQOL and associated factors, qualitative research is needed.

8.3 An individual, holistic approach to adolescents' pain

Based on our results demonstrating that adolescents with pain reported significantly more stress, loneliness, and lack of sleep and lower self-efficacy, self-esteem and HRQOL compared to adolescents without pain, an individual, holistic approach to adolescents' pain is recommended. It is important to see the whole person suffering from pain and consider different parts of the adolescent's life. Furthermore, pain duration is important to consider, as our results showed that adolescents with a longer pain duration reported worse on stress, loneliness, self-esteem, lack of sleep, school absence and pain, and lower HRQOL for the dimensions physical well-being, psychological well-being and autonomy and parent relations compared to adolescents with shorter pain duration. Using the multidimensional biobehavioral model of pediatric pain [34, 35] seems promising to better understand adolescents' pain and its' associated factors.

Our results demonstrated a high prevalence of pain among adolescents. Knowing that pain problems in adolescents may develop into persistent pain and continue into adulthood [108-110], it seems highly important to help adolescents reduce- and manage their pain. Increased knowledge of factors that characterize adolescents with and without pain may help parents, public health nurses and other health-care professionals, school staff, and researchers to better understand pain problems in adolescents. Such knowledge is valuable when aiming to find the best strategies and interventions to help adolescents with pain. Our findings emphasize the need to be especially aware of the negative association between pain and the HRQOL dimension school environment. Future research is needed to test and study interventions to reduce pain, help manage pain, and promote HRQOL in adolescents suffering from pain.

Our finding of a high consumption of OTC analgesics among adolescents and parents despite low levels of pain intensity indicates the need for continued efforts to increase adolescents' and adults' knowledge of responsible and appropriate use of OTC analgesics. Hence, information from health-care professionals, such as public health nurses, about responsible and appropriate use of OTC analgesics seems vital [224, 227]. This information can be relevant for adolescents, parents, and society in general and should be prioritized and made easily available.

9. Conclusions

This thesis, including the four related papers, contributes to and expands our knowledge of HRQOL and pain by investigating sociodemographic-, psychosocial-, pain-, sleep-, HL- and COVID-19-related factors associated with HRQOL in a school-based cohort of Norwegian adolescents and their parents during two years of youth, from age 14 to 16 years. It provides updated knowledge of adolescents' HRQOL before and during the COVID-19 pandemic.

The results provide insight into the complexity of adolescents' HRQOL and shows how pain, stress, loneliness, lack of sleep and COVID-19-related worries are associated to lower HRQOL in adolescents, and how self-efficacy, self-esteem and HL are associated to higher HRQOL. It also provides insight into the relationship between HRQOL and various sociodemographic factors. The results demonstrate a reduction in the adolescents' HRQOL from 14 to 16 years of age. One year into the COVID-19 pandemic, our results show that the HRQOL of 16–17-year-old adolescents is reduced compared to findings from previous Norwegian studies and European norm data, while parents' HRQOL is comparable to Norwegian norms prior to the pandemic. The thesis clarifies how the above-mentioned factors are associated with various HRQOL dimensions related to their present HRQOL and changes in their HRQOL and emphasizes the importance of considering and facilitating self-efficacy and self-esteem as important protective- and resilience factors for adolescents' HRQOL. Furthermore, this thesis provides insight into the prevalence of pain in adolescents, and demonstrates that adolescents with pain report more stress, loneliness and lack of sleep and lower self-esteem, self-efficacy and HRQOL compared to adolescents without pain. An individual, holistic approach to adolescent pain and increased focus of resilience factors associated with adolescent pain is recommended. The thesis outlines possible implications for adolescents, parents, public health nurses and other health-care professionals, teachers, politicians, and researchers.

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Paper I

Health-related quality of life is strongly associated with self-efficacy, self-esteem, loneliness, and stress in 14–15-year-old adolescents: A cross-sectional study.

Health and Quality of Life Outcomes

RESEARCH

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Health-related quality of life is strongly associated with self-efficacy, self-esteem, loneliness, and stress in 14–15-year-old adolescents: a cross-sectional study

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Abstract

Background: To enhance and better understand health-related quality of life (HRQOL) in adolescents, it is important to study factors associated with HRQOL. The present study aimed to assess possible associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress and HRQOL in 14 to 15-year-old adolescents.

Methods: A cross-sectional study was performed among 696 adolescents (14–15 years) in a school-based setting. Sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness and stress were analyzed. The variables were all assessed with well-validated instruments. HRQOL was analyzed using KIDSCREEN 27. Analyses included Chi-square, independent t-tests, Mann–Whitney U tests, linear regression analyses and hierarchical regression analyses. The results from linear regression models were expressed as standardized beta.

Results: The adolescents generally reported high levels of HRQOL. However, girls scored significantly worse on HRQOL, self-efficacy, self-esteem, pain, sleep, loneliness and stress compared to boys. Using hierarchical regression analyses we found that Self-efficacy (beta = 0.11–0.24), Self-esteem: (beta = 0.12–0.21), Loneliness: (beta = − 0.24 to − 0.45) and Stress: (beta = − 0.26 to − 0.34) revealed the strongest associations with the HRQOL dimensions. Sociodemographic-, pain- and sleep related covariates were all significantly associated with some of the KIDSCREEN subscales, however their effect on the outcome was smaller than for the psychosocial variables listed above. Being a girl, not living with both parents, not having both parents working, being absent from school more than 4 days, having pain and having lack of enough sleep were all independently negatively associated with HRQOL.

Conclusions: HRQOL is strongly associated with self-efficacy, self-esteem, loneliness and stress in 14 to 15-year-old adolescents. Our findings indicate that positive psychosocial factors such as self-efficacy and self-esteem might play a buffer role for negative psychosocial factors (e.g. stress) in adolescents. Further, our results show that girls score significantly worse on factors that are associated to HRQOL compared to boys. To improve HRQOL in school-based populations of adolescents, we suggest that future interventions should aim to strengthen self-efficacy and self-esteem. We recommend gender specific interventions.

Keyword: Health-related quality of life, Adolescents, Self-efficacy, Self-esteem, Loneliness, Stress

Introduction

Quality of life (QOL) is an important concept and target for research and practice in the fields of health and medicine [1]. The term "health-related quality of life"

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(HRQOL) is a multidimensional construct that includes the individual's subjective perspectives on the physical, psychological, social, and functional aspects of health [2]. The World Health Organization (WHO) emphasizes well-being and HRQOL as goals for public health, especially among adolescents, and underlines the need for research to identify the key determinants for health problems in this age group [3]. Moreover, WHO notes that adolescent health and well-being are essential for healthier and more sustainable societies [4, 5].

Adolescence is a life phase between childhood and adulthood in which the opportunities for health are great and where future patterns of adult health are established [4–7]. It is also a vulnerable period in life, and can be challenging with respect to independence from caregivers, increase of autonomy and social role transitions [5, 6, 8–11]. Although the vast majority of Norwegian adolescents are content with their lives and generally report good health [16], an increasing number of adolescents in Norway and other countries report psychosocial problems and health complaints in everyday life such as loneliness, stress, insufficient and poor-quality sleep, pain and high intake of over-the-counter analgesics (OTC analgesics) [9, 11–20], indicating a need for continued efforts in health promotion among adolescents.

Research has identified variables associated with HRQOL such as gender and age. HRQOL often declines during adolescence, and girls tend to report lower HRQOL than boys [16, 21–27]. Family, parents, and siblings are important for adolescents' HRQOL [8, 15, 28], and HRQOL have been observed to be generally lower in those with low socioeconomic status (SES) and poor social support [29–31]. Furthermore, studies have shown that positive psychosocial factors such as self-efficacy and self-esteem have a positive impact on HRQOL in adolescence [22, 25, 31–34], while health-related and negative psychosocial factors such as stress, pain, high intake of OTC analgesics, loneliness, school absenteeism and insufficient and poor-quality sleep are associated with lower HRQOL among adolescents [12, 16, 17, 22, 23, 30, 35–39].

From a health promotion perspective, more knowledge of how sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness and stress are related to adolescents' HRQOL is needed. In order to gain more knowledge of which of these factors future interventions among school-based populations of adolescents should prioritize, there is a need to simultaneously investigate the impact of these factors on HRQOL. Investigating such associations could inform practice and policy. Furthermore, considering that age is an important predictor of HRQOL, more knowledge about HRQOL in adolescents at a specific age is warranted.

The aim of this study was to assess the associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL in 14–15-year-old adolescents. Based on theory and earlier research, we hypothesized that there is a positive association between self-efficacy, self-esteem and HRQOL, and that there is a negative association between low SES, female gender, stress, loneliness, pain, higher school absenteeism, lack of sleep and HRQOL.

Methods

Sample and data collection

This cross-sectional study was a part of the "Start Young – quality of life and pain in generations" study, which is a longitudinal study that aims to acquire new knowledge about HRQOL and pain in adolescents and their parents, as well as investigate potential family and regional patterns. The present study used data collected at baseline. The Start Young study was conducted in the southeastern part of Norway, with approximately 1.6 million inhabitants (30% of the total Norwegian population) and an adolescent population (aged 14–15 years) of approximately 37,000. Schools covering 9th grade (aged 14–15 years) in elementary school were stratified according to region, rural and urban districts, and school size. Two schools were randomly selected from each stratum. The schools were each sent a letter of invitation, followed by a telephone call to the school's principal. Schools that did not choose to participate were replaced by alternative schools selected according to the same criteria. We invited 59 schools and 22 schools agreed to participate. The schools varied in size and localization (from city to suburb) and admitted adolescents with different sociocultural and economic backgrounds. Inclusion criteria for this study were being a student in 9th grade at one of the participating schools, having active informed consent to participate from one parent, giving their own consent to participate and being present at school by the time of data collection. Potential participants in the study were 1663 adolescents in 9th grade from the participating schools of which 967 adolescents were excluded due to lack of active informed consent from parents (n = 872), not giving their own consent to participate (n = 8), technical problems at one school (n = 10) or because they were not present at school by the time of data collection (n = 77). A total of 696 adolescents took part (response rate 41.8%). The response rate varied across schools from 92.1 to 8.6%.

One or two project members visited each school approximately 1 week before data collection to provide the adolescents with verbal and written information about the study. Written information was also distributed to the parents. Active informed consent

was obtained from both adolescents and their parents. Data collection was conducted from November 2018 to April 2019. A web-based questionnaire was administered and completed in the classrooms during school hours. One or two project members and a teacher were present to provide assistance when needed. The collected data were stored at a safe data server.

The "Start Young—quality of life and pain in generations" study was reviewed by the Norwegian Centre for Research Data (Ref: 60,981). Necessary approvals were obtained.

Instruments

Demographic variables

The first part of the questionnaire included self-reported data on demographic variables such as gender, date of birth, cohabitant status, parental marital status, parents' birthplace, whether the respondents had moved during the previous 5 years, and school absence.

Questionnaires

A list of instruments used in this study is presented in Table 1.The internal consistency for multi-item scales was assessed using Cronbach's alpha [40].

HRQOL was measured using the Norwegian version of the KIDSCREEN-27 questionnaire [41, 42]. The KIDSCREEN-27 is a well-validated, short, multidimensional measure of generic HRQOL in children and adolescents organized into five subscales: (1) Physical well-being; (2) Psychological well-being; (3) Autonomy and parent relations; (4) Social support and peers; and (5) School environment [41, 43–45]. The KIDSCREEN instrument is answered on a 5-point Likert scale referring to the last week. The scale indicates either the frequency of certain behaviors or feelings (ranging from "never" to "always") or the intensity of an attitude (ranging from "not at all" to "extremely"). Rasch scores were computed for each subscale and transformed into t-values as described in the KIDSCREEN manual [45]. The resulting t-values can be used to make comparisons with international t-values based on 14 European countries. These values are normed to a mean of 50 and a standard deviation of 10 [45].

Table 1 Overview of instruments used in this study

Factors	Instruments	Number of items	α[a]
HRQOL	KIDSCREEN-27		
	Physical well-being	5	0.81
	Psychological well-being	7	0.87
	Autonomy and parent relations	7	0.77
	Social support and peers	4	0.78
	School environment	4	0.80
Self-efficacy	Generalized Self-Efficacy Scale (GSE)	10	0.87
Self-esteem	Rosenberg Self-Esteem scale (RSES)	4	0.79
Pain	Brief Pain Inventory (BPI)		
	Having pain today	1	
	Pain on average	1	
	Pain interference with activity	3	0.81
	Pain interference with emotions	4	0.90
	Lübeck Pain-Screening Questionnaire (LPQ)		
	Pain duration	1	
	Pain frequency	1	
	OTC analgesic questions (derived from SUS)		
	Intake of OTC analgesics during the last 4 weeks	1	
	Frequency of OTC analgesics intake	1	
Sleep	School Sleep Habits Survey		
	Problems with sleepiness	1	
	Frequency of enough sleep	1	
Loneliness	UCLA Loneliness Scale (ULS-8)	8	0.80
Stress	Perceived Stress Questionnaire (PSQ)	30	0.93

OTC, Over-the-counter; SUS, "Pain, youth and self-medication study"

[a]Cronbach's α coefficient values in this study

The answers were recoded so that higher values always indicate better HRQOL in the respective subscales. The Norwegian version of the instrument has been demonstrated to be reliable and valid [42].

Self-efficacy was measured using the Norwegian version of the Generalized Self-Efficacy Scale (GSE) that measures optimistic self-beliefs in coping with the demands, tasks, and challenges of life in general [46, 47]. The GSE consists of 10 statements that the respondent rates on a scale from 1 (completely wrong) to 4 (completely right). The respondent's scores on each item are summed and divided by ten to a GSE score ranging from 1–4, with higher scores indicating higher levels of generalized self-efficacy. The GSE has been shown reliable and valid [34, 46].

Self-esteem was measured using a short version of the Rosenberg Self-Esteem scale (RSES) [48], wherein respondents rate four statements on self-perceptions on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The answers were recoded so that higher values always indicate higher levels of self-esteem. The respondent's scores on each item were summed and divided by 4 into an RSES score ranging from 1–4. The Norwegian four-item version has demonstrated a high degree of correlation (0.95) with the 10-item version [49] and has been used among adolescents [50, 51].

Pain was measured using the Brief Pain Inventory (BPI) [52, 53] and selected questions from the Lübeck Pain-Screening Questionnaire (LPQ) [54]. The BPI assesses the subjective intensity of pain and to what extent pain interferes with activity and emotions [52, 53]. Pain interference questions were only administered to those who rated ≥ 1 on the "pain on average" question (indicating that they had pain). The Norwegian BPI has satisfactory psychometric properties [53], and it has previously been used among Norwegian adolescents [55]. Respondents who rated ≥ 1 on the "pain on average" question of the BPI were also administered two follow-up questions from the LPQ referring to pain duration and pain frequency. The LPQ is a structured self-report questionnaire that evaluates the prevalence and consequences of pain [54]. The Norwegian LPQ has satisfactory feasibility, content, and face validity [56]. Finally, two questions derived from the Norwegian "Pain, youth and self-medication study" (SUS) [17, 57] were used to measure the intake of OTC analgesics. The study involved adolescents through a three-step process in the questionnaire development [17, 57]. In our study, the respondents were first asked about OTC analgesic intake during the last 4 weeks. If the answer was "yes," the respondents were asked about the frequency of intake.

Sleep was measured using two questions adapted from the School Sleep Habits Survey [58], one focusing on problems with sleepiness during daily activities and one focusing on frequency of enough sleep. The School Sleep Habits Survey has been widely used for adolescents and has an established validity in comparison to sleep diaries and actigraphy [59]. It has previously been used to assess sleep habits in Norwegian adolescents [60].

Loneliness was measured using the eight-item version of the revised UCLA Loneliness Scale (ULS-8) [61]. This instrument is a short version of the widely used 20-item revised UCLA Loneliness Scale (ULS-20) [62] and is considered to be a reliable and adequate measure of loneliness among adolescents [63]. ULS-8 uses a 4-point Likert scale with values ranging from "never" to "always." The total score ranges from 8 to 32 points, with higher scores suggesting a higher degree of loneliness. Previous studies have recommended ULS-8 as a good substitute for the ULS-20 [61, 63, 64]. The ULS-8 questionnaire was translated into Norwegian as part of this study by using standardized translation procedures according to an international cross-cultural translation manual, which includes forward and backward translations, pre-testing, and cognitive interviews [65]. The reliability of the ULS-8 Norwegian version was verified using the Cronbach's alpha coefficient, which in this study was 0.80, suggesting good internal consistency for the instrument [40].

Stress was measured using the Perceived Stress Questionnaire (PSQ) [66–68]. PSQ is a 30-item questionnaire referring to the last 4 weeks and can be answered with a 4-point rating scale ranging from 1 (almost never) to 4 (almost always). The answers were recoded so that higher values always indicate higher levels of perceived stress. The resulting PSQ total score was linearly transformed between 0 and 1; PSQ = (raw value—30)/90 [66]. Commonly used cutoff levels of stress with respect to the PSQ are low < 0.33, medium 0.33–0.45, moderate 0.45–0.60, and severe > 0.60. The Norwegian version of the instrument has been demonstrated to have good reliability and validity [68, 69].

Data analyses

Descriptive statistics were calculated for all variables according to gender and presented as means and standard deviation or as median and min/max for continuous variables. Categorical variables were presented as counts and percentages. Associations between pairs of variables were assessed using chi-square test for categorical data. For continuous data, the *t*-test were used for normal distributed data and Mann–Whitney *U* test were used for data that did not follow normal distribution. The study used an electronic survey tool which was designed to consecutively administer the following respective questionnaires. The adolescents were free to end the survey at

any time. Most questions included a neutral option. This resulted in all items being answered.

The five KIDSCREEN subscales were selected as the dependent variables for further analyses. The selected covariates were grouped into seven blocks (B1–B7); B1: Sociodemographic variables, B2: Self-efficacy, B3: Self-esteem, B4: Pain on average, B5: Frequency of enough sleep, B6: Loneliness, and B7: Stress. All selected covariates were theoretically known clinically relevant variables reported in previous HRQOL research [8, 22, 23, 25, 30, 33, 38]. To assess possible associations between the covariates in each block and HRQOL, linear regression analyses were fitted separately for each of the five KIDSCREEN subscales. Assumptions for linear regression were checked and fulfilled. Residuals followed normal distribution.

To further assess possible *adjusted* associations with HRQOL, hierarchical regression analyses were conducted (method enter) for the five KIDSCREEN subscales. The covariates were entered into the regression in seven steps based on B1–B7. Seven linear regression models (M1–M7) were fitted for each of the KIDSCREEN subscales by adding variables from a previous model (block) consecutively; later models always included the variables from the previous steps. All tests were two-sided. P-values ≤ 0.01 were considered statistically significant in order to adjust for multiple testing. All analyses were performed using IBM SPSS Statistics (version 26).

Results

Characteristics of the sample

Tables 2 and 3 show the sample characteristics for all included variables. In total, 696 participants (57.5% girls) with a median age of 14 years were included in the analyses. In total, more than two thirds of the participants lived with both parents, had parents who were both born in Norway, had parents who were both working, and had 1–2 siblings. There were no statistically significant differences between genders concerning any of the analyzed sociodemographic variables (Table 2).

Regarding the descriptive characteristics presented in Table 3, several variables significantly differed according to gender. The adolescents generally reported high levels of HRQOL assessed using the KIDSCREEN-27 scores, but girls reported significantly lower levels of HRQOL than boys for the subscales *Physical well-being*, *Psychological well-being,* and *School environment*. Moreover, girls reported significantly lower levels of *Self-efficacy* and *Self-esteem* and higher levels of *Loneliness* and *Stress* than boys. Significantly more girls (36.0%) than boys (18.9%) reported *Having pain today*, and the levels of *Pain on average* and *Pain interference with emotions* were also significantly higher for girls than boys. Further, significantly more girls (59.9%) than boys (34.8%) reported *Intake of OTC analgesics during the last 4 weeks*. Among those who rated ≥ 1 for *Pain on average* (76%), more than one third of the adolescents reported *Pain duration* of more than 3 months (persistent pain) and 34.7% experienced pain often. More than two thirds of the adolescents reported getting enough sleep usually or always. However, significantly more girls than boys reported having *Problems with sleepiness* and less frequently getting enough sleep.

Crude associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL examined by linear regression analyses

Multiple linear regression analyses were used to assess possible associations between selected variables and HRQOL. The strength of the associations between the covariates in each block (B1–B7) and the dependent variables (five KIDSCREEN subscales) is further described in terms of the effect sizes (standardized beta) and explained variance (Table 4). The psychosocial variables (*Self-efficacy*, *Self-esteem*, *Loneliness*, and *Stress*) had the largest effects on the outcome for all HRQOL dimensions. *Self-efficacy* and *Self-esteem* were positively associated with HRQOL whereas *Stress* and *Loneliness* were negatively associated. Sociodemographic- (B1), pain- (B4), and sleep-related covariates (B5) were all significantly associated with some of the subscales; however, their effect on the outcome was smaller than that of the psychosocial variables listed above. Being a girl, not living with both parents, not having both parents working, being absent from school more than 0–4 days, having pain, and lacking enough sleep were all independently negatively associated with HRQOL. The explained variance was the highest for *Psychological well-being* (the covariate *Stress* explained 51.8%) and lowest for *Physical well-being* (the covariate *Self-esteem* explained 19.2%).

Adjusted associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL examined by hierarchical regression analyses

Table 5 shows the strength of the adjusted associations from the hierarchical regression analyses between the covariates and the dependent variables described in terms of effect sizes (standardized beta) and explained variance. When all variables were added into model 7, the impact of the sociodemographic variables was diminished compared with the impact from the other covariates. However, *Gender* had the third largest effect size in relation to *Autonomy and parent relations*. Being a girl was positively associated with this KIDSCREEN

Table 2 Characteristics of the sample (N = 696)

Variable	Total (696)	Boys (n = 296)	Girls (n = 400)	*P* value
Age, mean (SD)	14.09 (0.33)	14.08 (0.36)	14.09 (0.30)	0.905
Adult members of the household, N (%)				0.185
Both parents	508 (73.0)	224 (75.7)	284 (71.0)	
Alternates between two parents	100 (14.4)	45 (15.2)	55 (13.8)	
One parent and one stepparent	20 (2.9)	6 (2.0)	14 (3.5)	
One parent	55 (7.9)	16 (5.4)	39 (9.8)	
Other caregivers	13 (1.9)	5(1.7)	8 (2.0)	
Parents' marital status, N (%)[a]				0.642
Two parent family	492 (70.7)	212 (71.6)	280 (70.0)	
Single/divorced parent family	204 (29.3)	84 (28.4)	120 (30.0)	
Parents' birthplace, N (%)				0.267
Both parents born in Norway	551 (79.2)	241 (81.4)	310 (77.5)	
One parent born in Norway	87 (12.5)	30 (10.1)	57 (14.2)	
Both parents born in another country	58 (8.3)	25 (8.4)	33 (8.3)	
Parents' work status, N (%)				0.013
Both parents working	547 (78.6)	247 (83.4)	300 (75.0)	
One parent working	133 (19.1)	46 (15.5)	87 (21.8)	
No parent working	16 (2.3)	3 (1.0)	13 (3.3)	
Number of siblings, N (%)[b]				0.730
None	30 (4.3)	11 (3.7)	19 (4.8)	
1	263 (37.8)	107 (36.1)	156 (39.0)	
2	244 (35.1)	109 (36.8)	135 (33.8)	
≥ 3	159 (22.8)	69 (36.8)	90 (22.5)	
Moved during the previous 5 years, N (%)[c]				0.027
No	474 (68.1)	215 (72.6)	259 (64.8)	
Yes	222 (31.9)	81 (27.4)	141 (35.3)	
School absence for the previous 3 months, N (%)[d]				0.812
0–4 days	595 (85.5)	255 (86.1)	340 (85.0)	
5–10 days	84 (12.1)	35 (11.8)	49 (12.3)	
> 10 days	17 (2.4)	8 (2.0)	11 (2.8)	

Continuous variables analyzed using independent *t*-test. Categorical variables analyzed using χ^2-test

SD, standard deviation

[a] The variable was dichotomized as "two parents" (married or cohabiting) or "single parent" (unmarried, divorced, or widowed)

[b] The variable was recoded into four categories: "none," "1," "2," or "≥ 3" (3, 4, 5, > 5)

[c] The variable was dichotomized as "yes" (moved 1 time, 2–4 times, ≥ 5 times) or "no."

[d] The variable was recoded into three categories: "0–4 days" (none, 1–4 days), "5–10 days" (5–7 days, 8–10 days), or "> 10 days."

subscale. The psychosocial variables (*Self-efficacy, Self-esteem, Loneliness,* and *Stress*) revealed the largest effect sizes and also contributed to a considerable increase of the explained variance for all five subscales, suggesting that the psychosocial variables are highly relevant for adolescents' HRQOL. *Self-efficacy* and *Self-esteem* were positively associated with HRQOL, whereas *Stress* and *Loneliness* were negatively associated. *Pain on average* had a significant negative effect on four KIDSCREEN subscales; however, its effect on the outcome was smaller than that of the psychosocial variables. *Frequency of enough sleep* had the second largest significant effect on *Physical well-being* (lacking enough sleep was negatively associated with HRQOL) but was no longer significantly associated with the other KIDSCREEN subscales when adjusted for available confounders. Given the analyzed variables, the explained variance of model 7 was the highest for *Psychological well-being* (65.8%) and the lowest for *Physical well-being* (30.8%).

Discussion

The aim of this cross-sectional study was to assess possible associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress,

Table 3 Descriptive characteristics for HRQOL, self-efficacy, self-esteem, pain, sleep, loneliness, and stress (N = 696)

Variable	Total (n = 696)	Boys (n = 296)	Girls (n = 400)	*P* value
Physical well-being, mean (SD)[a,b]	47.1 (9.3)	49.6 (9.6)	45.2 (8.6)	< 0.001*
Psychological well-being, mean (SD)[a,b]	46.6 (8.4)	49.5 (8.1)	44.4 (8.0)	< 0.001*
Autonomy and parent relations, mean (SD)[a,b]	52.6 (8.7)	53.4 (9.1)	51.9 (8.5)	0.027
Social support and peers, mean (SD)[a,b]	48.4 (8.5)	49.0 (8.5)	48.0 (8.4)	0.130
School environment, mean (SD)[a,b]	48.0 (8.6)	49.6 (9.1)	46.8 (7.9)	< 0.001*
Self-efficacy, mean (SD)[c]	3.1 (0.4)	3.2 (0.4)	3.0 (0.4)	< 0.001*
Self-esteem, mean (SD)[d]	3.1 (0.7)	3.3 (0.6)	2.9 (0.7)	< 0.001*
Having pain today, N (%)				< 0.001*
Yes	200 (28.7)	56 (18.9)	144 (36.0)	
No	496 (71.3)	240 (81.1)	256 (64)	
Pain on average, mean (SD)[e]	2.2 (1.9)	1.6 (1.7)	2.6 (1.9)	< 0.001*
Pain interference with activity, median (min, max)[f, g]	1.3 (0.0, 10.0)	1.0 (0.0, 10.0)	1.3 (0.0, 9.7)	0.372
Pain interference with emotions, median (min, max)[f, g]	1.2 (0.0, 9.7)	0.7 (0.0, 9.2)	1.2 (0.0, 9.7)	< 0.001*
Pain duration, N (%)[f, h]				0.069
Pain ≤ 3 months	335 (63.6)	133 (68.6)	202 (60.3)	
Pain > 3 months	192 (36.4)	61 (31.4)	131 (39.3)	
Pain frequency, N (%)[f, i]				0.146
Seldom	221 (41.9)	92 (47.4)	129 (38.7)	
Sometimes	123 (23.2)	42 (21.6)	81 (24.3)	
Often	183 (34.7)	60 (30.9)	123 (36.9)	
OTC analgesic intake during the last 4 weeks, N (%)				< 0.001*
Yes	342 (49.2)	103 (34.8)	239 (59.9)	
No	353 (50.8)	193 (65.2)	160 (40.1)	
Frequency of OTC analgesic intake, N (%)[j]				0.043
Daily	20 (5.8)	10 (9.7)	10 (4.2)	
Every week, but not daily	52 (15.2)	10 (9.7)	42 (17.6)	
Less often than every week	243 (71.1)	72 (69.9)	171 (71.5)	
No intake during the last 4 weeks	27 (7.9)	11 (10.7)	16 (6.7)	
Problems with sleepiness, N (%)				< 0.001*
No problem at all	280 (40.3)	151 (51.0)	129 (32.3)	
A slight problem	311 (44.7)	120 (40.5)	191 (47.9)	
More than a slight problem	68 (9.8)	17 (5.7)	51 (12.8)	
A big problem	26 (3.7)	7 (2.4)	19 (4.8)	
A very big problem	10 (1.4)	1 (0.3)	9 (2.3)	
Frequency of enough sleep, N (%)				0.002*
Always	59 (8.5)	34 (11.5)	25 (3.6)	
Usually	387 (55.7)	175 (59.1)	212 (53.1)	
Sometimes	177 (25.5)	69 (23.3)	108 (27.1)	
Rarely	63 (9.1)	15 (5.1)	48 (6.9)	
Never	9 (1.3)	3 (1.0)	6 (1.5)	
Loneliness, median (min, max)[k]	13.0 (8.0, 32.0)	12.0 (8.0, 27.0)	13.0 (8.0, 32.0)	< 0.001*
Stress, mean (SD)[l]	0.29 (0.15)	0.24 (0.13)	0.33 (0.16)	< 0.001*

Continuous variables analyzed using independent *t*-test and Mann–Whitney *U* test. Categorical variables analyzed using χ^2-test

HRQOL, health-related quality of life; OTC, over-the-counter; SD, standard deviation

[a] KIDSCREEN subscales

[b] Rasch scores were computed for each subscale and transformed into t-values with a mean of 50 and an SD of 10. Higher values indicate higher levels of HRQOL

[c] Range 1–4, where higher values indicate higher levels of self-efficacy

[d] Range 1–4, where higher values indicate higher levels of self-esteem

[e] Range 0–10, where 10 indicates pain as bad as you can imagine

Table 3 (continued)

[f] N = 527

[g] Range 0–10, where 10 indicates complete interference of pain

[h] The variable was dichotomized as "Pain ≤ 3 months" (only once, < 1 month, 1–3 months) or "Pain > 3 months" (> 3 months, > 6 months, > 12 months)

[i] The variable was recoded into three categories: "seldom" (< once/month, once/month), "sometimes" (2–3 times/month, once/week), or "often" (several times/week, every day)

[j] N = 342

[k] Range 8–32, where higher values indicate higher levels of loneliness

[l] Range 0–1, where higher values indicate higher levels of stress

[*] $P \leq 0.01$

and HRQOL in 14–15-year-old adolescents. We found that 14–15-year-old Norwegian adolescents generally report levels of HRQOL that are in line with the results of the European Normdata for KIDSCREEN-27 in 12–18-year old adolescents [45]. However, in line with previous research [21–27], our data confirmed that girls reported lower HRQOL than boys. One of the main findings in this study was that the psychosocial variables (*Self-efficacy*, *Self-esteem*, *Loneliness*, and *Stress*) had the largest effects on the outcome for all HRQOL dimensions both before and after adjustment for selected covariates. Sociodemographic-, pain-, and sleep-related covariates were all significantly associated with some of the subscales; however, their effect on the outcome was smaller than that of the psychosocial variables listed above.

According to our results, stress may be one of the greatest risk factors for adolescents' HRQOL. Moreover, our findings indicate that this may be especially important to consider in girls, because they reported having medium levels of stress compared with boys who only reported low values of stress. A Norwegian study by Moksnes and colleagues showed that girls had significantly higher mean scores on all stress domains and on emotional states compared with boys, who had higher self-esteem [7]. Additionally, our findings indicate that loneliness should also be considered as an important risk factor due to its large effect size for the KIDSCREEN subscale *Social support and peers*. Adolescence is considered a period of high risk for loneliness [9, 11], and failure to resolve loneliness before the end of adolescence may pose significant concerns for future social relationships and mental health [11].

Our findings highlight the importance of considering high self-efficacy and self-esteem as important protective or resource factors for HRQOL in adolescents, which is in line with previous research [8, 22, 25, 31–34]. Moreover, our results show that in the presence of self-efficacy and self-esteem, the negative effect of stress on HRQOL decreases. Similar to the findings of Freire and Ferreira [22], this indicates that positive psychosocial factors (e.g., self-efficacy and self-esteem) might play a buffer role for negative psychosocial factors (e.g., stress) in adolescents.

This study revealed that many adolescents experienced pain, and girls reported significantly more pain than boys. The intensity of pain reported is not considered high, yet the prevalence is a cause for concern. Even though pain was not found to be a strong explanatory factor for variations in HRQOL, our results support previous research showing that pain is negatively associated with HRQOL in adolescents [16, 23]. Furthermore, we found that approximately half of the adolescents reported intake of OTC analgesics, and more girls than boys reported such intake. Considering the relatively low intensity of pain reported, this might indicate that the adolescents use OTC analgesics for reasons other than only pain relief. Frequent consumption of OTC analgesics may cause health problems such as drug-induced headache and liver failure [70]; thus, our findings emphasize that the use of OTC analgesics among adolescents should be regarded as a significant health concern. According to Skarstein et al. [70], informing adolescents, parents, and the society in general about how to use OTC analgesics appropriately should be a high priority.

Sleep played an important role for the dimension *Physical well-being* in our study, confirming that sleep is highly important for HRQOL in adolescents [19, 20, 39]. Studies have shown that there are several barriers to healthy sleep among adolescents such as later preferred sleep timing, lower parental supervision of bedtime, longer study time, and early school start time [19, 38, 71]. Thus, prevention of and interventions against sleep problems require collaboration between adolescents, parents, schools, and healthcare professionals [39].

After adjusting for other factors related to HRQOL, gender was statistically significantly associated only with *Autonomy and parent relations*. An interesting finding was also that being a girl was positively associated with this subscale. Possible explanations of our results might be that gender is important to HRQOL, but that part of the differences between boys and girls in HRQOL can be explained by psychosocial factors. Also, our results show that girls scored significantly worse on pain- and sleep related factors which also are associated with HRQOL.

Table 4 Crude associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL examined by linear regression analyses[a,b,c] N = 696

	Physical well-being							Psychological well-being						
	B1	B2	B3	B4	B5	B6	B7	B1	B2	B3	B4	B5	B6	B7
Gender (ref = boy)	− 0.21*							− 0.27*						
Adult members of the household (ref = both parents)														
Part-time with each parent	− 0.07							− 0.09						
One parent and one stepparent	− 0.06							− 0.06						
One parent	− 0.08							− 0.12*						
Other caregivers	− 0.02							− 0.08						
Parents' work status (ref = both parents working)														
One parent working	− 0.10*							− 0.11*						
No parent working	− 0.08							− 0.00						
School absence (ref = 0–4 days)[d]														
5–10 days	− 0.14*							− 0.13*						
> 10 days	− 0.09							− 0.08						
Self-efficacy		0.43*							0.53*					
Self-esteem			0.44*							0.67*				
Pain on average				− 0.29*							− 0.41*			
Frequency of enough sleep (ref = always)														
Usually					− 0.23*							− 0.30*		
Sometimes					− 0.27*							− 0.39*		
Rarely					− 0.31*							− 0.38*		
Never					− 0.18*							− 0.24*		
Loneliness						− 0.37*							− 0.62*	
Stress							− 0.43*							− 0.72*
R^2 adj	0.106	0.186	0.192	0.086	0.083	0.133	0.187	0.150	0.276	0.449	0.171	0.112	0.390	0.518
	Autonomy and parent relations							**Social support and peers**						
	B1	B2	B3	B4	B5	B6	B7	B1	B2	B3	B4	B5	B6	B7
Gender (ref = boy)	− 0.06							− 0.05						
Adult members of the household (ref = both parents)														
Part-time with each parent	− 0.06							− 0.01						
One parent and one stepparent	− 0.07							− 0.08						
One parent	− 0.13*							− 0.05						
Other caregivers	− 0.11*							− 0.03						

Table 4 (continued)

	Autonomy and parent relations							Social support and peers						
	B1	**B2**	**B3**	**B4**	**B5**	**B6**	**B7**	**B1**	**B2**	**B3**	**B4**	**B5**	**B6**	**B7**
Parents' work status (ref = both parents working)														
One parent working	− 0.06							− 0.03						
No parent working	− 0.07							0.05						
School absence (ref = 0–4 days)[d]														
5–10 days	− 0.06							− 0.06						
> 10 days	− 0.02							− 0.05						
Self-efficacy		0.38*							0.32*					
Self-esteem			0.43*							0.35*				
Pain on average				− 0.29*							− 0.14*			
Frequency of enough sleep (ref = always)														
Usually					− 0.15							− 0.22*		
Sometimes					− 0.26*							− 0.24*		
Rarely					− 0.24*							− 0.20*		
Never					− 0.15*							− 0.16*		
Loneliness						− 0.39*							− 0.55*	
Stress							− 0.52*							− 0.39*
R^2 adj	0.049	0.145	0.181	0.080	0.053	0.153	0.270	0.010	0.104	0.123	0.018	0.032	0.297	0.153

	School environment						
	B1	**B2**	**B3**	**B4**	**B5**	**B6**	**B7**
Gender (ref = boy)	− 0.14*						
Adult members of the household (ref = both parents)							
Part-time with each parent	− 0.03						
One parent and one stepparent	− 0.04						
One parent	− 0.05						
Other caregivers	− 0.02						
Parents' work status (ref = both parents working)							
One parent working	− 0.07						
No parent working	− 0.05						
School absence (ref = 0–4 days)[d]							
5–10 days	− 0.12*						
> 10 days	− 0.06						
Self-efficacy		0.49*					

Table 4 (continued)

	School environment						
	B1	**B2**	**B3**	**B4**	**B5**	**B6**	**B7**
Self-esteem			0.51*				
Pain on average				−0.34*			
Frequency of enough sleep (ref = always)							
Usually					−0.23*		
Sometimes					−0.37*		
Rarely					−0.35*		
Never					−0.22*		
Loneliness						−0.40*	
Stress							−0.56*
R^2 adj	0.046	0.240	0.262	0.113	0.112	0.162	0.310

[a] Linear regression analyses were performed separately for each of the five KIDSCREEN subscales as the dependent variables.

[b] The independent variables were grouped into seven blocks: B1–B7.

[c] The strength of the associations is described in terms of standardized regression coefficients and adjusted R^2.

[d] The variable was recoded into three categories: "0–4 days" (none, 1–4 days), "5–10 days" (5–7 days, 8–10 days), or "> 10 days".

*P ≤ 0.01

Table 5 Adjusted associations between sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness, stress, and HRQOL examined by hierarchical regression analyses[a,b,c] N = 696

	Physical well-being							Psychological well-being						
	M1	M2	M3	M4	M5	M6	M7	M1	M2	M3	M4	M5	M6	M7
Gender (ref = boy)	−0.21*	−0.13*	−0.09*	−0.07	−0.06	−0.07	−0.06	−0.27*	−0.18*	−0.09*	−0.06	−0.06	−0.07*	−0.05
Adult members of the household (ref = both parents)														
Part-time with each parent	−0.07	−0.05	−0.04	−0.04	−0.04	−0.04	−0.03	−0.09	−0.06	−0.04	−0.04	−0.04	−0.04	−0.02
One parent and one stepparent	−0.06	−0.01	−0.01	−0.01	−0.00	0.00	−0.00	−0.06	−0.00	0.01	−0.00	0.00	0.01	0.01
One parent	−0.08	−0.05	−0.04	−0.03	−0.02	−0.02	−0.02	−0.12*	−0.09*	−0.06	−0.05	−0.05	−0.05	−0.04
Other caregivers	−0.02	−0.00	0.01	0.02	−0.02	−0.03	0.03	−0.08	−0.05	−0.03	−0.02	−0.02	−0.01	−0.01
Parents' work status (ref = both parents working)														
One parent working	−0.10*	−0.09*	−0.09*	−0.08	−0.09*	−0.09*	−0.08	−0.11*	−0.10*	−0.10*	−0.09*	−0.10*	−0.08*	−0.06*
No parent working	−0.08	−0.09*	−0.09*	−0.10*	−0.11*	−0.10*	−0.10*	0.00	−0.01	0.01	−0.01	−0.02	−0.02	−0.02
School absence (ref = 0–4 days)[d]														
5–10 days	−0.14*	−0.12*	−0.10*	−0.08	−0.08	−0.07	−0.07	−0.13*	−0.11*	−0.05	−0.03	−0.03	−0.02	−0.01
> 10 days	−0.09	−0.06	−0.05	−0.05	−0.05	−0.04	−0.04	−0.08	−0.04	−0.03	−0.03	−0.03	−0.01	0.00
Self-efficacy		0.38*	0.26*	0.25*	0.24*	0.22*	0.21*		0.46*	0.21*	0.20*	0.19*	0.14*	0.11*
Self-esteem			0.24*	0.21*	0.19*	0.15*	0.12*			0.50*	0.46*	0.45*	0.33*	0.21*
Pain on average				−0.13*	−0.11*	−0.10*	−0.10*				−0.18*	−0.17*	−0.15*	−0.12*
Frequency of enough sleep (ref = always)														
Usually					−0.12	−0.12	−0.11					−0.14*	−0.13*	−0.11
Sometimes					−0.18*	−0.18*	−0.17*					−0.12*	−0.11*	−0.05
Rarely					−0.11	−0.11	−0.10					−0.09*	−0.09*	−0.03
Never					−0.08	−0.08	−0.07					−0.08*	−0.07*	−0.02
Loneliness						−0.11*	−0.09						−0.32*	−0.24*
Stress							−0.07							−0.31*
R^2 adj	0.106	0.237	0.275	0.289	0.299	0.307	0.308	0.150	0.343	0.511	0.539	0.545	0.616	0.658
	Autonomy and parent relations							**Social support and peers**						
	M1	M2	M3	M4	M5	M6	M7	M1	M2	M3	M4	M5	M6	M7
Gender (ref = boy)	−0.06	0.02	0.07	0.10*	0.10*	0.10*	0.12*	−0.05	0.02	0.06	0.07	0.07	0.06	0.06
Adult members of the household (ref = both parents)														
Part-time with each parent	−0.06	−0.03	−0.02	−0.02	−0.02	−0.02	−0.01	−0.01	0.01	0.02	0.02	0.02	0.02	0.03
One parent and one stepparent	−0.07	−0.03	−0.02	−0.03	−0.03	−0.02	−0.03	−0.08	−0.04	−0.04	−0.04	−0.04	−0.02	−0.02
One parent	−0.13*	−0.10*	−0.09	−0.08	−0.07	−0.07	−0.06	−0.05	−0.03	−0.02	−0.02	−0.02	−0.02	−0.02
Other caregivers	−0.11*	−0.08	−0.07	−0.06	−0.06	−0.06	−0.05	−0.03	−0.00	0.00	0.01	0.01	0.02	0.02

Table 5 (continued)

	Autonomy and parent relations							Social support and peers						
	M1	M2	M3	M4	M5	M6	M7	M1	M2	M3	M4	M5	M6	M7
Parents' work status (ref = both parents working)														
One parent working	−0.06*	−0.06	−0.06	−0.05	−0.06	−0.04	−0.03	−0.03	−0.03	−0.03	−0.03	−0.03	−0.00	0.00
No parent working	−0.07*	−0.08	−0.08	−0.08	−0.09*	−0.09*	−0.09*	0.05	0.04	0.04	0.04	0.03	0.04	0.04
School absence (ref = 0–4 days)[d]														
5–10 days	−0.06	−0.05	−0.01	0.00	0.01	0.01	0.02	−0.06	−0.05	−0.02	−0.01	−0.01	0.00	0.00
> 10 days	−0.02	0.01	0.02	0.02	0.02	0.03	0.04	−0.05	−0.02	−0.01	−0.01	−0.02	0.02	0.02
Self-efficacy		0.36*	0.21*	0.20*	0.20*	0.17*	0.14*		0.31*	0.19*	0.19*	0.17*	0.10	0.09
Self-esteem			0.31*	0.27*	0.26*	0.19*	0.06			0.26*	0.25*	0.25*	0.06	0.03
Pain on average				−0.16*	−0.15*	−0.13*	−0.11*				−0.03	−0.03	0.02	0.02
Frequency of enough sleep (ref = always)														
Usually					−0.05	−0.04	−0.01					−0.13	−0.12	−0.11
Sometimes					−0.08	−0.08	−0.01					−0.10	−0.08	−0.07
Rarely					−0.06	−0.06	0.00					−0.05	−0.07	−0.05
Never					−0.05	−0.04	0.01					−0.08	−0.06	−0.04
Loneliness						−0.18*	−0.09						−0.48*	−0.45*
Stress							−0.34*							−0.10
R^2 adj	0.049	0.170	0.233	0.255	0.254	0.276	0.324	0.010	0.101	0.144	0.144	0.146	0.306	0.309

	School environment						
	M1	M2	M3	M4	M5	M6	M7
Gender (ref = boy)	−0.14*	−0.04	0.02	0.04	0.05	0.04	0.06
Adult members of the household (ref = both parents)							
Part-time with each parent	−0.03	−0.01	0.00	0.01	0.01	0.01	0.02
One parent and one stepparent	−0.04	0.02	0.03	0.01	0.03	0.03	0.03
One parent	−0.05	−0.02	−0.00	0.01	0.02	0.02	0.03
Other caregivers	−0.02	0.01	0.03	0.03	0.04	0.04	0.05
Parents' work status (ref = both parents working)							
One parent working	−0.07	−0.06	−0.07	−0.06	−0.07	−0.06	−0.05
No parent working	−0.05	−0.06	−0.06	−0.06	−0.07	−0.07	−0.07
School absence (ref = 0–4 days)[d]							
5–10 days	−0.12*	−0.10*	−0.06	−0.04	−0.03	−0.03	−0.02
> 10 days	−0.06	−0.02	−0.01	−0.01	−0.01	−0.00	0.01
Self-efficacy		0.47*	0.30*	0.30*	0.28*	0.26*	0.24*

Table 5 (continued)

	School environment						
	M1	M2	M3	M4	M5	M6	M7
Self-esteem			0.34*	0.30*	0.27*	0.23*	0.13*
Pain on average				−0.18*	−0.16*	−0.15*	−0.13*
Frequency of enough sleep (ref = always)							
Usually					−0.10	−0.09	−0.07
Sometimes					−0.16*	−0.16*	−0.11
Rarely					−0.13*	−0.14*	−0.09
Never					−0.11*	−0.10*	−0.06
Loneliness						−0.11*	−0.04
Stress							−0.26*
R^2 adj	0.046	0.250	0.327	0.355	0.369	0.377	0.404

[a] Hierarchical regression analyses were performed separately for each of the five KIDSCREEN subscales as dependent variables.

[b] The independent variables were entered into the regression in seven steps, leading to seven linear regression models (M1–M7).

[c] The strength of the associations is described in terms of standardized regression coefficients and adjusted R^2

[d] The variable was recoded into three categories: "0–4 days" (none, 1–4 days), "5–10 days" (5–7 days, 8–10 days), or "> 10 days".

*$P \leq 0.01$

Strengths and limitations

The main strengths of this study include the relatively large sample of 14–15-year-old adolescents in a school-based setting, and that the selected analyzed variables were all assessed with well-validated instruments. The results of this study may be regarded as representative of adolescents in the south-eastern part of Norway; however, we do not know whether they can be generalized to the rest of Norway. Nevertheless, the school system in Norway is fairly homogeneous considering that the majority of adolescents are attending public schools [72], indicating that the findings should be similar for the same age group in other Norwegian regions. However, more than two thirds of the participants lived with both parents, had parents that were both born in Norway and had parents that were both working, indicating that the results may not be representative for adolescents that come from families with lower SES. This should be taken into consideration when interpreting our results.

This was a cross-sectional study, which makes it impossible to determine causal inference. Another limitation is linked to non-participation. Overall response rate was only 41.8%, and we do not have information to assess whether the participants and nonparticipants differed in any respect. Still, it seems plausible that the use of active consent from parents may have resulted in a biased sample, considering the low response rate. Several adolescents said that they wanted to participate but had forgotten to ask their parents for consent or had forgotten to bring their parents' consent form at the time of data collection. We cannot assume if there were any differences between those who had the written consent or not. We may only speculate that parents with high education were more likely to deliver informed consent. However, due to General Data Protection Regulation laws we were not allowed to ask non-responders anything. Furthermore, we did not control for other possible confounders such as bullying and digital technology use. Hence, controlling for other confounders are recommended in future studies.

Clinical implications and future research

Overall, this study contributes to more knowledge of how sociodemographic variables, self-efficacy, self-esteem, pain, sleep, loneliness and stress are related to HRQOL in 14–15-year-old adolescents. To promote HRQOL among adolescents, we suggest that future interventions should prioritize their attention towards psychosocial factors. Interventions aimed at preventing negative psychosocial factors (e.g., stress), might be performed through the promotion of self-efficacy and self-esteem. Moreover, our findings indicate that to develop efficient HRQOL-promoting interventions, future studies should consider possible gender differences within factors that are associated with HRQOL. We encourage future research to use longitudinal designs to explore our findings more thoroughly. Considering that adolescents spend most of their time in school, we suggest the school setting as an important arena for HRQOL-promoting interventions.

Conclusions

In this cross-sectional study among 14–15-year-old adolescents in a school-based setting, we found that psychosocial factors (self-efficacy, self-esteem, loneliness, and stress) are more strongly associated with HRQOL, than sociodemographic-, pain-, and sleep-related factors. Our findings indicate that positive psychosocial factors such as self-efficacy and self-esteem might play a buffer role for negative psychosocial factors (e.g., stress) in adolescents. Furthermore, our results showed that girls score significantly worse on HRQOL, self-efficacy, self-esteem, pain, sleep, loneliness, and stress compared with boys. To improve HRQOL in school-based populations of adolescents, we suggest that future interventions should prioritize their attention towards psychosocial factors, especially towards a strengthening of the adolescents' self-efficacy and self-esteem. We recommend gender-specific interventions.

Abbreviations

BPI: Brief Pain Inventory; GSE: General self-efficacy scale; HRQOL: Health-related quality of life; LPQ: Lübeck Pain-Screening Questionnaire; OTC analgesics: Over-the-counter analgesics; PSQ: Perceived Stress Questionnaire; QOL: Quality of life; RSES: Rosenberg Self-Esteem scale; SES: Socioeconomic status; SUS: Pain, youth and self-medication study; ULS: UCLA Loneliness Scale; WHO: World Health Organization.

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Authors' contributions

All authors contributed to the study conception and design. HTM was responsible for the recruitment together with SS and GR. Data analysis were performed by HTM and MCS. The first draft of the manuscript was written by HTM and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are not publicly available due to General Data Protection Regulation laws but are available from the corresponding author on reasonable request and with permission from the Norwegian Centre for Research Data.

Ethics approval and consent to participate

The participants received oral and written information. Written information was also distributed to the parents. Informed consent was obtained from

both the individual participants included in the study and their parents/legal guardians. Data in the study were anonymized. All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Approval was obtained from the ethics committee of Faculty of Health and Sport Sciences' at the University of Agder and from the Norwegian Centre for Research Data (NSD Reference 60981).

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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Publisher's Note

Paper II

Pain and health-related quality of life in adolescents
and the mediating role of self-esteem and self-efficacy:
A cross-sectional study including adolescents and parents.

BMC Psychology

RESEARCH

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Pain and health-related quality of life in adolescents and the mediating role of self-esteem and self-efficacy: a cross-sectional study including adolescents and parents

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Abstract

Background: To promote health-related quality of life (HRQOL) in adolescents with pain, it is important to study factors associated with pain. This study aimed to describe selected factors and pain in 14–15-year-old adolescents and their parents, to assess how these factors are associated with adolescent pain groups, and to explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and self-efficacy.

Methods: A cross-sectional study was performed among 508 dyads of adolescents (14–15 years) and parents in a school-based setting. Among these, 148 adolescents had persistent pain. We explored the following variables: HRQOL, pain, self-efficacy, self-esteem, sleep, loneliness, stress and sociodemographic variables. All variables were assessed with well-validated instruments. HRQOL was measured with KIDSCREEN-27. Analyses included Chi-square, ANOVA, Mann–Whitney U tests, Kruskal–Wallis and the PROCESS macro method for mediation analyses.

Results: Adolescents with pain reported significantly higher levels of stress, loneliness and lack of sleep and lower levels of self-efficacy, self-esteem and HRQOL compared to adolescents without pain. More girls than boys reported pain. Adolescents with persistent pain scored significantly worse on self-esteem, stress, loneliness, lack of sleep, school absence, pain and HRQOL compared to adolescents with shorter pain duration. Adolescent pain groups did not differ significantly considering parental factors. However, more adolescents with persistent pain reported that someone in their family had pain. The associations between pain intensity and the HRQOL subscales in adolescents with persistent pain were completely mediated by self-esteem, but not by self-efficacy. The highest degree of mediation was estimated for the HRQOL subscale school environment (indirect effect = 73.5%).

Conclusions: Our findings highlight the complexity within adolescent pain, demonstrating that adolescents with pain differ from adolescents without pain when it comes to gender, school absence, factors within-person and between-persons. Longer pain duration makes adolescents more vulnerable. We confirm the importance of resilience factors for HRQOL but indicate that self-esteem is more important than self-efficacy. To promote HRQOL in

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adolescents with persistent pain, a strengthening of both their self-esteem and self-efficacy is recommended. We highlight the need for an individual, holistic approach to adolescent pain.

Keywords: Persistent pain, Health-related quality of life, Adolescents, Parents, Self-efficacy, Self-esteem, Resilience, Mediation

Introduction

Pain problems in adolescents have increased during the last 2 decades and is recognized as a substantial public health challenge in industrialized countries [1, 2]. Negative consequences of adolescent pain include peer relationship problems, sleeping problems, avoidance of activities and sports, school absenteeism, an increased risk of recurrent pain in adulthood and a decreased health-related quality of life (HRQOL) [3–9]. The term HRQOL is a multidimensional construct that includes the individual's subjective perspectives on the physical, psychological, social and functional aspects of health [10]. By measuring HRQOL in adolescents with pain, one can gain insight into adolescents' subjective experiences of pain and how pain affects different dimensions of their lives [11].

According to the International Association for the Study of Pain, pain is always a personal experience that is influenced by biological, psychological, and social factors [12]. Adolescents communicate pain more and less clearly, and causal factors range from identifiable to very diffuse [10]. Sociodemographic factors [e.g. age, gender, ethnicity, socioeconomic status (SES)] and factors within-person (e.g. stress, self-efficacy, self-esteem, sleeping problems) and between-persons (e.g. parents/family, loneliness, the school situation) contribute to and affect adolescent pain from both a resilience perspective and a risk perspective [2, 4, 8, 13–22]. Further, studies have shown that a history of pain in their parents may increase adolescent risk for chronic pain [14, 15, 23].

Internationally comparable data suggest persistent or chronic pain among adolescents in different countries is highly prevalent [24]. Chronic pain is defined as persistent or recurrent pain lasting longer than 3 months [25]. Persistent pain has consequences for the individual, their family and the society at large [19, 26–28]. More knowledge on factors that characterize adolescents with and without pain in a non-clinical population is necessary to better understand the cause of pain problems and find the best strategies to help adolescents with pain. Moreover, knowledge of whether there are factors in adolescents with persistent pain that differ from factors in adolescents with pain lasting less than 3 months is needed.

Adolescent pain research has mainly focused on maladjustment and risk factors. Thus, shifting the focus to protective and resilience factors has been recommended [18, 29, 30]. The term *resilience* refers to the state of an individual having a relatively good psychological outcome despite the presence of risk factors [31]. Both self-esteem and self-efficacy are considered resilient factors [22, 32, 33]. Self-esteem represents one's positive or negative attitude toward oneself [34], whereas self-efficacy represents a self-confident view of one's capability to deal with certain stressors in life [32]. Studies have shown that self-efficacy and self-esteem have a positive impact on both pain and HRQOL in adolescents [18, 35–43]. Higher levels of self-efficacy and self-esteem may protect an adolescent from experiencing pain, it can help to positively adapt and cope with pain, and it is associated with higher levels of HRQOL despite having pain [18, 22, 38, 41, 42].

There is a wide variety and complexity within adolescent pain, and it is therefore important to understand pain in light of a holistic model [11], such as the multidimensional biobehavioral model of pediatric pain [44, 45]. This model illustrates that pain may arise from several precipitants (such as disease, injury or stress) and that potentially modifiable intervening variables can influence both pain and HRQOL. According to this model, these intervening variables are biological predispositions (e.g. genetics, age, gender), family environment (e.g. family functioning, family pain models), perceived social support, cognitive appraisal and coping strategies [44, 45]. Inspired by the model, the present study focused on selected factors in adolescents (sociodemographic characteristics, self-efficacy, self-esteem, loneliness, stress, sleep, HRQOL and pain characteristics) and in their parents (sociodemographic characteristics, HRQOL, parental pain characteristics) that previous research has identified as being associated with adolescent pain [2, 4, 8, 13–22]. These factors can be viewed as both precipitants and intervening variables within the model. More knowledge of these factors in adolescents might shed light on the complexity of adolescent pain. Moreover, because we consider self-efficacy and self-esteem as highly relevant intervening factors within the model, we focused on the possible mediating effect of self-efficacy and self-esteem on the relationship between pain and HRQOL in adolescents with persistent pain.

This study aimed to describe selected sociodemographic- and psychosocial factors and pain in 14–15-year-old adolescents and their parents. Further, to assess how these factors were associated with adolescent

pain groups (no pain, pain lasting less than 3 months, persistent pain). Lastly, to explore whether the relationship between pain intensity and HRQOL in adolescents with persistent pain is mediated by self-esteem and/or self-efficacy.

Methods

Sample and data collection

The present study was conducted from November 2018 to April 2019 in the south-eastern part of Norway as part of the "Start Young—Quality of Life and Pain in Generations" study [43]. Schools covering ninth grade in elementary school (students aged 14–15 years) were stratified according to geographical region, school size, urban and rural districts. Two schools were randomly selected from each such stratum and invited to participate. Schools that declined were replaced by other schools selected according to the same criteria. In total, 22 schools that varied in size and localization participated. Project members visited participating schools to provide the adolescents with verbal and written information about the study. Parents received written information. Active informed consent was obtained from both adolescents and their parents. Potential participants in the study were 1663 adolescent–parent dyads from the participating schools. In total, 696 adolescents (41.8%) and 561 parents (33.7%) filled in the questionnaire. In this study, we included the 508 adolescent–parent dyads (30.5% of the invited) with responses from both adolescents and one of their parents. The response rate varied across schools, from 2.9 to 71.1%.

The data collection was done through a web-based questionnaire. Adolescents completed the questionnaire in classroom during school hours. Parents received a mail with a safe link to the questionnaire and completed the questionnaire at home. A safe data server was used to store the collected data [46]. Information from the parents' consent form enabled us to link the questionnaires from the adolescents with their parents' questionnaires by creating a mutual ID number.

All study procedures were approved by the Norwegian Centre for Research Data (Ref:60981).

Measures

The study used an electronic survey tool that consecutively administered the following questionnaires. Most questions included a neutral option. This resulted in all items being answered. Thirteen variables that had several categories were recoded into fewer categories. This is explained in Tables 1 and 2. All questionnaires that use sum scales showed satisfactory values of Cronbach's alpha above 0.7 in the present study (Additional file 1).

The first part of the survey contained *sociodemographic information*. Adolescents answered questions about gender, age, adult members of the household, parents' birthplace, parental work status and school absence. Parents answered questions about age, gender, marital status, education level, work status and household income. We used the variables regarding adult members of the household, parental education level and household income to indicate SES in further analyses.

Pain in adolescents and in parents was assessed using the Brief Pain Inventory (BPI), which asks participants to rate the subjective intensity of pain at its worst, least and in average, and how pain interferes with different aspects of life [47, 48]. Adolescents and parents answered questions about their own pain experiences. The items are presented as numeric rating scales, with 0 = no pain to 10 = pain as bad as you can imagine. For analysis, the interference items were combined into two indexes of interference: activity and emotions [47]. The Norwegian BPI has satisfactory psychometric properties and has been used among both adolescents and adults [48, 49]. We also used selected questions from the Lübeck Pain-Screening Questionnaire (LPQ), which assesses the presence and consequences of pain during the preceding 3 months [50]. Adolescents and parents were asked about pain duration and pain frequency. To be able to assess how selected factors were associated with adolescent pain groups, we used the adolescents' pain duration variable to divide adolescents into three different groups. The variable was recoded into: "no pain," "pain < 3 months" (only once, < 1 month or 1–3 months) or "persistent pain" (> 3 months, > 6 months or > 12 months). Additionally, the adolescents were asked about self-perceived triggers of pain. A list of possible causes (presented in the footnotes of Table 3) was derived from the LPQ questionnaire [50] and the adolescents were asked to tick all possible causes. The Norwegian LPQ has demonstrated satisfactory content validity and high internal consistency [8]. Only those who rated ≥ 1 on the "pain on average" question from the BPI (indicating that they had pain) were administered questions about pain interference (from the BPI) and questions about pain duration, frequency and self-perceived triggers of pain (from the LPQ). Finally, we used two questions derived from the Norwegian "Pain, Youth and Self-Medication study" [51, 52] to measure the intake of over-the-counter (OTC) analgesics in adolescents and in parents. First, the respondents were asked about OTC analgesic intake during the last 4 weeks. If they answered "yes," they were asked about the frequency of intake.

HRQOL in adolescents was assessed using the KIDSCREEN-27 questionnaire [53, 54]. The KIDSCREEN-27 is a multidimensional measure of generic HRQOL and consists of 27 questions grouped into five subscales: (1) physical well-being, (2) psychological well-being, (3)

Table 1 Sociodemographic characteristics in adolescents and their parents by adolescent pain group (N = 508)

	Total (N = 508)	No pain (n = 124)	Pain < 3 months (n = 236)	Persistent pain (n = 148)	*p* value
Adolescent characteristics					
Gender, N (%)					**< .001**[1,2]
Female	281 (55.3)	42 (33.9)	141 (59.7)	98 (66.2)	
Male	227 (44.7)	82 (66.1)	95 (40.3)	50 (33.8)	
Age, median (min, max)	14.0 (14.0, 15.0)	14.0 (14.0, 15.0)	14.0 (14.0, 15.0)	1.0 (14.0, 15.0)	.447
Adult members of the household, N (%)[a]					.204
Both parents	381 (75.0)	99 (79.8)	176 (74.6)	106 (71.6)	
Alternates between two parents	68 (13.4)	15 (12.1)	27 (11.4)	26 (17.6)	
One parent and/or other caregivers	59 (11.6)	10 (8.1)	33 (14.0)	16 (10.8)	
Parents' work status, N (%)[b]					.246
Both parents are working	414 (81.5)	104 (83.9)	196 (83.1)	114 (77.0)	
One parent is working	94 (18.5)	20 (16.1)	40 (16.9)	34 (23.0)	
School absence for the previous 3 months, N (%)[c]					**.016**[2]
No absence	180 (35.4)	54 (43.5)	78 (33.1)	48 (32.4)	
1–4 days	259 (51.0)	60 (48.4)	129 (54.7)	70 (47.3)	
≥ 5 days	69 (13.6)	10 (8.1)	29 (12.3)	30 (20.3)	
Parent characteristics					
Gender, N (%)					.568
Female	393 (77.4)	95 (76.6)	179 (75.8)	119 (80.4)	
Male	115 (22.6)	29 (23.4)	57 (24.2)	29 (19.6)	
Age, mean (SD)	45.2 (4.9)	45.4 (4.5)	45.2 (4.9)	45.2 (5.1)	.923
Marital status, N (%)[d]					.195
Married/cohabitant	422 (83.1)	109 (87.9)	195 (82.6)	118 (79.9)	
Single/divorced	86 (16.9)	15 (12.1)	41 (17.4)	30 (20.3)	
Education level, N (%)[e]					.697
≤ 12 years and/or certificate of apprenticeship	127 (25.0)	28 (22.6)	59 (25.0)	40 (27.0)	
13–15 years (< 4 years of higher education)	129 (25.4)	32 (25.8)	65 (27.5)	32 (21.6)	
≥ 16 years (≥ 4 years of higher education)	252 (49.6)	64 (51.6)	112 (47.5)	76 (51.4)	
Work status, N (%)					.297
Yes, full time	375 (73.8)	83 (66.9)	181 (76.7)	111 (75.0)	
Yes, part time	91 (17.9)	30 (24.2)	36 (15.3)	25 (16.9)	
No, not employed	42 (8.3)	11 (8.9)	19 (8.1)	12 (8.1)	
Household income, N (%)[f]					.527
≤ 450,000 NOK/year	44 (8.7)	9 (7.3)	20 (8.5)	15 (10.1)	
451,000–750,000 NOK/year	88 (17.3)	18 (14.5)	49 (20.8)	21 (14.2)	
751,000–1,000,000 NOK/year	116 (22.8)	33 (26.6)	51 (21.6)	32 (21.6)	
> 1,000,000 NOK/year	260 (51.2)	64 (51.6)	116 (49.2)	80 (54.1)	

Bold values indicates statistically significant differences between the groups ($p \leq 0.05$)

Continuous variables analyzed with ANOVA with Tukey's HSD post hoc test or Kruskal–Wallis and Mann–Whitney U tests between pairs of groups

Categorical variables analyzed with x^2-test. Significant differences between the marked groups: [1]No pain versus Pain < 3 months, [2]No pain versus Persistent pain and [3]Pain < 3 months versus Persistent pain. *p* values marked with bold indicate statistically significant differences between the groups ($p \leq 0.05$)

The pain group variable was recoded into three categories: "No pain," "Pain < 3 months" (only once, < 1 month, 1–3 months) or "Persistent pain" (> 3 months, > 6 months, > 12 months)

SD standard deviation, *PCS* physical component summary, *MCS* mental component summary

[a] The variable was recoded into three categories: "Both parents," "Alternates between two parents" or "One parent and/or other caregivers" (one parent and one step-parent, one parent, other caregivers)

[b] The variable was dichotomized as "Both parents are working" or "One parent is working" (one parent is working, no parents are working)

[c] The variable was recoded into three categories: "No absence," "1–4 days" or "≥ 5 days" (5–7 days, 8–10 days, > 10 days)

[d] The variable was dichotomized as "Married/cohabitant" or "Single/divorced" (single, divorced, widowed)

[e] The variable was recoded into three categories: "≤ 12 years and/or certificate of apprenticeship" (9 years, 10–11 years, 12 years, certificate of apprenticeship),

Table 1 (continued)

"13–15 years (< 4 years of higher education)" or "≥ 16 years (≥ 4 years of higher education)"

[f] the variable was recoded into four categories: "≤ 450,000 NOK/year" (< 250,000 NOK/year, 250,000–450,000 NOK/year), "451,000–750,000 NOK/year," "751,000–1,000,000 NOK/year" or "> 1,000,000 NOK/year."

Table 2 Descriptive data for adolescent- and parent pain-related factors by adolescent pain group (N = 508)

	Total (N = 508)	No pain (n = 124)	Pain < 3 months (n = 236)	Persistent pain (n = 148)	*p* value
Adolescent characteristics					
Physical well-being, mean (SD)[a,b]	47.4 (9.3)	51.2 (10.0)	47.4 (8.4)	44.2 (9.4)	**< .001**[1,2,3]
Psychological well-being, mean (SD)[a,b]	46.6 (8.6)	52.3 (8.2)	46.1 (7.0)	42.7 (8.6)	**< .001**[1,2,3]
Autonomy and parent relations, mean (SD)[a,b]	52.8 (8.7)	56.7 (9.0)	52.4 (8.0)	50.2 (8.6)	**< .001**[1,2,3]
Social support and peers, mean (SD)[a,b]	48.3 (8.4)	50.6 (8.3)	48.1 (8.2)	46.7 (8.6)	**0.004**[1,2]
School environment, mean (SD)[a,b]	48.2 (8.8)	52.5 (9.6)	47.6 (8.2)	45.6 (7.9)	**< .001**[1,2]
Self-efficacy, mean (SD)[c]	3.1 (0.4)	3.2 (0.4)	3.1 (0.4)	3.0 (0.4)	**< .001**[1,2]
Self-esteem, median (min, max)[d]	3.0 (1.0, 4.0)	3.5 (1.7, 4.0)	3.0 (1.0, 4.0)	3.0 (1.0, 4.0)	**< .001**[1,2,3]
Loneliness, median (min, max)[e]	12 (8, 32)	11 (8, 21)	13 (8, 32)	14 (8, 32)	**< .001**[1,2,3]
Stress, mean (SD)[f]	0.29 (0.16)	0.20 (0.12)	0.29 (0.15)	0.36 (0.17)	**< .001**[1,2,3]
Frequency of enough sleep N (%)[g]					**< .001**[1,2,3]
Usually/always	329 (64.9)	101 (82.1)	152 (64.4)	76 (51.4)	
Sometimes/rarely	178 (35.1)	22 (17.9)	84 (35.6)	72 (48.6)	
Problems with sleepiness N (%)[h]					**< .001**[1,2,3]
No	213 (42.0)	81 (65.9)	98 (41.5)	34 (23.0)	
Yes	294 (58.0)	42 (34.1)	138 (58.5)	114 (77.0)	
Parent characteristics					
RAND-36 PCS, mean (SD)[i]	51.5 (9.0)	52.0 (8.6)	51.4 (9.1)	51.4 (9.1)	.803
RAND-36 MCS, mean (SD)[i]	52.4 (8.0)	53.7 (7.3)	51.8 (8.6)	52.3 (7.6)	.106

Bold values indicates statistically significant differences between the groups ($p \leq 0.05$)

Continuous variables analyzed with ANOVA with Tukey's HSD post hoc test or Kruskal–Wallis and Mann–Whitney U tests between pairs of groups

Categorical variables analyzed with x^2-test. Significant differences between the marked groups: [1]No pain versus Pain < 3 months, [2]No pain versus Persistent pain and [3]Pain < 3 months versus Persistent pain. *p* values marked with bold indicate statistically significant differences between the groups ($p \leq 0.05$)

The pain group variable was recoded into three categories: "No pain," "Pain < 3 months" (only once, < 1 month, 1–3 months) or "Persistent pain" (> 3 months, > 6 months, > 12 months)

SD standard deviation, *PCS* physical component summary, *MCS* mental component summary

[a] KIDSCREEN subscales

[b] Rasch scores were computed for each subscale and transformed into t-values with a mean of 50 and an SD of 10. Higher values indicate higher levels of HRQOL

[c] Range 1–4, where higher values indicate higher levels of self-efficacy

[d] Range 1–4, where higher values indicate higher levels of self-esteem

[e] Range 8–32, where higher values indicate higher levels of loneliness

[f] Range 0–1, where higher values indicate higher levels of stress

[g] The variable was dichotomized as "Usually/always" (usually, always) or "Sometimes/rarely" (sometimes, rarely, never)

[h] The variable was dichotomized as "No" or "Yes" (a slight problem, more than a slight problem, a big problem, a very big problem)

[i] RAND-36 scores range from 0 to range 0–100, where 100 means perfect health

autonomy and parent relations, (4) social support and peers and (5) school environment [53, 55, 56]. The KIDSCREEN questionnaire is scored on a 1–5 Likert scale referring to the last week. The scale indicates either the intensity of an attitude or the frequency of certain behaviors or feelings. In line with the KIDSCREEN-handbook [55], Rasch scores were computed for each subscale and transformed into t-values that can be compared with international t-values. These t-values are normed to a mean (SD) of 50 (10) [55]. The answers were recoded so that higher scores indicate better HRQOL. The Norwegian version of the KIDSCREEN-27 has been shown to be reliable and valid [54].

HRQOL in parents was assessed using the 36-item Medical Outcomes Study Short Form (RAND-36), which consists of eight domains (general health, bodily pain,

Table 3 Descriptive pain characteristics of adolescents and parents by adolescent pain group (N = 508)

	Total (N = 508)	No pain (n = 124)	Pain < 3 months (n = 236)	Persistent pain (n = 148)	*p* value
Adolescent characteristics					
Pain worst, median (min, max)[a]	3.0 (0.0, 10.0)	0.0 (0.0, 10.0)	3.0 (0.0,9.0)	5.0 (0.0, 10.0)	**< .001**[1,2,3]
Pain least, median (min, max)[a]	0.0 (0.0, 8.0)	0.0 (0.0, 5.0)	1.0 (0.0, 8.0)	1.0 (0.0, 6.0)	**< .001**[1,2]
Pain average, median (min, max)[a]	2.0 (0.0, 10.0)	0.0 (0.0, 3.0)	2 (1.0, 10.0)	3 (1.0, 9.0)	**< .001**[1,2,3]
Pain interference on activity, median (min, max)[b,c]	1.3 (0.0, 10.0)		1.0 (0.0, 10.0)	1.7 (0.0, 9.0)	**< .001**[3]
Pain interference on emotions, median (min, max)[b,c]	1.2 (0.0, 9.2)		1.0 (0.0, 9.0)	1.4 (0.0, 9.2)	**.002**[3]
Pain frequency, N (%)[b,d]					**< .001**[3]
Seldom	159 (41.4)		148 (62.7)	11 (7.4)	
Sometimes	90 (23.4)		49 (20.8)	41 (27.7)	
Often	135 (35.2)		39 (16.5)	96 (64.9)	
Self-perceived triggers of pain[b,e]					
Emotions	78 (20.3)		44 (18.6)	34 (23.0)	.305
School	97 (25.3)		52 (22.0)	45 (30.4)	.066
Lack of sleep	99 (25.8)		59 (25.0)	40 (27.0)	.659
Cold/illness	58 (15.1)		45 (19.1)	13 (8.8)	**.006**[3]
Digital technology use	50 (13.0)		28 (11.9)	22 (14.9)	.395
Loneliness	115 (29.9)		58 (24.6)	57 (38.5)	**.004**[3]
Sport/physical activities	33 (8.6)		18 (7.6)	15 (10.1)	.393
Menstruation[f]	85 (35.6)		51 (36.2)	34 (34.7)	.815
Other	200 (52.1)		115 (48.7)	85 (57.4)	.097
Family members having pain, N (%)					**< .001**[2,3]
Yes	154 (30.4)	26 (21.1)	63 (26.7)	65 (43.9)	
Do not know	198 (39.1)	44 (35.8)	100 (42.4)	54 (36.5)	
No	155 (30.6)	53 (43.1)	73 (30.9)	29 (19.6)	
OTC analgesic intake during the last 4 weeks, N (%)					**.001**[1,2]
Yes	242 (47.7)	41 (33.3)	118 (50.0)	83 (56.1)	
No	265 (52.3)	82 (66.7)	118 (50.0)	65 (43.9)	
Frequency of OTC analgesic intake, N (%)[g,h]					.674
Every week	48 (19.8)	7 (17.1)	22 (18.6)	19 (22.9)	
Less often than every week	194 (80.2)	34 (82.9)	96 (81.4)	64 (77.1)	
Parent characteristics					
Pain worst, median (min, max)[a]	2.0 (0.0, 10.0)	1.0 (0.0, 10.0)	2.0 (0.0, 10.0)	2.0 (0.0, 9.0)	.138
Pain least, median (min, max)[a]	0.0 (0.0, 9.0)	0.0 (0.0, 5.0)	0.0 (0.0, 9.0)	0.0 (0.0, 9.0)	.529
Pain on average, median (min, max)[a]	1.0 (0.0, 10.0)	1.0 (0.0, 9.0)	1.0 (0.0, 9.0)	1.0 (0.0, 6.0)	.692
Pain interference on activity, median (min, max)[c,i]	0.7 (0.0, 10.0)	0.3 (0.0, 9.0)	0.7 (0.0, 10.0)	0.7 (0.0, 8.0)	.518
Pain interference on emotions, median (min, max)[c,i]	1.0 (0.0, 10.0)	0.5 (0.0, 9.0)	1.0 (0.0, 10.0)	1.0 (0.0, 8.0)	.465
Pain frequency, N (%)[d,i]					.944
Seldom	87 (28.2)	20 (27.4)	40 (27.6)	27 (30.0)	
Sometimes	58 (18.8)	13 (17.8)	30 (20.7)	15 (16.7)	
Often	163 (52.9)	40 (54.8)	75 (51.7)	48 (53.3)	
Pain duration, N (%)[i,j]					.963
No pain	200 (39.4)	51 (41.1)	91 (38.6)	58 (39.2)	
Pain < 3 months	100 (19.7)	24 (19.4)	49 (20.8)	27 (18.2)	
Persistent pain	208 (40.9)	49 (9.6)	96 (40.7)	63 (42.6)	
OTC analgesic intake during the last 4 weeks, N (%)					.661
Yes	296 (58.3)	68 (54.8)	141 (59.7)	87 (58.8)	
No	212 (41.7)	56 (45.2)	95 (49.3)	61 (41.2)	
Frequency of OTC analgesic intake, N (%)[h,k]					.587
Every week	96 (32.4)	21 (30.9)	43 (30.5)	32 (36.8)	

Table 3 (continued)

	Total (N = 508)	No pain (n = 124)	Pain < 3 months (n = 236)	Persistent pain (n = 148)	*p* value
Less often than every week	200 (67.6)	47 (69.1)	98 (69.5)	55 (63.2)	

Bold values indicates statistically significant differences between the groups ($p \leq 0.05$)

Continuous variables analyzed with Mann–Whitney U test or Kruskal–Wallis with Mann–Whitney U tests between pairs of groups

Categorical variables analyzed with x^2-test. Significant differences between the marked groups: [1]No pain versus Pain < 3 months, [2]No pain versus Persistent pain and [3]Pain < 3 months versus Persistent pain. *p* values marked with bold indicate statistically significant differences between the groups ($p \leq 0.05$)

The pain group variable was recoded into three categories: "No pain," "Pain < 3 months" (only once, < 1 month, 1–3 months) or "Persistent pain" (> 3 months, > 6 months, > 12 months)

OTC over the counter

[a] Range 0–10, where 10 indicates pain as bad as you can imagine

[b] N = 384

[c] Range 0–10, where 10 indicates complete interference of pain

[d] The variable was recoded into three categories: "seldom" (< once/month, once/month), "sometimes" (2–3 times/month, once/week) or "often" (several times/week, every day)

[e] The variable was recoded into nine categories: "Emotions" (anger/disputes, sadness, agitation), "School" (school situation, school work), "Lack of sleep," "Cold/illness," "Digital technology use" (social media, screen time), "Loneliness," "Sport/physical activities," "Menstruation" and "Other" (change of weather, noise, family condition, a new situation, nutrition/sweets, nonspecific factors)

[f] N = 239 (only girls were asked about this possible trigger of pain)

[g] N = 242

[h] The variable was dichotomized as "Every week" (daily, every week but not daily) or "Less often than every week" (less often than every week, nointake)

[i] N = 308

[j] The variable was recoded into three categories: "No pain," "Pain < 3 months" (only once, < 1 month, 1–3 months) or "Persistent pain" (> 3 months, > 6 months, > 12 months)

[k] N = 296

physical function, role limitations [physical], mental health, vitality, social function and role limitations [emotional]). These eight domains can be combined into a physical component summary scale (PCS) and a mental component summary scale (MCS), which reflect physical and mental health, respectively [57, 58]. We used the PCS and MCS scales in this study. The RAND-36 scales were scored according to recommended scoring procedures, and sum scales were expressed using values from 0 to 100, with 100 representing excellent health [57, 58].

Self-efficacy in adolescents was assessed using the 10-item Generalized Self-Efficacy scale (GSE), which measures optimistic self-beliefs in coping with the tasks, demands and challenges of life in general [59, 60]. The scale includes 10 statements that the respondent rates on a 1–4-point scale. The respondent's scores on each item are summed and divided by 10 to obtain a GSE score ranging from 1 to 4. Higher scores indicate higher levels of GSE. The GSE has been found to be valid and reliable, with satisfactory internal consistency [40, 59].

Self-esteem in adolescents was assessed using the four-item version of the Rosenberg Self-Esteem Scale (RSES) [61, 62] consisting of four statements on self-perceptions related to attitude toward oneself, feeling of uselessness, having something to be proud of, and self-worth. RSES is rated on a 1–4 Likert scale. Scores are summed and divided by 4 to obtain a RSES score ranging from 1 to 4, where higher scores represent higher self-esteem. The four-item version correlates highly with the original 10-item version (0.95) [62], which is considered a valid measure of self-esteem in a large body of literature. The four-item version has previously been used among Norwegian adolescents and has good internal consistency [63–65].

Loneliness in adolescents was assessed using the eight-item version of the revised UCLA Loneliness Scale (ULS-8), which is considered to be a reliable and adequate measure of loneliness among adolescents [66–68]. The eight items are rated on a 1–4-point scale, with values ranging from "never" to "always." The total score ranges from 8 to 32 points, with higher scores indicating higher levels of loneliness. The Norwegian version of ULS-8 has been found reliable with satisfactory internal consistency [43].

Stress in adolescents was assessed using the 30-item Perceived Stress Questionnaire (PSQ) [69–71]. PSQ refers to the last 4 weeks and is rated on a 4-point rating scale. PSQ contains both negatively and positively formulated items to reduce acquiescent bias. The answers were recoded so that higher scores indicate higher levels of perceived stress. The resulting PSQ total score is transformed linearly between 0 and 1: PSQ = (raw value − 30)/90. Commonly applied cutoff levels of stress within PSQ are low: < 0.33, medium: 0.33–0.45,

moderate: 0.45–0.60 and severe: > 0.60 [69]. The Norwegian version of PSQ has shown good reliability and validity [71].

Sleep was assessed using two questions derived from the School Sleep Habits Survey, which has been widely used in adolescents [72]. We used one question focusing on frequency of enough sleep and one focusing on problems with sleepiness during daily activities. The School Sleep Habits Survey has an established validity compared to sleep diaries and actigraphy [73] and has previously been used among Norwegian adolescents [74].

Data analyses

The statistical analyses were conducted using IBM SPSS Statistics (version 26.0). Descriptive statistics were calculated for all variables according to three previously defined adolescent pain groups. Continuous variables were described with mean and standard deviation or as median and min/max, categorical variables with counts and percentages. Strength of associations between pairs of selected variables was assessed using chi-square test for categorical data and ANOVA with Tukey's HSD post hoc test or Kruskal–Wallis and Mann–Whitney U tests for continuous data. To fulfill the assumption of "minimum expected cell frequency" for chi-square analyses [75], some of the items that had several categories were recoded into fewer categories.

Mediation analyses were conducted using the PROCESS macro method developed for SPSS by Hayes [76]. We proceeded using the parallel multiple mediation model depicted in Fig. 1. PROCESS was used to estimate (1) the direct effect of pain on HRQOL (C′), (2) the total effect of pain on HRQOL (C) and (3) the specific indirect effects through mediator 1 (self-efficacy) and mediator 2 (self-esteem) ($a_i b_i$). Gender, adult members of the household, parental education and household income were entered as covariates. Proportions mediated for the direct and indirect effects were estimated as the direct effect/total effect and the indirect effect/total effect and multiplied by 100 to be interpreted as percentages. The calculation of direct and total indirect effect as percentages was not applicable for the HRQOL subscales autonomy and parent relations and social support and peers due to opposite directions of the total effects and the direct effects. The mediation effect was considered statistically significant if the 95% confidence interval (CI) for the effect did not include zero. All the analyses were considered exploratory. Hence, no correction for multiple testing was done, and p values < 0.05 were considered significant. All the tests were two-sided. Assumptions for mediation analyses were checked and fulfilled. According to Preacher and Hayes, a significant indirect effect is no longer seen as a prerequisite for mediation [77]. Thus, all HRQOL subscales were included.

Results

Descriptive data for sociodemographic variables in adolescents and their parents

In total, 508 dyads of adolescents with one parent each participated in the study. The majority were girls (55.3%) and mothers (77.4%), respectively. The adolescents' ages ranged from 14 to 15 years, with a median age of 14 years. The mean (SD) age for the parents were 45.2 (4.9) years. Among the adolescents, 148 had persistent pain. The three adolescent pain groups were similar concerning all the selected sociodemographic variables in adolescents

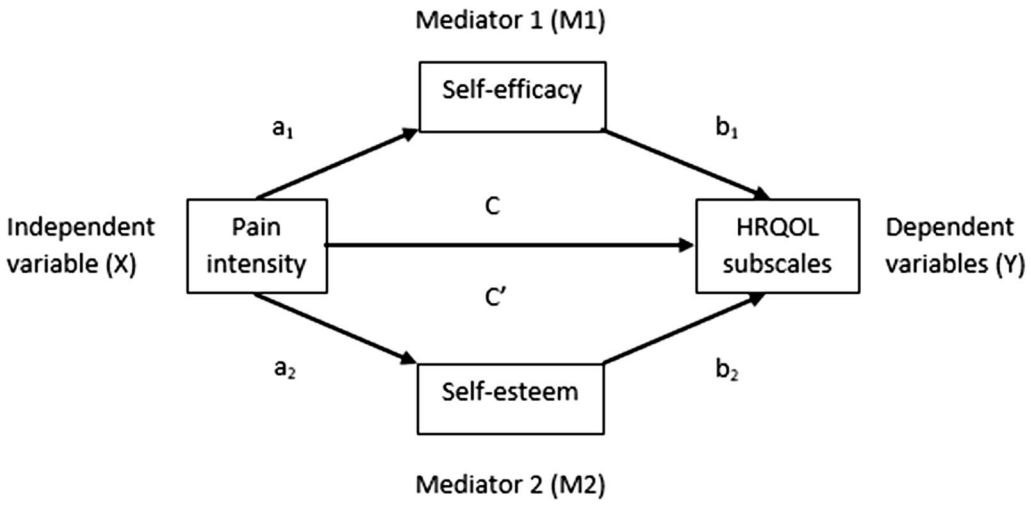

Fig. 1 Schematic of our parallel multiple mediation model

and their parents, except for adolescents' gender and school absence (Table 1).

Descriptive data for adolescent- and parent pain-related factors

Descriptive data for adolescent- and parent pain-related factors by adolescent pain groups are presented in Table 2. Adolescents with pain lasting less than 3 months and persistent pain reported significantly higher levels of stress, loneliness and lack of sleep and lower levels of self-efficacy, self-esteem and HRQOL compared to adolescents without pain. Adolescents with persistent pain reported significantly lower HRQOL than adolescents with pain lasting less than 3 months for the KIDSCREEN subscales physical well-being, psychological well-being and autonomy and parent relations. Moreover, adolescents with persistent pain reported significantly lower levels of self-esteem and significantly higher levels of loneliness, stress and lack of sleep than adolescents with pain lasting less than 3 months. Considering the parents' HRQOL, there were no statistically significant differences between the adolescent pain groups.

Descriptive pain characteristics of adolescents and parents

Table 3 shows the descriptive pain characteristics of adolescents and parents by adolescent pain groups (Table 3). Adolescents with persistent pain experienced pain significantly more often and reported significantly higher values of the worst pain and average pain compared to adolescents with pain lasting less than 3 months. Moreover, adolescents with persistent pain also reported significantly higher levels of pain interference in both activity and emotions.

The most prevalent self-perceived triggers of pain, as reported by the adolescents, were loneliness (29.9%), lack of sleep (25.8%) and school (25.3%). Girls also rated menstruation (35.6%) as a prevalent trigger of pain. More adolescents with persistent pain (38.5%) reported loneliness as a trigger compared to adolescents with pain lasting less than 3 months (24.6%).

Almost two-thirds of the adolescents and more than half of the parents with pain experienced pain in multiple body locations. Head pain and neck/shoulder pain were the most common pain locations for both adolescents and the parents. Among both adolescents and parents, about half reported intake of OTC analgesics during the last 4 weeks. Among these, almost one-third of the parents reported intake every week, while about 20% of the adolescents reported intake every week. Our univariate analyses showed no significant relationship between the adolescents' and their parents' use of OTC analgesics.

There were no statistically significant differences between the adolescent pain groups concerning any of the parents' pain characteristics. However, more adolescents with persistent pain (43.9%) reported that someone in their family had pain compared to adolescents with pain lasting less than 3 months (26.7%) and adolescents without pain (21.1%).

Mediation by self-efficacy and self-esteem on the relationship between pain intensity and HRQOL in adolescents with persistent pain

We have suggested a parallel multiple mediation by self-efficacy (M1) and self-esteem (M2) of the association between pain intensity (X) and the scores for HRQOL subscales (Y) in adolescents with persistent pain, as depicted in Fig. 2. Unstandardized estimates of the Bs of the associated variables are depicted in the figure. We found that pain was associated with decreased self-efficacy ($a_1 = -0.04$) and self-esteem ($a_2 = -0.13$). However, the associations were only significant for self-esteem. Further, we found that having a higher self-efficacy score (b_1) was significantly associated with higher HRQOL scores for the subscales physical well-being ($b_1 = 4.65$) and school environment ($b_1 = 5.25$). Moreover, we found that having a higher self-esteem score (b_2) was significantly associated with higher HRQOL scores for all the subscales: physical well-being ($b_2 = 3.43$), psychological well-being ($b_2 = 7.00$), autonomy and parent relations ($b_2 = 3.37$), social support and peers ($b_2 = 4.45$) and school environment ($b_2 = 4.25$).

The total effect (C) of pain on HRQOL was statistically significant for the subscales physical well-being ($C = -1.37$), psychological well-being ($C = -1.52$) and school environment ($C = -1.03$). This indicates that for these subscales, an increased pain score is associated with a decreased HRQOL score after adjusting for the two mediators and holding the covariates gender, adult members of the household, parental education and household income constant. The direct effect (C') of pain on HRQOL was no longer statistically significant for any of the subscales, indicating that the association were completely mediated by self-efficacy and self-esteem.

Table 4 shows the reduction in HRQOL subscales (presented as percentages) in adolescents with persistent pain explained by the direct (pain intensity) and indirect (self-efficacy and self-esteem) effects. Self-efficacy was not a mediator in the relationship between pain and HRQOL. Self-esteem completely mediated the relationship between pain and HRQOL for the subscales physical well-being, psychological well-being and school environment. More than half of the reductions in the HRQOL subscale scores for

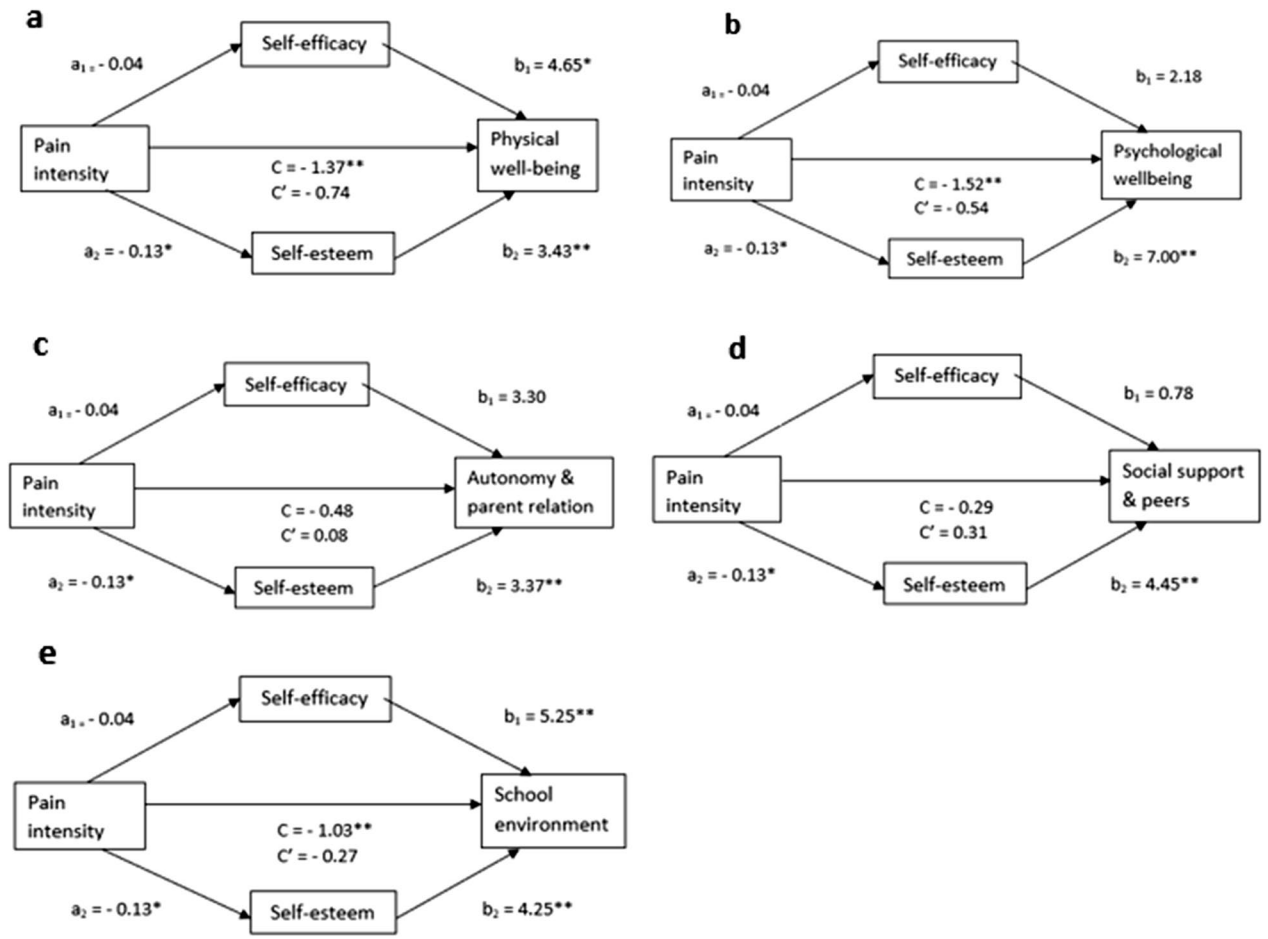

Fig. 2 Parallel multiple mediation by self-efficacy and self-esteem of the association between pain and HRQOL subscales in adolescents with persistent pain. Gender, Adult members of the household, Parental education and Household income were entered as covariates. **a** Physical well-being, **b** Psychological well-being, **c** Autonomy and parent relation, **d** Social support and peers and **e** School environment. *HRQOL* health-related quality of life. *$p < 0.05$, **$p < 0.01$. Path a and b represents the indirect effects through the mediators. Path C′ depicts the direct effect and C the total effect

Table 4 Reduction in HRQOL subscales in adolescents with persistent pain explained by direct (pain intensity) and indirect (self-efficacy and self-esteem) effects

	Direct effect	Indirect effect of self-efficacy	Indirect effect of self-esteem	Total indirect effect[a]
Physical well-being[b]	54.2%	13.7%	32.1%*	45.8%*
Psychological well-being[b]	35.4%	5.7%	58.8%*	64.6%*
Autonomy and parent relation[b]	–	–	–	–
Social support and peers[b]	–	–	–	–
School environment[b]	26.5%	20.5%	53.0%*	73.5%*

HRQOL health-related quality of life

[*] Statistically significant; the 95% confidence interval for the effect did not include zero

[a] The specific indirect effect of self-efficacy + the specific indirect effect of self-esteem ($a_1b_1 + a_2b_2$)

[b] KIDSCREEN subscales

psychological well-being and school environment, and about one-third of the reduction for physical well-being were explained by the mediating variable self-esteem. Among the five HRQOL subscales, the total indirect effect was highest for the subscale school environment (73.5%).

Discussion

Overall, we believe our findings support the need to understand pain through a holistic model such as the multidimensional biobehavioral model of pediatric pain [44, 45]. In light of this model, self-esteem, self-efficacy, stress, loneliness, sleep and sociodemographic factors might serve as both precipitants that pain may arise from and intervening variables that can influence both pain and HRQOL. Specifically, we believe our results highlight that self-esteem and self-efficacy should be considered as important intervening variables.

The complexity within adolescent pain

The current findings demonstrate the complexity within adolescent pain. We found that adolescents with pain differ from adolescents without pain when it comes to gender and school absence and factors within-person (self-efficacy, self-esteem, stress, sleeping problems) and between-persons (loneliness). Further, in line with previous studies [3, 38], this study shows that having pain is negatively associated with HRQOL, indicating that pain affects physical, psychological, social and functional aspects of adolescents' lives. As highlighted in another Norwegian study [8], pain problems seem to have widespread and generally negative effects on several aspects of adolescents' lives. We also found a wide variety considering the adolescents' self-perceived triggers of pain, emphasizing the subjectivity within pain experiences.

Our results demonstrate that adolescents with persistent pain constitute a vulnerable group, as they reported higher levels of stress, loneliness, lack of sleep and lower levels of self-efficacy, self-esteem and HRQOL compared to adolescents with less pain. Negative findings related to having persistent pain have also been highlighted in other studies [4, 7, 22]. Further, our results indicate that a longer pain duration is making the adolescents more vulnerable to pain interference.

It is notable that in addition to reporting higher scores of loneliness, more adolescents with persistent pain reported loneliness as a self-perceived trigger of pain compared to adolescents with a shorter pain duration. This indicate that loneliness is a significant problem among adolescents with persistent pain. Our findings are in line with the review of Forgeron et al. [9], who found that adolescents with persistent pain have peer relationship deficiencies. Across studies, this review found that adolescents with persistent pain were viewed as more isolated than healthy peers, were reported to have fewer friends and may be subjected to more peer victimization. Loneliness is strongly associated with HRQOL in adolescents [43]. Thus, an increased awareness of peer relationship challenges for adolescents with persistent pain is very important.

The mediating role of self-esteem and self-efficacy on the relationship between pain and HRQOL in adolescents with persistent pain

The effect of pain on HRQOL was completely mediated by self-esteem but not by self-efficacy, indicating that self-esteem plays a more important role than self-efficacy on the relationship between pain and HRQOL. Our findings contrast with the study of Grasaas et al. [38], who found that the associations between pain intensity and several HRQOL subscales were mediated by self-efficacy in adolescents with persistent pain. However, unlike Grasaas et al.'s study, our study included self-esteem as a parallel mediator and controlled for gender as a possible confounder, which may explain the different results. Previous studies have found important gender differences among adolescents when it comes to pain, HRQOL, self-esteem and self-efficacy [13, 35, 38, 43]. This may explain our results.

The review of Cousins and colleagues ([18] pp. 843–844) highlights that "the concept of resilience empowers youth to foster their skills and strengths to positively adapt and live successfully with their pain," and previous research have highlighted the importance of considering high self-esteem and self-efficacy as important protective or resource factors for HRQOL in adolescents [35–39, 43]. Our results confirm the importance of resilience factors for well-being in adolescents with persistent pain by showing that up to 73.5% of the reduction in the HRQOL subscale scores for physical well-being, psychological well-being and school environment could be explained by the mediating variables self-esteem and self-efficacy. Furthermore, the total indirect effect was highest for the HRQOL subscale school environment, indicating that self-esteem and self-efficacy especially play an important part in adolescents with pain's well-being at school. Previous studies have found that low self-esteem relate to relative increases in loneliness over time and vice versa [78]. Peer relationship is important at school and adolescents experience relationships with peers as vital to their well-being [79]. Considering that loneliness was found to be a significant problem among the adolescents with persistent pain, this might explain our findings. Another noteworthy finding was that the associations between the

HRQOL subscales and self-esteem were statistically significant for all five HRQOL subscales, while self-efficacy was only significantly associated with the subscales physical well-being and school environment. However, for these two subscales, self-efficacy had a higher effect than self-esteem. This shows that self-esteem and self-efficacy affect physical, psychological, social and functional aspects of adolescents' lives in different ways, suggesting that both resilience factors are important for the well-being of adolescents.

Resilience factors such as self-esteem and self-efficacy are especially important during adolescence. The social and emotional development of adolescents is characterized by a struggle with sense of identity, where adolescents strive for independence from caregivers while becoming increasingly influenced by peers [80]. Support from family and friends is considered vital to enhance resilience [33]. To increase the sense of self-esteem and self-efficacy, Stewart and Yuen [33] recommends that individuals should be encouraged to think of other challenging situations they have mastered. According to their review, encouraging a sense of hope, realistic optimism and mastery over either the problem (e.g. pain) or one's ability to cope with it might be helpful.

Family influence on adolescent pain

Parent history of pain may increase adolescent risk for chronic pain [14, 15, 23]. Surprisingly, our study found no differences between the adolescent pain groups considering any of the parents' pain characteristics. However, more adolescents with persistent pain reported that someone in their family had pain, indicating that family history of pain still plays a significant role. It is possible that other elements in the family environment may have contributed to our results considering that the relationship between parental and adolescent pain may be a result of complex interactions between genetics, environmental factors and learned pain behavior [14–17]. Parent factors may shape adolescents' pain development and pain management from both a resilience perspective and a risk perspective [16, 18, 19], and differences in adolescents' attachment to their caregivers and how they communicate about pain might affect how adolescents experience and manage pain [81].

We found that about half of adolescents and parents reported intake of OTC analgesics and that parents reported more frequent intake compared to the adolescents. Considering the relatively low intensity of pain reported, this might indicate that adolescents and parents use OTC analgesics for reasons other than only pain relief. According to Skarstein et al.'s [82] review, parents are the most important source of information regarding adolescents' use of OTC analgesics, as well as the main supplier. Thus, our findings highlight that informing parents, adolescents, and society about how to use OTC analgesics appropriately should be a high priority.

Contrary to previous studies that have shown that children from families with low SES experience pain more frequently [2, 20, 21], we found that the three adolescent pain groups were similar concerning SES factors such as adult members of the household, parental work status, parental education level and household income. A possible explanation for this might be that our sample mainly consisted of adolescents from families with higher levels of SES. However, it is important to highlight that although significant shared effects between family members (e.g., economy, education, cohabitant status) is associated with chronic pain, most explanations for chronic pain are considered to be at the individual level [83].

Strengths and limitations

The main strengths of this study include the relatively large sample of adolescent–parent dyads recruited from a variety of schools and that the selected analyzed variables were assessed with well-validated instruments. The limitations of this study include the cross-sectional design, which makes causal inference challenging to determine. Further, our meditation analyses are of an exploratory nature and based on our assumptions and understanding of the current research area. Thus, we can assume the direction of the indirect and direct effects. Another limitation is linked to the low response rate. We do not have information about the nonparticipating adolescents and parents. Therefore, we cannot assess whether the nonparticipants and participants differed in any way. Also, we only included one of each adolescent's parents, which may have affected the results. Hence, the inclusion of both parents is recommended in future studies. However, more than three quarters of the adolescents lived with both parents and had parents who were both working. Further, among the participating parents, around three quarters had higher education level, were working full time and had a household income of more than 750,000 NOK/year. This indicates that the results may not be representative of adolescents within families with lower SES, which should be considered when interpreting our results. Further, the pain intensity reported by the adolescents is not considered high, which indicates that the results may not be representative of adolescents with higher levels of pain. Moreover, sample size and heterogeneity in the sample may have led to self-efficacy not being significant in our mediation analyses. We can therefore not exclude a possible significant influence from self-efficacy even if we were not able to show it in our study. Thus, we recommend a larger sample in future studies.

Implications

This study contributes to more knowledge of factors that characterizes adolescents with and without pain in a school-based setting, which can help teachers, public health nurses, parents and researchers better understand the cause of pain problems and find the best strategies to help adolescents with pain. It seems nearly impossible to focus solely on singular factors when helping adolescents to cope with pain. Thus, we recommend an individual, holistic approach to adolescents' pain. In order to have an increased focus on protective and resilience factors, we suggest that public health nurses include routine-questions about self-esteem and self-efficacy in their consultations with adolescents who experience pain. Moreover, considering that the current COVID-19 pandemic is associated with increased stress and loneliness in adolescents [84, 85] parents, teachers, health professionals and researchers should be aware of the risk for an increase in pain problems among adolescents during and after the pandemic.

Based on our results from the mediation analyses, we recommend that HRQOL-promoting interventions among adolescents with pain should focus on a strengthening of their self-esteem and self-efficacy. It is demanding to intervene on risk-factors associated with adolescents' pain such as SES, stress, and parental factors. However, interventions aimed at increasing self-esteem and self-efficacy is promising and also possible to carry out, for instance in a school setting, and should thus be a high priority. Considering that the basis for self-esteem and self-efficacy is founded during childhood, we recommend that a strengthening of these resilience factors should be a focus in early age, not only when reaching adolescence. We suggest the school setting as an important arena for resilience-promoting interventions.

Conclusions

This cross-sectional study among 14–15-year-old adolescents demonstrates the complexity and subjectivity within adolescent pain and shows that adolescents with pain differ from adolescents without pain when it comes to gender and school absence and factors within-person (self-efficacy, self-esteem, stress, sleeping problems) and between-persons (loneliness). We found no statistically significant differences between the adolescent pain groups, considering the selected parental factors; however, more adolescents with persistent pain reported that someone in their family had pain. Our results emphasize that longer pain duration makes adolescents more vulnerable, especially considering peer relationship. Furthermore, the results of our mediation analyses confirm the importance of resilience factors for HRQOL in adolescents with persistent pain but indicate that self-esteem plays a more important role than self-efficacy. Still, to promote HRQOL in adolescents with persistent pain, we suggest a strengthening of both their self-esteem and self-efficacy. We highlight the need for an individual, holistic approach to adolescent pain.

Abbreviations

BPI: Brief pain inventory; GSE: General self-efficacy scale; HRQOL: Health-related quality of life; LPQ: Lübeck pain-screening questionnaire; MCS: Mental component summary scale; OTC: Over the counter; PCS: Physical component summary scale; PSQ: Perceived stress questionnaire; RSES: Rosenberg self-esteem scale; SES: Socioeconomic status; RAND-36: The 36-item medical outcomes study short form; ULS: UCLA loneliness scale.

Supplementary Information

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Additional file 1. Cronbach's alpha values for instruments used in this study.

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Authors' contributions

All authors contributed to the conception of the study and its design. HTM, along with SS and GR, was responsible for the recruitment. HTM and MCS performed the data analyses. HTM wrote the first draft of the manuscript, and all the authors (HTM, KH, SH, SS, MCS and GR) commented on previous versions of the manuscript. All the authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are not publicly available due to General Data Protection Regulation laws but are available from the corresponding author on reasonable request and with permission from the Norwegian Centre for Research Data.

Declarations

Ethics approval and consent to participate

The adolescents received oral and written information. The written information was distributed to the parents. Active informed consent was obtained from both the adolescents and their parents. Data in the study were anonymized. All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee, as well as with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Approval was obtained from the ethics committee of the Faculty of Health and Sport Sciences at the University of Agder and from the Norwegian Centre for Research Data (NSD Reference: 60981).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Paper III

Health-related quality of life, health literacy and COVID-19-related worries of 16- to 17-year-old adolescents and parents one year into the pandemic: A cross-sectional study.

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Health-related quality of life, health literacy and COVID-19-related worries of 16- to 17-year-old adolescents and parents one year into the pandemic: a cross-sectional study

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Abstract

Background: The uncertain and challenging situation caused by the COVID-19 pandemic affects adolescents and their parents in an exceptional way. More knowledge of health-related quality of life (HRQoL), health literacy (HL) and COVID-19-related worries in adolescents and parents 1 year into the pandemic is needed. The present study aimed to describe HRQoL, HL and COVID-19-related worries of 16- to 17-year-old adolescents and parents of adolescents. Further, to assess the strength of associations between gender, HL, COVID-19-related worries and HRQoL.

Methods: A cross-sectional study involving 215 adolescents and 320 parents was conducted, exploring HRQoL, HL, COVID-19-related worries and sociodemographic variables. KIDSCREEN-10 and RAND-36 were used to measure HRQoL. Data were analyzed using bivariate methods, multiple linear regression and robust regression.

Results: Adolescents' HRQoL was notably lower compared to previous Norwegian studies and European norms. Parents' HRQoL was comparable to Norwegian norms. Adolescents and parents reported moderate-to-high HL and high degrees of COVID-19-related worries. Females reported significantly lower HRQoL and more worries compared to males. In adolescents, higher HL was significantly associated with higher HRQoL. COVID-19-related worries were not significantly associated with HRQoL. In parents, higher HL in the "understand health information" domain was significantly associated with higher HRQoL for mental well-being (mental component sum scores [MCS]) and with lower HRQoL for physical well-being (physical component sum scores [PCS]). Being worried a lot about infecting others and about family/friends becoming sick was significantly associated with higher MCS and lower MCS, respectively. COVID-19-related worries were not significantly associated with PCS.

Conclusions: Our results indicate that the pandemic has a major negative impact on adolescents' HRQoL. Parents' HRQoL remained unchanged and comparable to previous studies. Our study demonstrates that HL, gender and COVID-19-related worries are significantly associated with adolescents' and parents' HRQoL, indicating that efforts aimed at increasing their HL might indirectly affect their HRQoL as well and that gender-specific interventions or strategies could be beneficial.

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Keywords: health-related quality of life, health literacy, COVID-19, worries, adolescents, parents

Background

In 2020, coronavirus disease 2019 (COVID-19) spread around the world, and in March 2020, the World Health Organization (WHO) characterized the situation as a pandemic [1]. The pandemic led to major changes in people's lives through protective strategies aimed at limiting the transmission of COVID-19—for example, the practice of hand hygiene, the use of face masks in public places, social distancing instructions, lockdowns, closed or limited leisure activities, homeschooling and increased use of home offices. One year later, despite an overall encouraging picture related to COVID-19 vaccines, mutations of the virus pose additional challenges, and the pandemic still affects daily life.

The uncertain situation caused by the pandemic affects adolescents and their families in an exceptional way [2–5]. The negative effects of social distancing might be particularly challenging for adolescents, for whom peer interaction is especially important [6, 7]. Studies conducted during the pandemic have revealed increased loneliness in both adolescents and adults [3, 8, 9]. COVID-19-related restrictions and potential health risks affect emotions and perceived stress in adolescents and parents and may be associated with COVID-19-related worries and deteriorated mental health [3, 9–16]. More perceived stress and deteriorated mental health have been identified in parents as compared to adults without children in the same household [3, 10]. Further, the pandemic has major economic implications for several families [5, 10, 13]. During the pandemic, more frequent negative and positive interactions between parents and adolescents have been reported—for example, increased conflicts, more quality time with family and increased feelings of closeness [2, 10, 17–19]. The pandemic has affected many lives both positively and negatively [14, 15, 19].

The pandemic has been linked to lower life satisfaction and reduced health-related quality of life (HRQoL) in adolescents and adults [4, 16, 20–23]. HRQoL is a multidimensional construct that includes the individual's subjective perspectives on the physical, psychological, functional and social aspects of health [24]. Previous studies have demonstrated that sociodemographic factors (e.g., male gender and higher socioeconomic status [SES]) are associated with higher HRQoL in adolescents and adults both before and during the initial phase of the pandemic [4, 16, 21, 25–27]. However, more knowledge of HRQoL in adolescents and parents 1 year into the COVID-19 pandemic is needed.

For the protective strategies to be successful, COVID-19-related information and advice need to be understood and acted upon by the population. Hence, individuals' health literacy (HL) can have an important impact on the effective use of health knowledge [21]. HL is a concept within health promotion that represents the skills that determine the ability and motivation of individuals to gain access to, interpret, understand and use health information to maintain and promote good health [28].

A relationship between HL and health behaviors in adolescents has been revealed [29]. Thus, more knowledge on adolescents' HL during the pandemic is needed, as they are increasingly becoming independent and responsible for their health behaviors [21]. Although adolescents are less likely to become seriously ill from COVID-19 [30], their willingness to, for example, follow social distancing guidelines is essential for reducing the risk of spreading the virus. Further, parents are important role models; thus, more knowledge of HL in parents of adolescents during the pandemic is needed.

Low HL has been associated with reduced quality of life [31, 32]. A recent study among Norwegian adolescents during the pandemic found that HL is positively associated with HRQoL [8]. HL has also been found to be a protective factor for improving adults' HRQoL during the pandemic [26, 33]. However, the literature regarding the impact of HL on adolescents' and parents' HRQoL during the pandemic is scarce. Increased knowledge of this association will be valuable for health promotion interventions and policy.

The aim of this study is to describe HRQoL of 16- to 17-year-old adolescents and parents of adolescents, their HL and degree of COVID-19-related worries about 1 year into the pandemic, and to assess the strength of associations between gender, HL, COVID-19-related worries and HRQoL.

Methods

Sample and data collection

This study is a part of *Start Young – Quality of Life and Pain in Generations* [34]—a Norwegian longitudinal study aiming to acquire new knowledge about HRQoL and pain in adolescents and their parents. The present study uses data collected from January to February 2021, around 2 years after the overall study's baseline data collection and approximately 1 year into the COVID-19 pandemic.

Potential participants of this study were 647 adolescents and 561 adults (all parents of a 16- to 17-year-old

adolescent) who had participated in the baseline study and thereby provided their telephone numbers. The potential participants received a text message with an invitation to participate in the study and a safe link to the questionnaire. Informed consent was given at the beginning of the questionnaire. In total, 215 adolescents (response rate: 33.2%) and 320 parents (response rate: 57.0%) took part in this study.

Data collection was carried out through a web-based questionnaire the participants completed in their spare time. We used a safe data server to store the collected data [35]. All study procedures were approved by an ethics committee at the University of Agder and by the Norwegian Centre for Research Data (Ref:60981).

Measures

An electronic survey tool that consecutively administered the following questionnaires was used. Most questions included a neutral option, resulting in all items being answered. All questionnaires using sum scales showed satisfactory Cronbach's alpha values above 0.7 (see Additional file 1).

The first part of the questionnaire included self-reported data on sociodemographic variables. Adolescents answered questions about gender, age, parents' birthplace, adult members of the household and parental work status. Parents answered questions about age, gender, marital status, education level, work status and household income.

HRQoL in adolescents was assessed using the KIDSCREEN-10 Index [36, 37]—a unidimensional self-report measure of HRQoL that represents a global score for the dimensions of the longer KIDSCREEN versions [38]. KIDSCREEN-10 consists of 10 items covering perceptions of physical well-being, psychological well-being, autonomy and parent relations, social support and peers, and school environment. We computed Rasch scores and transformed them into t-values in line with the KIDSCREEN handbook [38]. These t-values are normed to a mean (standard deviation [SD]) of 50 (10) and can be used to make comparisons with international t-values. The Norwegian KIDSCREEN-10 is considered valid and reliable [39].

HRQoL in parents was assessed using the 36-item Medical Outcomes Study Short Form (RAND-36). RAND-36 is a generic questionnaire consisting of eight domains that can be combined into a physical component sum score (PCS), reflecting physical health (general health, bodily pain, physical function and role limitations), and a mental component sum score (MCS), reflecting mental health (mental health, vitality, social function and role limitations) [40, 41]. The Norwegian RAND-36 is considered valid and reliable [42].

HL in adolescents was assessed using the 10-item Health Literacy in School-Aged Children (HLSAC) questionnaire [43], which includes two items from each of the following theoretical components: theoretical knowledge, practical knowledge, critical thinking, self-awareness and citizenship. Based on the sum score, HL levels can be defined as follows: "low" (score 10–25), "moderate" (score 26–35) or "high" (score 36–40) [44, 45]. The Norwegian HLSAC has been used among adolescents and has shown satisfactory internal consistency and a dominant first factor with eigenvalue = 3.88 [21].

HL in parents was assessed using the Health Literacy Questionnaire (HLQ)—a generic, multidimensional instrument [46] comprising 44 questions representing nine independent HL domains. We used five of the nine HLQ-domains that were considered the most relevant for our purpose. The chosen domains focus on having sufficient information to manage health, actively managing health, and understanding health information, as well as on the appraisal of health information and the ability to find good health information. Each domain comprises four to six items. The domain scores are calculated as the average of the item scores. Higher scores indicate better HL. The Norwegian HLQ is considered reliable and valid [47].

COVID-19-related-worries in adolescents and parents were assessed using selected questions derived from the Norwegian study *Adolescents in Oslo in the Time of the COVID-19 Pandemic* [14, 48]. We used two questions concerning whether the COVID-19 pandemic had changed the participants' lives positively and/or negatively. We used six questions concerning different COVID-19-related worries: becoming sick and infecting others, as well as worried about family/friends becoming sick, school grades (for adolescents) or work (for parents), the family's economy and Norwegian economy. In the regression analyses, we selected "worried about infecting others with COVID-19" and "worried about family/friends becoming sick" as independent variables because these were the COVID-19-related worries most highly reported by adolescents and parents.

Data analyses

Descriptive statistics were calculated for all variables stratified by gender and presented as counts and percentages for categorical variables and as means with SDs or medians with min/max for continuous variables, as appropriate. Crude associations between pairs of variables were assessed using the chi-square test for categorical variables and an independent samples t-test or Mann–Whitney U test for continuous variables. Some variables with several categories were recoded into fewer categories to fulfill the assumptions for validity of the

chi-square test [49]. For variables where these assumptions were not met, associations between pairs of variables were not assessed. This is explained in the footnotes of Tables 1 and 2.

Further, we used multiple linear regression to explore associations between gender, HL, COVID-19-related worries and HRQoL in adolescents. KIDSCREEN-10 was the dependent variable. Assumptions for linear regression were checked and fulfilled. To estimate the associations between gender, HL, COVID-19-related worries and HRQoL in parents, we used robust regression analyses because the assumptions for multiple linear regression were not fulfilled. The two RAND-36 sum scores (PCS and MCS) were the dependent variables. Age and education level were entered as covariates. The results are presented as regression coefficients with 95% confidence intervals (CI). *P*-values ≤0.05 were considered statistically significant. All analyses were considered exploratory; hence, no correction for multiple testing was performed. All analyses were conducted using IBM SPSS Statistics (version 27)—except for the robust regression analyses, which were conducted using Stata (version 16).

Results

Descriptive sociodemographic characteristics of adolescents and parents

In total, 215 adolescents and 320 parents participated in the study (Table 1). Most were girls (69.3%) and women (81.0%), respectively. The median age for the adolescents was 16 years, and the mean (SD) age for

Table 1 Sociodemographic characteristics of adolescents and parents

Adolescent characteristics	**Total (*N* = 215)**	**Boys (*n* = 66)**	**Girls (*n* = 149)**	***P*-value**
Age, median (min, max)	16.0 (16.0, 18.0)	16.0 (16.0, 18.0)	16.0 (16.0, 18.0)	.942
Adult members of the household, N (%) [a]				.927
Both parents	154 (71.6)	48 (72.7)	106 (71.1)	
Alternates between two parents	32 (14.9)	10 (15.2)	22 (14.8)	
One parent and/or other caregivers	29 (13.5)	8 (12.1)	21 (14.1)	
Parent characteristics	Total (*N* = 320)	Men (*n* = 62)	Women (*n* = 258)	*P*-value
Age, mean (SD)	47.6 (4.6)	49.1 (4.8)	47.2 (4.5)	**.022**
Marital status, N (%) [b]				.528
Married/cohabitant	252 (78.8)	47 (75.8)	205 (79.5)	
Single/divorced	68 (21.3)	15 (24.2)	53 (20.5)	
Education level, N (%) [c]				.558
≤ 12 years and/or certificate of apprenticeship	61 (19.1)	9 (14.5)	52 (20.2)	
13–15 years (< 4 years of higher education)	73 (22.8)	16 (25.8)	57 (22.1)	
≥ 16 years (≥ 4 years of higher education)	186 (58.1)	37 (59.7)	149 (57.8)	
Work status, N (%) [d]				
Yes, full time	250 (78.1)	59 (95.2)	191 (74.0)	
Yes, part time	42 (13.1)	1 (1.6)	41 (15.9)	
No, not employed	28 (8.8)	2 (3.2)	26 (10.1)	
Household income, N (%) [d, e]				
≤ 450,000 NOK/year	19 (5.9)	1 (1.6)	18 (7.0)	
451,000–750,000 NOK/year	50 (15.6)	8 (12.9)	42 (16.3)	
751,000–1,000,000 NOK/year	63 (19.7)	5 (8.1)	58 (22.5)	
> 1,000,000 NOK/year	188 (58.8)	48 (77.4)	140 (54.3)	

Continuous variables analyzed using an independent t-test and Mann–Whitney U test. Categorical variables analyzed with χ^2-test

P-values marked with bold print indicate statistically significant differences between gender ($P \leq 0.05$)

SD Standard deviation

[a] The variable was recoded into three categories: "Both parents," "Alternates between two parents" and "One parent and/or other caregivers" (one parent and one step-parent, one parent, other caregivers)

[b] The variable was dichotomized as "Married/cohabitant" or "Single/divorced" (single, divorced, widowed)

[c] The variable was recoded into three categories: "≤ 12 years and/or certificate of apprenticeship" (9 years, 10–11 years, 12 years, certificate of apprenticeship), "13–15 years (< 4 years of higher education)" and "≥ 16 years (≥ 4 years of higher education)"

[d] Assumptions for chi-square analysis were not fulfilled. Associations between pairs of variables were not assessed

[e] The variable was recoded into four categories: "≤ 450,000 NOK/year" (< 250,000 NOK/year and 250,000–450,000 NOK/year), "451,000–750,000 NOK/year," "751,000–1,000,000 NOK/year" and "> 1,000,000 NOK/year"

Table 2 Descriptive data for health-related quality of life, health literacy and COVID-19-related worries of adolescents and parents

Adolescent characteristics	**Total (*N* = 215)**	**Boys (*n* = 66)**	**Girls (*n* = 149)**	***P*-value**
HRQoL, mean (SD) [a]	44.3 (7.8)	47.5 (8.8)	42.8 (6.8)	**<.001**
Health literacy, median (min, max) [b]	34 (20, 40)	35 (20,40)	34 (21,40)	.096
The COVID-19 pandemic changing life negatively, N (%) [c]				.092
No, not at all	29 (13.5)	12 (18.2)	17 (11.4)	
Yes, a little	78 (36.3)	28 (42.4)	50 (33.6)	
Yes, considerably	108 (50.2)	26 (39.4)	82 (55.0)	
The COVID-19 pandemic changing life positively, N (%) [c]				**.047**
No, not at all	42 (19.5)	19 (28.8)	23 (15.4)	
Yes, a little	115 (53.5)	34 (51.5)	81 (54.4)	
Yes, considerably	58 (27.0)	13 (19.7)	45 (30.2)	
Worried about becoming sick with COVID-19 [d]				**.032**
Not worried at all	92 (42.8)	37 (56.1)	55 (36.9)	
A little worried	99 (46.0)	23 (34.8)	76 (51.0)	
Worried a lot	24 (11.2)	6 (9.1)	18 (12.1)	
Worried about infecting others with COVID-19 [d]				**.001**
Not worried at all	15 (7.0)	9 (13.6)	6 (4.0)	
A little worried	58 (27.0)	25 (37.9)	33 (22.1)	
Worried a lot	142 (66.0)	32 (48.5)	110 (73.8)	
Worried about family/friends becoming sick with COVID-19 [e]				**.021**
Not worried at all	17 (7.9)	9 (13.6)	8 (7.9)	
A little worried	67 (31.2)	25 (37.9)	67 (31.2)	
Worried a lot	131 (60.9)	32 (48.5)	131 (60.9)	
Worried about my school grades [e]				.120
Not worried at all	72 (33.5)	26 (39.4)	46 (30.9)	
A little worried	84 (39.1)	28 (42.4)	56 (37.6)	
Worried a lot	59 (27.4)	12 (18.2)	47 (31.5)	
Worried about my family's economy [d]				.503
Not worried at all	152 (70.7)	49 (74.2)	103 (69.1)	
A little worried	32 (14.9)	7 (10.6)	25 (16.8)	
Worried a lot	31 (14.4)	10 (15.2)	21 (14.1)	
Worried about the economy in Norway [d]				**.001**
Not worried at all	103 (47.9)	42 (63.6)	61 (40.9)	
A little worried	88 (40.9)	15 (22.7)	73 (49.0)	
Worried a lot	24 (11.2)	9 (13.6)	15 (10.1)	
Parent characteristics	Total (*N* = 320)	Men (*n* = 62)	Women (*n* = 258)	*P*-value
HRQoL				
RAND-36 PCS, median (min, max) [e]	54.7 (14.7, 67.5)	55.0 (35.2, 62.4)	54.6 (14.7, 67.5)	.152
RAND-36 MCS, median (min, max) [e]	54.4 (10.1, 67.3)	55.6 (28.5, 65.8)	54.0 (10.1, 67.2)	**.041**
Health literacy [f]				
Having sufficient information to manage my health, mean (SD)[g]	3.2 (0.5)	3.3 (0.5)	3.2 (0.4)	.480
Actively managing my health, mean (SD) [g]	3.0 (0.5)	2.9 (0.5)	3.0 (0.5)	.117
Appraisal of health information, mean (SD) [g]	2.9 (0.5)	2.8 (0.4)	2.9 (0.5)	.954
Ability to find good health information, mean (SD) [h]	4.9 (0.5)	4.1 (0.5)	4.0 (0.5)	.168
Understand health information well enough to know what to do, mean (SD) [h]	4.1 (0.5)	4.1 (0.5)	4.1 (0.5)	.324
The COVID-19 pandemic changing life negatively, N (%) [c]				.539
No, not at all	62 (19.4)	9 (14.5)	53 (16.6)	
Yes, a little	155 (48.4)	31 (50.0)	124 (48.1)	
Yes, considerably	103 (32.2)	22 (35.5)	81 (31.4)	
The COVID-19 pandemic changing life positively, N (%) [c]				**<.001**

Table 2 (continued)

Adolescent characteristics	Total ($N=215$)	Boys ($n=66$)	Girls ($n=149$)	*P*-value
No, not at all	103 (32.2)	32 (51.6)	71 (27.5)	
Yes, a little	165 (51.6)	27 (43.5)	138 (53.5)	
Yes, considerably	52 (16.3)	3 (4.8)	49 (19.0)	
Worried about becoming sick with COVID-19 [d]				**.013**
Not worried at all	161 (50.3)	41 (66.1)	120 (46.5)	
A little worried	139 (43.4)	20 (32.3)	119 (46.1)	
Worried a lot	20 (6.3)	1 (1.6)	19 (7.4)	
Worried about infecting others with COVID-19[d]				**.003**
Not worried at all	58 (18.1)	19 (30.6)	39 (15.1)	
A little worried	142 (44.4)	29 (46.8)	113 (43.8)	
Worried a lot	120 (37.5)	14 (22.6)	106 (41.1)	
Worried about family/friends becoming sick with COVID-19 [d]				**.005**
Not worried at all	44 (13.8)	16 (25.8)	28 (10.9)	
A little worried	151 (47.2)	29 (46.8)	122 (47.3)	
Worried a lot	125 (39.1)	17 (27.4)	108 (41.9)	
Worried about work [d]				.729
Not worried at all	225 (70.3)	42 (67.7)	183 (70.9)	
A little worried	66 (20.6)	15 (24.2)	51 (19.8)	
Worried a lot	29 (9.1)	5 (8.1)	24 (9.3)	
Worried about my family's economy [d]				.989
Not worried at all	224 (70.0)	43 (69.4)	181 (70.2)	
A little worried	70 (21.9)	14 (22.6)	56 (21.7)	
Worried a lot	26 (8.1)	5 (8.1)	21 (8.1)	
Worried about the economy in Norway [d]				.891
Not worried at all	78 (24.7)	16 (25.8)	63 (24.4)	
A little worried	172 (53.8)	34 (54.8)	138 (53.5)	
Worried a lot	69 (21.6)	12 (19.4)	57 (22.1)	

Continuous variables analyzed using an independent t-test and Mann–Whitney U test. Categorical variables analyzed with χ^2-test

P-values marked with bold print indicate statistically significant differences between gender ($P \leq 0.05$)

HRQoL, health-related quality of life; SD, standard deviation; PCS, physical component sum score; MCS, mental component sum score

[a] KIDSCREEN-10. Rasch scores were computed and transformed into t-values, with a mean of 50 and an SD of 10. Higher values indicate higher levels of HRQoL

[b] Sum score obtained from the Health Literacy in School-Aged Children questionnaire (min–max: 10–40). Higher scores indicate higher levels of health literacy

[c] The variable was recoded into three categories: "No, not at all," "Yes, a little" and "Yes, considerably" (yes, partly, a lot, considerably)

[d] The variable was recoded into three categories: "Not worried at all," "A little worried" and "Worried a lot" (quite worried, worried a lot)

[e] RAND-36 scores range from 0 to 100, where 100 means perfect health

[f] Sum scores obtained from the Health Literacy Questionnaire. Higher scores indicate higher levels of health literacy

[g] Scales with a possible total score of 1–4

[h] Scales with a possible total score of 1–5

the parents was 47.6 (4.6) years. Among the adolescents, most lived with both parents (71.6%), had parents who were both born in Norway (76.3%) and had parents who were both working (81.9%). Among the parents, most were married or cohabiting (78.8%), had higher education of 4 years or more (58.1%), worked full time (78.1%) and had a household income of more than one million NOK/year (58.8%).

Descriptive data for HRQoL, HL and COVID-19-related worries of adolescents and parents

Table 2 shows the descriptive data for HRQoL, HL and COVID-19-related worries in adolescents and parents. The adolescents' mean (SD) for KIDSCREEN-10 was 44.3 (7.8). Boys reported significantly higher levels of HRQoL compared to girls. The adolescents' median (min, max) score for HL was 34 (20, 40), with no significant gender

differences. Adolescents reported that the COVID-19 pandemic had changed their lives in both a positive and a negative way. More girls reported a positive change; however, the proportion of adolescents who reported a considerably negative change was higher than the proportion who reported a positive change. Further, adolescents reported a high degree of COVID-19-related worries, especially concerning worries about infecting others with COVID-19 and about family/friends becoming sick with COVID-19. Girls were significantly more worried about becoming sick, infecting others, family/friends becoming sick and about the economy in Norway compared to boys.

The parents' median (min, max) score for RAND-36 was 54.7 (14.7, 67.5) for PCS and 54.4 (10.1, 67.3) for MCS. Men reported significantly higher MCS values compared to women. Parents' mean (SD) scores for the five HL domains were 3.2 (0.5) for the domain "having sufficient information to manage my health," 3.0 (0.5) for "actively managing my health," 2.9 (0.5) for "appraisal of health information," 4.9 (0.5) for "ability to find good health information" and, finally, 4.1 (0.5) for the domain "understand health information well enough to know what to do." There were no statistically significant gender differences, considering the parents' HL. Parents reported that the COVID-19 pandemic had changed their lives both positively and negatively; however, a higher proportion of parents reported a negative change compared to the proportion of parents who reported a positive change. Considering COVID-19-related worries, parents were mostly worried about infecting others with COVID-19 and about family/friends becoming sick. A significantly higher proportion of women compared to men reported having worries related to becoming sick and infecting others and worries about family/friends becoming sick with COVID-19. Still, a significantly higher proportion of women compared to men reported a positive change in life due to the pandemic. Details are provided in Table 2.

Associations between gender, HL, COVID-19-related worries and HRQoL in adolescents and parents

Table 3 shows the results from the multiple linear regression analysis of gender, HL, COVID-19-related worries and HRQoL in adolescents. Being a girl was significantly associated with lower HRQoL compared to being a boy (B = −3.77; 95% CI [−5.95; −1.06]). Higher HL was significantly positively associated with increased HRQoL. As the adolescents' HL score increased by one point, their HRQoL score increased by 0.52 (95% CI [0.28; 0.76]) points. There were no statistically significant associations between worries about infecting others with COVID-19, worries about family/friends becoming sick with COVID-19 and HRQoL.

Table 3 Associations between gender, health literacy, COVID-19-related worries and health-related quality of life in adolescents ($N = 215$) [a, b]

	B	95% CI	*P*-value
Gender (ref = boy)	−3.72	−5.89 – − 1.55	**.001**
Health literacy [c]	0.53	0.29–0.77	**<.001**
Worried about infecting others with COVID-19 (ref = a little worried) [d]			
Not worried at all	0.53	−4.07 – 5.14	.820
Worried a lot	−0.88	−3.34 – 1.59	.485
Worried about family/friends becoming sick with COVID-19 (ref = a little worried) [d]			
Not worried at all	−0.71	−5.10 – 3.68	.751
Worried a lot	−2.23	−4.54 – 0.08	.059

B, unstandardized coefficient, *CI* Confidence interval

P-values marked with bold print indicate statistically significant differences between the groups ($P \leq 0.05$)

[a] Multiple linear regression analysis

[b] Health-related quality of life was analyzed with KIDSCREEN-10. Higher values indicate higher levels of health-related quality of life

[c] Sum score obtained from the Health Literacy in School-Aged Children questionnaire. Higher scores indicate higher levels of health literacy

[d] The variable was recoded into three categories: "Not worried at all," "A little worried" and "Worried a lot" (quite worried, worried a lot)

Table 4 shows the results from the robust regression analyses between gender, HL, COVID-19-related worries and HRQoL in parents. There was no statistically significant association between gender and PCS or gender and MCS. Higher HL in the domain "understand health information well enough to know what to do" was significantly associated with lower levels of HRQoL for PCS (B = −2.68; 95% CI [−4.64; −0.72]) and higher levels of HRQoL for MCS (B = 4.62; 95% CI [1.72; 7.52]). There were no significant associations between the other four HL domains and PCS or MCS. For MCS, being worried a lot about infecting others was significantly associated with higher HRQoL compared to being a little worried (B = 2.69; 95% CI [0.52; 4.86]). Further, being worried a lot about family/friends becoming sick was significantly associated with lower HRQoL compared to being a little worried (B = −3.84; 95% CI [−5.97; −1.72]). For PCS, there was no statistically significant association between COVID-19-related worries and HRQoL.

Discussion

One of the main findings of this study was that the adolescents' HRQoL scores were notably lower compared to European norms [38] and the results of previous studies among Norwegian adolescents [50, 51]. This corresponds with recent studies among adolescents during the pandemic [4, 16, 20, 21], indicating that the uncertain and

Table 4 Associations between gender, health literacy, COVID-19-related worries and health-related quality of life in parents ($N = 320$) [a]

Physical component summary [b]	**B**	**95% CI**	***P*-value**
Gender (ref = man)	−0.11	− 1.56 – 1.34	.885
Health literacy			
Having sufficient information to manage my health [c]	1.04	−0.62 – 2.71	.217
Actively managing my health [c]	0.92	−0.40 – 2.25	.172
Appraisal of health information [c]	−0.34	−1.63 – 0.94	.598
Ability to find good health information [c]	1.56	−0.35 – 3.47	.110
Understand health information well enough to know what to do [c]	−2.68	−4.64 – −0.72	**.007**
Worried about infecting others with COVID-19 (ref = a little worried) [d]			
Not worried at all	0.11	−1.65 – 1.88	.898
Worried a lot	−0.68	−2.15 – 0.78	.357
Worried about family/friends becoming sick with COVID-19 (ref = a little worried) [d]			
Not worried at all	1.36	−0.59 – 3.31	.172
Worried a lot	−0.28	−1.71 – 1.16	.705
Mental component summary [b]	**B**	**95% CI**	***P*-value**
Gender (ref = man)	−1.17	−3.32 – 0.98	.285
Health literacy			
Having sufficient information to manage my health [c]	2.10	−0.36 – 4.56	.095
Actively managing my health [c]	0.67	−1.29 – 2.64	.501
Appraisal of health information [c]	−1.41	−3.31 – 0.49	.145
Ability to find good health information [c]	−2.08	−4.92 – 0.74	.148
Understand health information well enough to know what to do [c]	4.62	1.72–7.52	**.002**
Worried about infecting others with COVID-19 (ref = a little worried) [d]			
Not worried at all	−1.60	−4.21 – 1.02	.230
Worried a lot	2.69	0.52–4.86	**.015**
Worried about family/friends becoming sick with COVID-19 (ref = a little worried) [d]			
Not worried at all	1.70	−1.19 – 4.59	.248
Worried a lot	−3.84	−5.97 – −1.72	**<.001**

B, unstandardized coefficient, *CI* Confidence interval

P-values marked with bold print indicate statistically significant differences between the groups ($P \leq 0.05$)

[a] Robust regression analysis with control for age and education level

[b] RAND-36 sum scale. Higher values indicate higher levels of health-related quality of life

[c] Sum scores obtained from Health Literacy Questionnaire domains. Higher scores indicate higher levels of health literacy

[d] The variable was recoded into three categories: "Not worried at all," "A little worried" and "Worried a lot" (quite worried, worried a lot)

demanding situation caused by the pandemic has had a major negative impact on the physical, psychological, functional and social aspects of adolescents' health. The result is unsurprising, considering the increase in mental health problems and the high prevalence of loneliness, stress, worries and uncertainty related to COVID-19 found in other studies during the initial phase of the pandemic [3, 4, 8, 15, 22].

In contrast, parents' HRQoL scores were comparable to Norwegian normative data [27, 52]. Parents have also experienced great challenges caused by the pandemic—for example, changes in everyday routines, social restrictions, the use of home offices and possible financial challenges while having to take care of the family as well. Still, parents' HRQoL scores seem to be rather stable. There is diversity in the literature related to adults' HRQoL during the pandemic, which may be explained through differences related to being quarantined, SES, work situation, financial concerns and/or existing physical or mental health problems [10, 22, 23].

The adolescents reported moderate-to-high levels of HL [44]. Considering the association between HL and adolescents' health behaviors [29], our findings indicate that Norwegian adolescents have the necessary skills to understand and act upon COVID-19-related information. This highlights the importance of including adolescents in communication about the pandemic and matters related to their health behaviors, as this will empower adolescents in health decision-making processes. Further, this study provides insight into the impact of HL on

adolescents' HRQoL, confirming the positive association between HL and HRQoL [21, 31]. Therefore, one would assume that the adolescents' HRQoL scores were higher. However, high HL may have caused high fidelity considering COVID-19-restrictions, which according to Riiser et al. [21], requires great sacrifice because the pandemic strategies seem to conflict with aspects that are important for adolescents' HRQoL (e.g., socializing with friends and participating in leisure activities). This might explain our results.

The high HL levels reported by the parents indicate higher HL levels compared to the results of a recent Norwegian national HL survey [53]. The parents' HL scores for the five HLQ domains indicate they are up to date, feel confident they have all the necessary information, can identify and understand information and reliable sources of information and can make good decisions about health [25]. In contrast, the recent national survey found that a significant proportion of the Norwegian population finds it difficult to critically assess health information and experience that it is challenging to assess the advantages and disadvantages of different treatment options [26]. Our findings could possibly be explained by a high SES in our sample. Both Norwegian and international studies have shown that education affects HL, with higher education associated with higher HL levels [26–29]. Further, regarding the association between HL and HRQoL in parents, our results confirm that higher HL is associated with higher HRQoL [26, 33] but only for mental well-being (MCS). Surprisingly, for physical well-being (PCS), results show that higher HL is associated with decreased PCS. We have no explanation for this association between HL and PCS; we may only speculate that increased health knowledge and understanding may lead to increased awareness of one's physical condition. Moreover, only the domain "understand health information well enough to know what to do" was significantly associated with MCS and PCS, indicating that during the pandemic, this HLQ domain might be more important for parents' HRQoL than the other four domains.

The proportion of adolescents and parents who reported a negative change in life due to the pandemic was higher than the proportion who reported a positive change. This indicates that although the pandemic might lead to improvements in some areas of life for adolescents and parents [15, 22, 23, 34], 1 year into the pandemic, this is outweighed by deteriorations in other important areas of life.

We found no statistically significant association between COVID-19-related worries and HRQoL in adolescents. Still, the high degree of worries reported by the adolescents, especially concerning worries about infecting others and about family/friends becoming sick, is in line with findings from the initial phase of the pandemic [14–16] and emphasizes the pandemic's impact on adolescents' psychological health. Interestingly, compared to parents, a higher proportion of adolescents reported being worried a lot, indicating that adolescents have more COVID-19-related worries. However, in parents, we did find a significant association between COVID-19-related worries and HRQoL. The results show that being worried a lot about family/friends becoming sick has a negative impact on parents' MCS. Further, and surprisingly, being worried a lot about infecting others was significantly associated with higher MCS.

Our results confirm that male gender is associated with higher HRQoL in adolescents and parents [4–6, 9, 12, 31]. Interestingly, in women, we found a larger variation in HRQOL scores for both PCS and MCS compared to in men. Considering HL, we found no significant gender differences in adolescents or parents, indicating HL is equally distributed across gender in this sample population. However, despite similar levels of HL, girls and women reported significantly more COVID-19-related worries compared to boys and men, respectively. These results might be explained through gender-related differences shown in Galasso et al. [54], who found that women are more likely to perceive COVID-19 as a serious health problem, agree with restraining public policy measures and comply with them.

Unlike international studies that emphasize the burden of financial worries due to the pandemic [5, 10, 13], we found that most adolescents and parents were not worried about work and/or the economy. This may be explained by the Norwegian welfare system, which provides schemes such as pensions and unemployment benefits, sickness and child benefits for the Norwegian population [55]. Further, an important agenda for the Norwegian policy response to the COVID-19 crisis is to mitigate the impact on the economy [56], and the Norwegian government introduced significant measures to secure jobs, help people and businesses and strengthen health services [57]. Our findings indicate that the Norwegian population might be less affected by the economic impact of the pandemic compared to other countries.

Limitations

This is a cross-sectional study; thus, causal inference cannot be determined. Another limitation is the response rate of only 33.2% among adolescents and 57.0% among parents. Unfortunately, due to General Data Protection Regulation laws, we do not have information to assess whether the nonparticipants and participants differ in any respect. However, our results indicate that most participating adolescents and parents come from families with high SES and that few have an immigrant

background. Thus, the study results may not be representative of the whole population of Norwegian adolescents and parents. Previous research among adolescents and parents shows that HRQoL, HL, physical and mental consequences of and worries related to the pandemic vary across sociodemographic groups [4, 14, 15, 23, 26, 58]. Furthermore, most participants in the present study were girls (69.3%) and women (81.0%). Hence, a selection bias may exist in our findings. Together, this must be taken into consideration when interpreting our results.

Implications and future research

Overall, this study contributes to more knowledge of HRQoL of 16- to 17-year-old adolescents and parents, their HL and COVID-19-related worries about 1 year into the pandemic. Importantly, the study provides insight into the impact of gender, HL and COVID-19-related worries on adolescents' and parents' HRQoL. Given the uncertainty of pandemic development in the future, these insights provide valuable information for interventions aiming to increase the well-being of adolescents and parents. This knowledge is highly relevant for public health and health policy, indicating that efforts aimed at increasing people's HL might indirectly affect their HRQoL as well and that gender-specific interventions or strategies could be beneficial.

In line with previous research [2, 4, 12, 22], this study supports calls for strategies to enhance adolescents' HRQoL and mental health during and after the pandemic by, for example, increasing adolescents' access to mental health services and providing clear and correct information to parents, teachers and health professionals on how to help adolescents cope with emotions, stress and problem solving related to the pandemic. Further, as highlighted in previous studies, we emphasize that it is important to be particularly attentive to vulnerable groups whose mental health and HRQoL might already be poor—such as families with low SES, adolescents and/or parents with mental health problems or chronic diseases and people with problems related to violence, substance abuse or mental illness in close relatives [2, 4, 12, 14, 15, 21, 22].

More in-depth research (e.g., qualitative data) is needed to further explore factors that characterize those who experience a positive change in life and those who experience a negative change due to the pandemic. Further, we encourage future studies to use longitudinal designs and include a higher percentage of male gender, participants with low SES and an immigrant background to explore our findings more thoroughly. Making a short information video and/or using communication platforms such as social media to provide oral information about a study, might be a promising way to increase study recruitment among adolescents and their parents.

Conclusions

Our results indicate that the pandemic has had a major negative impact on adolescents' HRQoL. Parents' HRQoL remained unchanged and comparable to previous studies. Our study demonstrates that HL, gender and COVID-19-related worries are significantly associated with adolescents' and parents' HRQoL, indicating that efforts aimed at increasing their HL might indirectly affect their HRQoL as well and that gender-specific interventions or strategies could be beneficial. We highlight the need for strategies to enhance adolescents' HRQoL and mental health during and after the pandemic.

Abbreviations

CI: Confidence intervals; COVID-19: Coronavirus disease 2019; HL: Health literacy; HLQ: The Health Literacy Questionnaire; HLSAC: The Health Literacy in School-Aged Children questionnaire; HRQoL: Health-related quality of life; MCS: Mental component sum scores; SD: Standard deviation; SES: Socioeconomic status; PCS: Physical component sum scores; RAND-36: The 36-Item Medical Outcomes Study Short Form; WHO: The World Health Organization.

Supplementary Information

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Additional file 1. Cronbach's alpha values for instruments used in this study. Cronbach's alpha values for KIDSCREEN-10, RAND-36, The Health Literacy in School-Aged Children Questionnaire, The Health Literacy Questionnaire.

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Authors' contributions

All authors (HTM, SS, SH, MCS, KH and GR) contributed to the study conception and design. The recruitment process was mainly conducted by HTM. Data analysis were performed by HTM and MCS. The first draft of the manuscript was written by HTM and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are not publicly available due to General Data Protection Regulation laws but are available from the corresponding author on reasonable request and with permission from the Norwegian Centre for Research Data.

Declarations

Ethics approval and consent to participate

The participants received written information. Informed consent was obtained from all participants. All participants in this study were over the age of 16. Data

in the study was anonymized. All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Approval was obtained from the ethics committee of Faculty of Health and Sport Sciences at the University of Agder and from the Norwegian Centre for Research Data (NSD Reference 60981).

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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Publisher's Note

Paper IV

Changes in health-related quality of life in adolescents and the impact of gender and selected variables: A two-year longitudinal study.

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RESEARCH

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Changes in health-related quality of life in adolescents and the impact of gender and selected variables: a two-year longitudinal study

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Abstract

Background: Increased knowledge about factors that can impact changes in adolescents' health-related quality of life (HRQOL) is needed. The present study aimed to investigate possible HRQOL changes in adolescents at 14 and 16 years, and assess the impact of sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL changes over time. Further, to assess HRQOL stratified by gender.

Methods: A longitudinal study involving 211 adolescents was conducted. Sociodemographic variables, pain, self-esteem, self-efficacy, loneliness, and stress were all assessed with well-validated instruments. KIDSCREEN-27 was used to measure HRQOL. Data were analyzed using independent t-tests, paired samples t-tests, and linear mixed models for repeated measures.

Results: When all variables were added to the linear mixed models, stress, loneliness, and pain were significantly, independently associated with a reduction in HRQOL change scores for four of the five KIDSCREEN subscales. Time was significantly associated with a reduction in physical and psychological well-being. Self-efficacy and self-esteem were significantly associated with an increase in HRQOL change scores for four and two subscales, respectively. Male gender was significantly negatively associated with changes in social support and peers compared to female gender.

Conclusion: Our results demonstrated a significant decline in adolescents' HRQOL regarding physical and psychological well-being for the age range 14–16 years. Furthermore, we found that stress, loneliness, and pain have a significant negative impact on HRQOL changes, whereas self-esteem and self-efficacy have a significant positive impact. Our results highlight the importance of increased understanding regarding factors associated with changes in adolescents' HRQOL to enable accurate and strategic interventions.

Keywords: Health-related quality of life, Longitudinal, Adolescent, Resilience, Stress, Loneliness

Background

Adolescence is an important transitional phase in life, central in the development of capabilities related to health and well-being and where future patterns of adult health are established [1, 2]. According to the World Health Organization, "Investments in adolescent health bring a triple dividend of benefits for adolescents now,

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for their future adult lives, and for the next generation. Their health and well-being are engines of change in the drive to create healthier, more sustainable societies" [3, p. iv]. To invest in adolescent health, more information about their own perspectives is needed. Thus, in recent years, there has been an increased focus on understanding, improving, and mapping adolescents' health-related quality of life (HRQOL) [3–5]. HRQOL is a multidimensional construct that includes the individual's subjective perspectives of the physical, psychological, functional, and social aspects of health [6].

HRQOL is influenced by both individual and environmental characteristics [7]. The adolescence phase is characterized by rapid physical, cognitive, emotional, pubertal, and social changes and an increase in autonomy and independence from caregivers that may lead to vulnerability related to health and HRQOL [1–3, 8]. Previous studies have found that adolescents' HRQOL seems to deteriorate with age and that girls tend to report lower HRQOL than boys [4, 9, 10]. Self-efficacy, self-esteem, and social support have been found to be positively associated with HRQOL, while low socioeconomic status (SES), pain, loneliness, and stress have been negatively associated with HRQOL in general adolescent populations [11–20]. Most Norwegian adolescents report good health [21]; however, health challenges such as loneliness, stress, and pain seem to be increasing in both Norwegian and international adolescent populations [2, 21–24]. Recent studies have shown that the COVID-19 pandemic and its protective strategies (e.g., social distancing) have affected the well-being and behavior of adolescents—leading to, for example, increased stress and loneliness, lower life satisfaction, and reduced HRQOL [24–30].

Longitudinal studies of adolescents' HRQOL can provide a clearer picture of the magnitude and direction of change in adolescents' HRQOL, help identify factors associated with change over time, and confirm or disconfirm the results of cross-sectional studies [10, 31]. Relatively few studies have investigated how HRQOL changes over time in general adolescent populations. It should be noted that most previous studies are cross-sectional, and most longitudinal studies have focused on specific groups of adolescent populations, such as clinical populations (e.g., selected patient groups). Furthermore, most longitudinal studies have considered only a limited set of potential predictive factors of adolescents' HRQOL—for example, gender, SES, and age. Thus, there is a need for longitudinal studies that investigate HRQOL in general adolescent populations and include a wide range of potential predictive factors of HRQOL changes. Considering that adolescence is a period when different behaviors are adopted and may track into adulthood, increased knowledge of factors related to changes in adolescents' HRQOL is necessary to plan effective policies and health promotion interventions [32]. We have previously demonstrated that HRQOL is associated with sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress in a school-based population of 14-to-15-year-old adolescents [14, 20]. In the present study, we aim to further investigate the impact of these specific factors on HRQOL changes over time.

In Norway, the transition from lower secondary to upper secondary school normally involves a change in school institutions for 16-year-old adolescents. School transitions might disrupt established peer groups but also provide opportunities for developing new friendships [33], which may affect adolescents' well-being [34]. Peer interaction is especially important during adolescence [35], and spending time with friends is considered essential for adolescents' quality of life [36]. Therefore, longitudinal HRQOL studies covering the transition period from lower secondary to upper secondary school are important.

The primary aims of this study are to investigate possible HRQOL changes in adolescents at 14 and 16 years, and assess the impact of sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL changes over time. Secondary aim was to assess HRQOL stratified by gender.

Methods

Sample and data collection

This longitudinal study was part of the "Start Young—Quality of Life and Pain in Generations" study [14], which is a Norwegian mixed-method four-year prospective study in adolescents and their parents. The present study used data collected at baseline (time 1), when the adolescents were 14–15 years (November 2018 to April 2019) [14], and data collected from January to February 2021 (time 2), when the adolescents were 16–17 years. All adolescents that participated at time 1 (N = 696) were sent a text message at time 2 with link to the survey. They received up to three reminders if they did not complete the survey. In total, 211 adolescents (response rate: 30.3%) completed the survey at time 2 and were included in this study.

The data collection was done through a web-based questionnaire. At time 1, the questionnaire was administered and completed in classrooms during school hours. At time 2, the adolescents completed the questionnaire in their spare time. Participants gave their informed consent at the beginning of the survey. We used a safe data server to store the collected data [37]. The questionnaires from time 1 was linked to the questionnaires at time 2 through a mutual ID number. All study procedures were approved by the Norwegian Centre for Research Data (Ref: 60981).

Measures

An electronic survey tool that consecutively administered the following questionnaires was used. All questionnaires had previously been translated into Norwegian. Most questions included a neutral option, resulting in all items being answered. All questionnaires that used sum scales showed satisfactory Cronbach's alpha values above .7 (Additional file 1).

The first part of the questionnaire included self-reported data on demographic variables such as gender, age, parental members of the household, parents' birthplace, and parents' work status.

HRQOL was assessed using the KIDSCREEN-27 questionnaire [38, 39], which is a multidimensional measure of generic HRQOL in adolescents. KIDSCREEN-27 consists of 27 questions organized into five subscales: (1) physical well-being, (2) psychological well-being, (3) autonomy and parent relations, (4) social support and peers, and (5) school environment [38, 40, 41]. The questionnaire is scored on a 5-point Likert scale referring to the last week, indicating either the frequency of certain feelings or behaviors or the intensity of an attitude. Higher scores indicate better HRQOL. In line with the KIDSCREEN handbook [40], Rasch scores were computed for each subscale and transformed into t-values normed to a mean (SD) of 50 (10) which can be compared with international t-values. The Norwegian KIDSCREEN-27 version has been shown to be valid and reliable [39].

Self-esteem was assessed using the Rosenberg Self-Esteem scale (RSES) four-item version [42], where respondents rate four self-perception statements on a 4-point Likert scale. The respondent's scores were summed and divided by 4 to obtain an RSES score ranging from 1 to 4. Higher scores indicate higher levels of self-esteem. The Norwegian RSES four-item version has demonstrated a high degree of correlation (0.95) with the original 10-item version [43] and has previously been used among adolescents [14, 44].

Self-efficacy was assessed using the Generalized Self-Efficacy Scale (GSE), which consists of 10 items that measure optimistic self-beliefs in coping with the challenges, demands, and tasks of life in general [45, 46]. The items are rated on a 4-point scale, and scores on each item are summed and divided by 10 to obtain a GSE score ranging from 1 to 4. Higher scores indicate higher levels of generalized self-efficacy. The Norwegian GSE has been shown to be valid and reliable [14, 47].

Loneliness was assessed using the revised UCLA Loneliness Scale eight-item version (ULS-8), which is rated on a 4-point scale [48]. The total score ranges from 8 to 32. Higher scores indicate a higher degree of loneliness. ULS-8 is an adequate and reliable measure of loneliness among adolescents [48–50], and the Norwegian ULS-8 has shown satisfactory internal consistency [14].

Stress was assessed using the Perceived Stress Questionnaire (PSQ), which consists of 30 items that refer to the previous four weeks [51, 52]. The items are rated on a 4-point scale. The PSQ total score is linearly transformed between 0 and 1; PSQ = (raw value – 30) / 90. Higher scores indicate higher levels of perceived stress. Commonly used cutoff levels of stress within PSQ are as follows: low (<.33), medium (.33–.45), moderate (.45–.60), and severe (>.60) [51]. The Norwegian PSQ has demonstrated good reliability and validity [53].

Pain was assessed using one question from the Brief Pain Inventory (BPI) [54, 55]—which measures the subjective intensity of pain on average and is rated on a 0–10-point scale, where higher scores indicate more pain. The Norwegian BPI has satisfactory psychometric properties [55] and has been used among adolescents [56]. We also used two questions from the Lübeck Pain-Screening Questionnaire to assess pain duration and pain frequency [57]. These questions were only administered to those who rated 1 or more on the BPI's "pain on average" question (indicating they had pain). The Lübeck Pain-Screening Questionnaire has shown satisfactory validity, and the Norwegian version has been used among adolescents [58].

Data analyses

All statistical analyses were conducted using IBM SPSS Statistics (version 27). First, we calculated descriptive characteristics for gender, sociodemographic factors, pain,

self-esteem, self-efficacy, loneliness, and stress at time 1. Then, we used paired sample t-tests to analyze unadjusted differences in HRQOL between time 1 and time 2. Continuous data are presented as means with SDs or medians with min/max and as counts and percentages for categorical variables, as appropriate. Next, we used independent t-tests to analyze unadjusted differences in HRQOL between genders. Gender differences in HRQOL are presented as the estimated means with 95% confidence intervals (CIs).

Finally, we used linear mixed models for repeated measures to assess the impact of gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, and stress on changes in HRQOL over time and time 1 and time 2.The models were fitted separately for each of the five KIDSCREEN-27 subscales as the dependent variables. Time, gender, parental members of the household, parents' birthplace, parents' work status, pain on average, self-esteem, self-efficacy, loneliness, and stress were entered into each of the models as fixed effects. These independent variables were collected at time 1 (baseline).

We used an unstructured covariance structure with no specific parametric form. The random effects of variables schools (N = 22) and county (N = 4) were also estimated; however, this did not affect the estimates of fixed effects and the overall performance of the models. Thus, we removed the random effects from the models to save statistical power. The results are presented as regression coefficients B with 95% CI and p-values. All analyses were considered exploratory, and no correction for multiple testing was done. Hence, our results should be confirmed by other longitudinal studies. p values $\leq .05$ were considered statistically significant.

Results

Characteristics of the sample

In total, 211 adolescents participated in this longitudinal study, and most were girls (68%). Table 1 shows the descriptive characteristics for gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, and stress at time 1, assessed when the adolescents were 14–15 years. More than two-thirds of the participants lived with both parents, had parents who were both born in Norway, and had parents who were both employed. Among the 161 adolescents (76.3%) who rated one or higher on pain on average (indicating they had pain), about one-third reported they experienced pain often, and 42.2% reported a pain duration of more than three months. The adolescents' mean (SD) scores for self-esteem and self-efficacy were 3.1 (0.7) and 3.1 (0.4), respectively. The median (min, max) loneliness score was 13 (8, 31), and the mean (SD) stress score was 0.30 (0.16). Details are provided in Table 1.

Table 2 shows the descriptive characteristics for HRQOL at time 1 (age: 14–15 years) and time 2 (age: 16–17 years). At time 1, the highest mean (SD) HRQOL score was 53.4 (8.4) for autonomy and parent relations. The lowest HRQOL scores were reported for psychological well-being (46.1 [8.6]). At time 2, the adolescents reported statistically significantly lower HRQOL scores for physical well-being (43.9 [9.5]), psychological well-being (42.7 [8.1]), and school environment (46.4 [9.7]; Table 2) compared to their scores at time 1. Table 3 shows the descriptive characteristics for HRQOL at time 1 and time 2 by gender. At time 1, girls reported statistically significantly lower levels of HRQOL for physical well-being, psychological well-being, and school environment compared to boys. At time 2, girls reported statistically significantly lower levels of HRQOL for psychological well-being, autonomy and parent relations, and school environment (Table 3).

Table 4 shows the adjusted associations between time, gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, stress, and changes in HRQOL.

Table 1 Descriptive characteristics for gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, and stress at time 1 (N = 211)

Variables	Time 1 (14–15 years)
Gender, N (%)	
Girls	144 (68.2)
Boys	67 (31.8)
Parental members of the household, N (%)[a]	
Both parents	159 (75.4)
Alternates between two parents	26 (12.3)
One parent and/or other caregivers	26 (12.3)
Parents' birthplace, N (%)[b]	
Both parents born in Norway	161 (76.3)
One or both parents born in another country	50 (23.7)
Parents' work status, N (%)[c]	
Both parents employed	168 (79.6)
One parent employed	43 (20.4)
Pain	
Pain on average, median (min, max)[d]	2.0 (0.0, 9.0)
Pain frequency, N (%)[e,f]	
Seldom	68 (42.2)
Sometimes	32 (19.9)
Often	61 (37.9)
Pain duration, N (%)[e,g]	
Pain ≤ 3 months	93 (57.8)
Pain > 3 months	68 (42.2)
Self-esteem, mean (SD)[h]	3.1 (0.7)
Self-efficacy, mean (SD)[i]	3.1 (0.4)
Loneliness, median (min, max)[j]	13 (8, 31)
Stress, mean (SD)[k]	0.30 (0.16)

SD Standard deviation

[a] The variable was recoded into three categories: "Both parents," "Alternates between two parents," and "One parent and/or other caregivers" (one parent and one step-parent, one parent, other caregivers)

[b] The variable was dichotomized as "Both parents born in Norway" or "One or both parents born in another country" (one parent born in another country, both parents born in another country)

[c] The variable was dichotomized as "Both parents are working" or "One parent is working" (one parent is working, no parents are working)

[d] Range: 0–10, where 10 indicates pain as bad as you can imagine

[e] N = 161

[f] The variable was recoded into three categories: "seldom" (< once/month, once/month), "sometimes" (2–3 times/month, once/week), and "often" (several times/week, every day)

[g] The variable was dichotomized as "Pain ≤ 3 months" (only once, < 1 month, 1–3 months) or "Pain > 3 months" (> 3 months, > 6 months, > 12 months)

[h] Range 1–4, where higher values indicate higher levels of self-esteem

[i] Range 1–4, where higher values indicate higher levels of self-efficacy

[j] Range 8–32, where higher values indicate higher levels of loneliness

[k] Range 0–1, where higher values indicate higher levels of stress

When all variables were added into the models, stress, loneliness, and pain were all significantly, independently, and negatively associated with a reduction in HRQOL

Table 2 Descriptive characteristics for health-related quality of life at time 1 and time 2 (N = 211)

	Time 1 (14–15 years)	Time 2 (16–17 years)	*p* values
HRQOL			
Physical well-being, mean (SD)[a]	47.0 (9.7)	43.9 (9.5)	**< .001**
Psychological well-being, mean (SD)[a]	46.1 (8.6)	42.7 (8.1)	**< .001**
Autonomy and parent relations, mean (SD)[a]	53.4 (8.4)	52.2 (8.6)	.052
Social support and peers, mean (SD)[a]	48.2 (8.0)	46.9 (9.2)	.086
School environment, mean (SD)[a]	49.4 (8.9)	46.4 (9.7)	**< .001**

Paired-sample t-tests were used to compare differences in HRQOL between time 1 and time 2

HRQOL Health-related quality of life, *SD* Standard deviation

p values marked in bold indicate $p \leq .05$

[a] KIDSCREEN subscales. Higher values indicate higher levels of HRQOL

Table 3 Descriptive characteristics for health-related quality of life at time 1 and time 2 for girls (N = 144) and boys (N = 67)

	Time 1 (14–15 years)		Time 2 (16–17 years)	
	Girls	Boys	Girls	Boys
Physical well-being, mean [95% CI][a]	45.6 [44.2–47.1][b]	49.9 [47.2–52.6][b]	43.1 [41.6–44.5]	45.9 [43.2–48.6]
Psychological well-being, mean [95% CI][a]	44.4 [43.1–45.6][b]	49.7 [47.4–52.0][b]	41.4 [40.2–42.6][b]	45.6 [43.4–47.8][b]
Autonomy and parent relations, mean [95% CI][a]	52.6 [51.3–53.9]	55.0 [52.8–57.2]	51.0 [49.9–52.1][b]	55.0 [52.1–57.8][b]
Social support and peers, mean [95% CI][a]	48.1 [46.8–49.4]	48.3 [46.4–50.2]	46.4 [44.9–47.9]	48.1 [45.9–50.3]
School environment, mean [95% CI][a]	48.3 [47.0–49.6][b]	51.6 [49.1–54.1][b]	45.2 [43.7–46.8][b]	49.1 [46.7–51.6][b]

Continuous variables analyzed using independent t-tests. HRQOL, health-related quality of life; CI, confidence interval

[a] KIDSCREEN subscales. Higher values indicate higher levels of HRQOL

[b] Significant difference between genders, $p \leq 0.05$

for four of the five KIDSCREEN subscales. Stress had its highest negative effect on autonomy and parent relations (B = −2.00; 95% CI [−2.61 to −1.39]), loneliness had its highest negative effect on social support and peers (B = −0.95; 95% CI [−1.13 to −0.77]), and pain had its highest negative effect on school environment (B = −0.68; 95% CI [−1.07 to −0.29]). Time was significantly associated with a reduction in physical well-being (B = −1.50; 95% CI [−2.76 to −0.26]) and psychological well-being (B = −1.22; 95% CI [−2.11 to −0.33]). In contrast, self-efficacy was significantly positively associated with an increase in HRQOL considering four of the five KIDSCREEN subscales, with the highest positive effect on school environment (B = 5.73; 95% CI [3.72 to 7.74]). Furthermore, self-esteem was significantly associated with an increase in physical well-being (B = 1.63; 95% CI [0.08 to 3.16]) and psychological well-being (B = 3.31; 95% CI [2.28 to 4.36]). Gender was only significantly associated with changes in social support and peers. For this subscale, being a boy was associated with lower HRQOL (B = −1.76; 95% CI [−3.42 to −0.11]) compared to being a girl. The selected sociodemographic variables were not significantly associated with changes in HRQOL—except for parents' work status, which indicated that when both parents were employed (B = 2.41; 95% CI [0.21 to 4.62]), this was significantly associated with an increase in the adolescents' physical well-being compared to when only one parent was employed. Details are provided in Table 4.

Discussion

This longitudinal study aimed to investigate possible HRQOL changes in adolescents at 14 and 16 years, and assess the impact of sociodemographic factors, gender, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL changes over time. Further, we aimed to assess HRQOL stratified by gender. Our results showed that stress, loneliness, and pain had a significantly negative impact on HRQOL changes, whereas self-esteem and self-efficacy had a significantly positive impact. Time was significantly associated with a reduction in physical and psychological well-being and male gender was significantly negatively associated with changes in social support and peers compared to female gender. Girls reported statistically significantly lower levels of HRQOL for three of the KIDSCREEN subscales at time 1 and at time 2 compared to boys.

Our results showed that HRQOL decreased with age; however, this result was only significant for the physical

Table 4 Adjusted associations between time, gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, stress and changes in health-related quality of life estimated with linear mixed model analyses (N = 211)

	Physical well-being			**Psychological well-being**		
	B	**95% CI**	***p* value**	**B**	**95% CI**	***p* value**
Time						
2021	**−1.50**	**−2.76 to −0.26**	**.018**	**−1.22**	**−2.11 to −0.33**	**.007**
2019 (Ref.)	1			1		
Gender						
Boy	−0.44	−2.38 to 1.51	.659	0.70	−0.54 to 1.94	.268
Girl (Ref.)	1			1		
Parental members of the household						
Both parents	0.19	−2.38 to 2.75	.886	−0.71	−2.40 to 0.97	.406
Alternates between two parents	0.28	−2.68 to 3.24	.853	−0.51	−2.50 to 1.47	.612
One parent and/or other caregivers (Ref.)	1			1		
Parents' birthplace						
Both parents born in Norway	0.45	−1.65 to 2.54	.675	−0.14	−1.48 to 1.19	.834
One or both parents born in another country (Ref.)	1			1		
Parents' work status						
Both parents are working	**2.41**	**0.21 to 4.62**	**.032**	1.14	−0.03 to 2.58	.121
One parent is working (Ref.)	1			1		
Pain on average	**−0.49**	**−0.90 to −0.09**	**.017**	**−0.54**	**−0.81 to −0.27**	**<.001**
Self-esteem	**1.63**	**0.08 to 3.16**	**.038**	**3.31**	**2.28 to 4.36**	**<.001**
Self-efficacy	**4.80**	**2.68 to 6.92**	**<.001**	**2.31**	**0.90 to 3.73**	**.001**
Loneliness	**−0.23**	**−0.43 to −0.04**	**.017**	**−0.49**	**−0.62 to− −0.36**	**<0.001**
Stress	**−1.10**	**−1.76 to −.45**	**0.001**	**−1.17**	**−1.61 – −.73**	**<0.001**
	Autonomy and parent relations			**Social support and peers**		
	B	**95% CI**	***p* value**	**B**	**95% CI**	***p* value**
Time						
2021	0.67	−0.53 to 1.86	.272	0.70	−0.56 to 1.96	.275
2019 (Ref.)	1			1		
Gender						
Boy	0.35	−1.41 to 2.11	.695	**−1.76**	**−3.42 to −0.11**	**.037**
Girl (Ref.)	1			1		
Parental members of the household						
Both parents	0.77	−1.57 to 3.13	.518	0.44	−1.83 to 2.73	.701
Alternates between two parents	−0.11	−2.86 to 2.64	.936	1.01	−1.71 to 3.74	.465
One parent and/or other caregivers (Ref.)	1			1		
Parents' birthplace						
Both parents born in Norway	1.82	−0.07 to 3.72	.059	−0.06	−1.85 to 1.72	.947
One or both parents born in another country (Ref.)	1			1		
Parents' work status						
Both parents are working	1.61	−0.42 to 3.63	.119	−1.15	−3.1 to 0.80	.245
One parent is working (Ref.)	1			1		
Pain on average	**−0.45**	**−0.82 to −0.07**	**.020**	−0.23	−0.60 to 0.14	.224
Self-esteem	−0.07	−1.51 to 1.36	.917	0.11	−1.31 to 1.5	.876
Self-efficacy	0.79	−1.17 to 2.76	.427	**1.94**	**0.01 to 3.87**	**.049**
Loneliness	−0.09	−0.27 to 0.09	.323	**−0.95**	**−1.13 to −0.77**	**<.001**
Stress	**−2.00**	**−2.61 to −1.39**	**<.001**	−0.37	98 – .23	.228

Table 4 (continued)

	School environment		
	B	**95% CI**	***p* value**
Time			
2021	− 1.27	− 2.61 to 0.06	.062
2019 (Ref.)	1		
Gender			
Boy	− 0.58	− 2.28 to 1.12	.503
Girl (Ref.)	1		
Parental members of the household			
Both parents	− 1.94	− 4.29 to 0.42	.106
Alternates between two parents	− 1.19	− 4.02 to 1.64	.409
One parent and/or other caregivers (Ref.)	1		
Parents' birthplace			
Both parents born in Norway	− 0.03	− 0.87 to 1.80	.972
One or both parents born in another country (Ref.)	1		
Parents' work status			
Both parents are working	1.21	− 0.80 to 3.22	.238
One parent is working (Ref.)	1		
Pain on average	**− 0.68**	**− 1.07 to − 0.29**	**.001**
Self-esteem	1.10	− 0.38 to 2.58	.146
Self-efficacy	**5.73**	**3.72 to 7.74**	**< .001**
Loneliness	**− 0.20**	**− 0.39 to − 0.02**	**.030**
Stress	**− 1.33**	**− 1.9 to − 0.70**	**< .001**

Linear mixed model analyses were performed separately for each of the five KIDSCREEN-27 subscales as the dependent variables

HRQOL was analyzed with KIDSCREEN-27 subscales. Higher values indicate higher levels of HRQOL

B, Unstandardized coefficient; CI, Confidence interval; HRQOL, Health-related quality of life

p values marked in bold indicate $p \leq .05$

well-being and psychological well-being scales. It is important to note that while the adolescents' HRQOL scores reported at time 1 are comparable to European norms, their HRQOL scores reported at time 2 are notably lower compared to European norms [40]. This should be viewed in light of the COVID-19 pandemic. During the pandemic, several studies have reported lower HRQOL scores in adolescents compared to the results of previous studies in adolescent populations [26–30].

Stress at age 14–15 years was significantly negatively associated with a reduction in HRQOL change scores in four KIDSCREEN subscales, although the stress score in our sample indicated low levels of stress. In line with previous findings [14], we found that stress had the highest negative effect on the KIDSCREEN subscale autonomy and parent relations, underscoring the need to be aware of the negative impact stress seems to have on this HRQOL dimension, which reflects the quality of adolescent and parent interactions, the feeling of love and support by family, and adolescents' perceived autonomy [40]. Our findings confirm that stress is a considerable risk factor for adolescents' HRQOL [14, 17], and add to existing knowledge by indicating that this is evident even with low levels of stress.

Higher levels of loneliness were associated with a decrease in HRQOL change scores, confirming the result from a previous cross-sectional study [14]. Adolescence is a life phase where biological, cognitive, social, and demographic changes may influence loneliness [59]. Furthermore, feelings of loneliness may have increased during the COVID-19 pandemic [24]. Hence, we emphasize that loneliness should be viewed as a significant threat to changes in adolescents' HRQOL during and after the pandemic.

The median intensity of pain reported at time 1 of 2.0 is not considered high. Nevertheless, pain was significantly associated with a reduction in HRQOL change scores in four KIDSCREEN subscales. Thus, our results support previous studies demonstrating a negative association between pain and HRQOL in adolescents [14, 20] and indicate that this is evident even with low levels of pain. Moreover, we found that pain had its highest negative effect on school environment, which explores the adolescents' feelings about school, the perception of

their cognitive capacity, concentration, and learning; and their views of the relationship with their teachers [40]. Hence, we accentuate the need for interventions aiming to reduce the negative impact pain seems to have on changes in HRQOL related to the school environment.

Our results confirm the positive association between higher levels of self-esteem and self-efficacy and an increase in HRQOL change scores. Self-efficacy and self-esteem are both considered resilient factors [60]. Resilience refers to having a relative resistance to risk experiences or overcoming adversity or stress [61]. Thus, our results emphasize the importance of resilience factors for HRQOL over time and call attention to the need for interventions aimed at increasing adolescents' resilience. Resilience interventions can increase adolescents' protective behaviors and coping skills—which can help them manage daily stressors, allowing for greater well-being and academic success [62]. Moreover, resilience factors may protect adolescents' mental health in times of crisis, such as the COVID-19 pandemic [63].

Girls reported lower levels of HRQOL compared to boys at age 14–15 years and at age 16–17 years. This confirms findings from previous longitudinal studies among adolescents [4, 9, 10]. Nevertheless, in four KIDSCREEN subscales, we found no significant association between gender and changes in HRQOL. For these subscales, our results may indicate that gender-related differences in HRQOL remained unchanged during youth. A possible explanation may be that gender is an important factor concerning HRQOL but that part of the gender-related differences in HRQOL might be explained by gender-related differences within other factors associated with HRQOL [10, 14, 15]. Surprisingly, for the subscale social support and peers, we found that male gender was associated with lower HRQOL scores compared to female gender. The subscale social support and peers explores adolescents' perceived support and the quality of the interaction between adolescents and peers [40]. Hence, our findings may be explained by previous research showing that adolescent boys report higher levels of social loneliness, which refers to the absence of a broader accessible and supportive social network, compared to girls [59]. Moreover, loneliness in boys is considered more sensitive to their interpersonal relationships [64].

A negative association between changes in HRQOL and low SES was not supported by our findings—except for the factor parents' work status, which showed that both parents being employed was associated with higher scores in the adolescents' physical well-being compared to when only one parent was employed. We have searched similar studies to find an explanation for this but have found none. Thus, we recommend future studies to further explore our findings. A possible explanation for our results regarding SES may be that other factors (e.g., stress, loneliness, and self-efficacy) outweighed the effect of SES. Furthermore, the results may have been influenced by high SES in our sample.

Strengths and limitations

The main strengths of this study are the longitudinal design and use of a sample that is representative of an unselected adolescent population and the inclusion of a wide range of potential predictive factors associated with a change in HRQOL. All these factors were assessed with well-validated instruments. The overall response rate was only 30.3%, which is a limitation. Attrition can be a major methodological problem in longitudinal studies and may deteriorate the generalizability of findings [65]. The scores for sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, and stress among the responders (N = 211) are similar to previous findings among the potential participants (N = 696) [14], indicating that the responders at time 2 were similar to the non-responders. However, the responders consisted of more girls (68%) compared to the sample of potential participants (57.5%). This may have influenced the results. Furthermore, it is important to note that more than two-thirds of the participants lived with both parents, had parents who were both born in Norway, and had parents both employed, indicating high SES. Thus, the results may not be representative of adolescents from low SES families. This should be considered when interpreting our results. Moreover, we did not control for other possible confounders—for example, depression, anxiety, bullying, and physical activity. Hence, we recommend controlling for other confounders in future studies.

Implications

Our results provide important insights into HRQOL changes in adolescents during the transition period from lower secondary to upper secondary school, from 14 to 16 years, and the impact of gender, sociodemographic factors, pain, self-esteem, self-efficacy, loneliness, and stress on HRQOL changes over time. The findings provide insight into a complex life phase and confirm that several factors can influence changes in adolescents' HRQOL, such as stress, loneliness, pain, self-esteem, and self-efficacy. We recommend future health-promoting interventions among adolescents to target these factors. Considering that the ongoing COVID-19 pandemic is leading to increased stress and loneliness and reduced HRQOL in adolescents [25–30], an increased understanding of factors associated with HRQOL seems highly relevant.

Based on previous research [11, 14, 15, 17] and our results showing the importance of self-esteem and

self-efficacy for HRQOL, we recommend an increased focus on resilience-promoting interventions at school. School interventions can support positive growth and changes to all students within a class, although with more significant effects in the at-risk group [62, 66]. Teachers are considered an important resource in the development of resilience, as they are more likely to know the students' lived experiences and current help-seeking and coping strategies [62]. We also highlight the need to involve parents regarding resilience promotion. The involvement of parents is considered a key component of effective resilience interventions, as parents are important influencers and role models for adolescents [66, 67].

In future studies to explore our findings more thoroughly, the sample should be extended and include more boys and adolescents with an immigrant background, with low SES, and who live with only one parent. Future studies may also analyze the development of HRQOL in adolescents over a longer period and include possible confounders not included in the present study, such as depression, anxiety, bullying, and physical activity. Furthermore, qualitative data are needed to gain more in-depth knowledge of factors associated with changes in adolescents' HRQOL over time.

Conclusions

Our study provides important insight into changes in adolescents' HRQOL at two time points when they were 14 and 16 years, and into factors associated with these changes. We found a significant decline in adolescents' HRQOL regarding physical and psychological well-being during these two years. Further, we found that stress, loneliness, and pain have a significant negative impact on HRQOL changes, whereas self-esteem and self-efficacy have a significant positive impact. Our results highlight the importance of increased understanding regarding factors associated with changes in adolescents' HRQOL to be able to intervene accurately and strategically.

Abbreviations

BPI: Brief pain inventory; CI: Confidence interval; GSE: General self-efficacy scale; HRQOL: Health-related quality of life; LPQ: Lübeck Pain-Screening Questionnaire; PSQ: Perceived Stress Questionnaire; RSES: Rosenberg self-esteem scale; SD: Standard deviation; SES: Socioeconomic status; ULS: UCLA loneliness scale.

Supplementary Information

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Additional file 1. Cronbach's alpha values for instruments used in this study. A table providing cronbach's alpha values for KIDSCREEN-27, Generalized Self-efficacy scale, Rosenberg Self-Esteem Scale, UCLA Loneliness Scale, Perceived Stress Questionnaire.

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Author contributions

All authors (HTM, MCS, KH, SH, SS and GR) contributed to the study conception and design. HTM was responsible for the recruitment together with SS and GR. Data analysis were performed by HTM and MCS. The first draft of the manuscript was written by HTM and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are not publicly available due to General Data Protection Regulation laws but are available from the corresponding author on reasonable request and with permission from the Norwegian Centre for Research Data.

Declarations

Ethics approval and consent to participate

All procedures performed in the study were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Approval was obtained from the ethics committee of Faculty of Health and Sport Sciences at the University of Agder and from the Norwegian Centre for Research Data (NSD Reference 60981). The participants received oral, written and digital information. Written information was also distributed to the parents at time 1. Informed consent was obtained from all participants. At time 1, informed consent was also obtained from the adolescents' parents/legal guardians. Data in the study was anonymized.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Appendix 1

Information letter to the school principal (time 1)

UNIVERSITETET I AGDER

OSLOMET

Start Ung – livskvalitet og smerte i generasjoner

Til Rektor ved Skole Dato

Søknad om å gjennomføre et forskningsprosjekt

Dette er en forespørsel om elever i 9.trinn og deres foresatte ved din skole kan inviteres til et forskningsprosjekt om livskvalitet og smerter blant ungdom og deres foresatte som gjennomføres høsten 2018.

Bakgrunn og formål

Formålet med prosjektet er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. Bakgrunn for prosjektet er at man i de senere år har sett en negativ utvikling når det gjelder subjektive helseplager hos barn og ungdom slik som hodepine, rygg/nakkesmerter og magesmerter. Disse problemene går utover dagliglivet og aktiviteter, og kan blant annet føre til dårlig søvn og fravær fra skole. Vi vet ikke nok om årsaker til eller omfang av disse problemene og hvordan de utvikler seg over tid, men flere forskere peker på at disse trendene gir grunn til bekymring når det gjelder norske ungdommers helse. Vi ønsker å studere hvilke faktorer som påvirker livskvalitet, smerte og mestring av smerte, samt sammenhengen mellom smerter og livskvalitet. Videre ønsker vi å undersøke hvordan sosiale sammenhenger (for eksempel livsstil, søvn, stress, ensomhet, psykososiale faktorer og familie) påvirker smerte og livskvalitet hos ungdom og deres foresatte. Vi vil også undersøke potensielle familie- og regionale mønstre.

Forskningsprosjektet vil foregå blant 800 tilfeldig valgte ungdom på 9. trinn og deres foreldre på Agder og i Oslo-regionen. Elevene er valgt ut på bakgrunn av skoleklassetilhørighet. En statistiker har trukket ut skolene tilfeldig med utgangspunkt i en liste fra Statistisk Sentralbyrå. En forskergruppe fra Universitet i Agder, fakultet for helse- og idrettsvitenskap, og OsloMet – storbyuniversitetet, fakultet for helsefag, er ansvarlige for forskningsprosjektet. Forskningsprosjektet er en doktorgradsstudie som ledes av professor Gudrun E. Rohde. På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hva innebærer deltakelse i forskningsprosjektet for skolen?

- Doktorgradsstipendiat Hilde T. Mikkelsen vil kontakte skolen ved rektor for å gjøre avtale om en dag hvor en prosjektmedarbeider kan besøke skolen og informere elever på 9.trinn om prosjektet. Rektor vil også bli bedt om å formidle informasjon om prosjektet videre til aktuelle klasselærere slik at det eventuelt kan gjøres avtaler direkte med klasselærerne.
- En prosjektmedarbeider vil besøke skolen og informere elever på 9.trinn om prosjektet både muntlig og skriftlig. Om mulig, er det også ønskelig at prosjektarbeidereren kan delta med informasjon på et foreldremøte. Ungdom under 16 år må få samtykke av sine foresatte for å få lov til å delta i prosjektet. Det vil sendes ut informasjon til elevenes foresatte, og deres samtykke til ungdommenes og egen deltagelse vil innhentes gjennom et samtykkeskjema som foresatte får tilgang til på Start Ung sitt eget nettsted (https://startung.uia.no). Ungdom samtykker til egen deltakelse i begynnelsen av spørreskjemaet de får tilsendt.
- Hvis rektor tillater det, er det ønskelig å legge ut informasjon om prosjektet samt link til prosjektets nettside på skolens hjemmeside og eventuelt også på facebook-siden til 9.trinn på skolen og/eller facebook-gruppen til de ulike 9.klassene ved skolen.
- Elever og deres foresatte vil bli bedt om å svare på en internettbasert spørreundersøkelse som kan besvares via mobil/nettbrett/PC. Kun elever som har fått samtykke fra sine foresatte til deltakelse, kan delta. Aktuelle elever vil fortrinnsvis fylle ut spørreskjemaene i en skoletime, dette vil ta ca 20 minutter. En prosjektmedarbeider vil være tilstede på skolen for å hjelpe til den dagen spørreundersøkelsen gjennomføres. Spørreskjemaet vil bestå av en rekke spørsmål som til sammen gir informasjon om ungdoms helse og livskvalitet. Det vil blant annet bli stilt spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, skole/fritid, kroppsbilde, opplevelse av smerter, stress, helserelatert livskvalitet og søvn. Foresatte som ønsker å se hele spørreskjemaet kan henvende seg til prosjektleder for Start Ung. Svarene som elevene gir vil bli koblet sammen med svarene fra deres foresatte for å se om man kan finne noen sammenhenger her. Elevene vil ikke få tilgang til svarene som foresatte gir i spørreundersøkelsen, og omvendt.
- For å sikre elevene en mulighet til å ta eget valg vedrørende deltakelse uten påvirkning fra foresatte, de andre elevene eller fra skolen, er det ønskelig at skolen gir elevene et tilbud om å jobbe på egen hånd med skolearbeid som er tilrettelagt slik at alle jobber på pc/nettbrett/mobil i klasserommet mens undersøkelsen pågår. På denne måten vil det ikke være åpenbart hvem som besvarer undersøkelsen og hvem som ikke deltar.

- Skolehelsetjenesten ved skolen vil bli kontaktet og informert muntlig og skriftlig om prosjektet, da undersøkelsen inneholder noen spørsmål om forhold som kan oppleves sensitive og vekke negative følelser.

Frivillig deltakelse i forskningsprosjektet

Det er frivillig å delta i prosjektet. Elever og deres foresatte kan når som helst og uten å oppgi noen grunn trekke seg fra prosjektet, uten konsekvenser.

For videre informasjon om forskningsprosjektet henviser vi til Start Ung sitt nettsted (https://startung.uia.no).

Vi håper på et positivt samarbeid med deres skole. For at den innsamlede informasjonen skal være mest mulig nøyaktig er det viktig at så mange som mulig deltar - uansett om man er plaget av smerte eller ikke.

Med vennlig hilsen

Gudrun E. Rohde
Professor, prosjektleder
Universitetet i Agder

Kristin Haraldstad
Førsteamanuensis
Universitetet i Agder

Sølvi Helseth
Professor
OsloMet - storbyuniversitetet

Siv Skarstein
Førsteamanuensis
OsloMet - storbyuniversitetet

Hilde T. Mikkelsen
Doktogradsstipendiat
Universitetet i Agder

Vennligst send svar til:

Hilde Timenes Mikkelsen
Tlf: 38141316 / 41107112
hilde.e.mikkelsen@uia.no

Appendix 2

Informed consent adolescents (time 1)

Vil du delta i forskningsprosjektet

Start Ung – livskvalitet og smerte i generasjoner?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Formålet med Start Ung er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. Bakgrunn for prosjektet er at man i de senere år har sett en negativ utvikling hos ungdom når det gjelder subjektive helseplager og smerter slik som hodepine, magesmerter eller muskel- og skjelett plager. Dette kan påvirke livskvalitet og dagliglivet negativt. Forskningsprosjektet Start Ung vil studere hvilke faktorer som påvirker livskvalitet, smerte og mestring av smerte, samt hvilken sammenheng det er mellom smerter og livskvalitet. Videre ønsker vi å undersøke hvordan sosiale sammenhenger påvirker smerte og livskvalitet hos ungdom og deres foresatte. Vi vil også undersøke potensielle familie- og regionale mønstre samt undersøke hvordan ungdommers livskvalitet og smerter utvikler seg gjennom ungdomsårene.

Hvem er ansvarlig for forskningsprosjektet?
Det er en forskergruppe/prosjektgruppe fra Universitet i Agder (UiA) og OsloMet – storbyuniversitetet som gjennomfører og er ansvarlig for prosjektet. Prosjektet er en doktorgradsstudie.

Hvorfor får du spørsmål om å delta?
Deltakerne i prosjektet vil være ca. 800 tilfeldig valgte ungdommer på 9. trinn og deres foresatte i Agder og i Oslo- og Akershus. Ungdommene er valgt ut på bakgrunn av skoletilhørighet. Alle elever ved 9.trinn samt deres foresatte ved utvalgte skoler vil bli invitert til deltakelse. Kun én av de foresatte til hver enkelt ungdom vil kunne delta i studien. Skolen din er trukket ut til deltakelse, og du og dine foresatte får derfor invitasjon til deltakelse.

Hva innebærer det for deg å delta?
Du og dine foresatte vil bli bedt om å svare på hvert sitt internettbaserte spørreskjema som vil bli sendt via en link på SMS/email. Det tar ca. 20 minutter å svare på spørreskjemaet, og vi håper det er mulighet for at du kan få gjøre dette i en skoletime. Dine foresatte må svare på spørreundersøkelsen på sin fritid.

Spørreskjemaet inneholder spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, skole/jobb, kroppsbilde, opplevelse av smerter, stress, helserelatert livskvalitet og søvn. Svar fra spørreskjemaet blir registrert elektronisk. Svarene du gir vil bli koblet sammen med svarene fra din foresatte for å se om man kan finne noen sammenhenger her.

For å ha mulighet til å se hvordan livskvalitet og smerter utvikler seg gjennom ungdomsårene, vil du og din foresatte få en ny henvendelse to og fire år etter at dere har deltatt i spørreundersøkelsen, med spørsmål om å besvare spørreskjemaet en gang til. Svarene som gis på spørreskjemaet to og fire år senere vil bli koblet sammen med svarene som er gitt tidligere.

Ved å delta i prosjektet vil du bidra til økt kunnskap omkring ungdommers opplevelse av smerte og livskvalitet, som på sikt kan brukes til å bedre helsen til ungdom i Norge. Prosjektet vil totalt ha ca. 1600 deltakere, og alle deltakere vil bli med i trekning av 8 gavekort á 500kr. Du vil måtte bruke av din tid i forbindelse med utfylling av spørreskjemaet, men vi håper det er mulighet for at du kan få gjøre dette i en skoletime. Undersøkelsen inneholder noen spørsmål om forhold som kan oppleves sensitive og vekke negative følelser. Ved behov for oppfølging i etterkant er det mulig å ta kontakt med skolehelsetjenesten ved din skole. Skolehelsetjenesten er informert om at undersøkelsen pågår.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn ved å kontakte prosjektleder Gudrun E. Rohde. Alle opplysninger vil da bli anonymisert. Det vil ikke påvirke ditt eller dine foresattes forhold til skolen/lærer eller ha noen andre negative konsekvenser for deg/dere hvis du eller dine foresatte ikke vil delta eller senere velger å trekke deg/dere.

Ønsker du å delta, må du i starten av spørreskjemaet du får tilsendt huke av for at du har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. Deretter må du huke av for at du samtykker til egen deltakelse i spørreskjemaundersøkelse. Ungdom under 16 år må i tillegg få samtykke av sine foresatte for å få lov til å delta i prosjektet. Dine foresatte kan i forkant av undersøkelsen gi samtykke til at du kan delta ved å gå inn på Start Ung sin nettside (https://startung.uia.no) og velge «Samtykke til deltakelse». De vil da bli sendt til et nettbasert samtykkeskjema. Her kan de huke av for at de gir samtykke til din deltakelse. Ved oppfølgingsstudier etter 2 og 4 år vil det innhentes nytt samtykke fra deg etter at du har fylt 16 år.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet, og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Det er kun prosjektgruppen som vil ha tilgang til dine personopplysninger. Dine foresatte vil ikke få tilgang på svarene som du gir i spørreundersøkelsen, og omvendt. Det vil ikke være mulig å identifisere deg i resultatene av prosjektet når disse publiseres. Informasjonen om deg vil bli anonymisert eller slettet ved prosjektslutt 01.august 2032.

Hvor kan jeg finne ut mer?
Du kan gå inn på Start Ung sin egen nettside (https://startung.uia.no) for videre informasjon om forskningsprosjektet. Hvis du har spørsmål til prosjektet, eller senere ønsker å trekke ditt samtykke, kan du kontakte:

- Gudrun E. Rohde, prosjektleder, professor, UiA, gudrun.e.rohde@uia.no, Tlf: 38 14 18 46
- Hilde E.T. Mikkelsen, doktorgradsstipendiat, UiA, hilde.e.mikkelsen@uia.no, Tlf: 38 14 13 16.

Med vennlig hilsen

Gudrun E. Rohde
Prosjektleder, professor

Hilde E. Timenes Mikkelsen
Doktorgradsstipendiat

Samtykkeerklæring

- ☐ Jeg har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål.

- ☐ Jeg samtykker til å delta i spørreskjemaundersøkelse

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 01.august 2032.

(Signert av prosjektdeltaker, dato)

Appendix 3

Informed consent parents (time 1)

Vil du delta i forskningsprosjektet

Start Ung – livskvalitet og smerte i generasjoner?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Formålet med Start Ung er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. Bakgrunn for prosjektet er at man i de senere år har sett en negativ utvikling hos ungdom når det gjelder subjektive helseplager og smerter slik som hodepine, magesmerter eller muskel- og skjelett plager. Dette kan påvirke livskvalitet og dagliglivet negativt. Forskningsprosjektet Start Ung vil studere hvilke faktorer som påvirker livskvalitet, smerte og mestring av smerte, samt hvilken sammenheng det er mellom smerter og livskvalitet. Videre ønsker vi å undersøke hvordan sosiale sammenhenger (for eksempel livsstil, søvn, stress, ensomhet, psykososiale faktorer og familie) påvirker smerte og livskvalitet hos ungdom og deres foresatte. Vi vil også undersøke potensielle familie- og regionale mønstre samt undersøke hvordan ungdommers livskvalitet og smerter utvikler seg gjennom ungdomsårene.

Hvem er ansvarlig for forskningsprosjektet?
Det er en forskergruppe/prosjektgruppe fra Universitet i Agder (UiA), fakultet for helse- og idrettsvitenskap, og OsloMet - storbyuniversitetet, fakultet for helsefag, som gjennomfører og er ansvarlig for prosjektet. Prosjektet er en doktorgradsstudie. Universitetet i Agder er behandlingsansvarlig institusjon.

Hvorfor får du spørsmål om å delta?
Deltakerne i prosjektet vil være ca. 800 tilfeldig valgte ungdom på 9. trinn og deres foresatte i Agder og i Oslo- og Akershus. Ungdommene er valgt ut på bakgrunn av skoletilhørighet. Alle elever ved 9.trinn samt deres foresatte ved utvalgte skoler vil bli invitert til deltakelse. Kun én av de foresatte til hver enkelt ungdom vil kunne delta i studien. Skolen til ditt barn er trukket ut til deltakelse, og du som foresatt får spørsmål om å delta for å gi prosjektet et familieperspektiv. Ungdom under 16 år trenger samtykke av foresatte for å delta i prosjektet, og du får derfor også spørsmål om å la ditt barn delta i forskningsprosjektet.

Hva innebærer det for deg og ditt barn å delta?
Du og ditt barn vil bli bedt om å svare på hvert sitt internettbaserte spørreskjema som vil bli sendt via en link på SMS/email. Det tar ca. 20 minutter å svare på spørreskjemaet. Vi håper det er mulighet for at ungdommene kan få gjøre dette i en skoletime. Foresatte må svare på spørreundersøkelsen på sin fritid.

Spørreskjemaet inneholder spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, skole/jobb, kroppsbilde, opplevelse av smerter, stress, helserelatert livskvalitet og søvn. Svar fra spørreskjemaet blir registrert elektronisk. Foresatte kan få se spørreskjemaet på forhånd ved å henvende seg til prosjektleder for Start Ung. Svarene som ungdommene gir vil bli koblet sammen med svarene fra foresatte for å se om man kan finne noen sammenhenger her.

For å ha mulighet til å se hvordan livskvalitet og smerter utvikler seg gjennom ungdomsårene, vil ungdom og foresatte få en ny henvendelse to og fire år etter at de har deltatt i spørreundersøkelsen, med spørsmål om å besvare spørreskjemaet en gang til. Svarene som gis på spørreskjemaet to og fire år senere vil bli koblet sammen med svarene som er gitt tidligere.

Ved å delta i prosjektet vil du og ditt barn bidra til økt kunnskap omkring ungdommers opplevelse av smerte og livskvalitet, som på sikt kan brukes til å bedre helsen til ungdom i Norge. Prosjektet vil totalt ha ca. 1600 deltakere, og alle deltakere vil bli med i trekning av 8 gavekort á 500kr. Du vil måtte bruke av din tid i forbindelse med utfylling av spørreskjemaet. Undersøkelsen inneholder noen spørsmål om forhold som kan oppleves sensitive og vekke negative følelser. Ved behov for oppfølging i etterkant er det mulig å ta kontakt med skolehelsetjenesten tilknyttet ditt barns skole. Skolehelsetjenesten er informert om at undersøkelsen pågår.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn ved å kontakte prosjektleder Gudrun E. Rohde. Alle opplysninger vil da bli anonymisert. Det vil ikke påvirke ungdom eller foresattes forhold til skolen/lærer eller ha noen andre negative konsekvenser for deg/dere hvis du eller ditt barn ikke vil delta eller senere velger å trekke deg/dere.

Ønsker du å delta, må du gå til Start Ung sin nettside (https://startung.uia.no) og velge «Samtykke til deltakelse». Du vil da bli sendt til et nettbasert samtykkeskjema. Her må du først huke av for at du har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. Deretter må du huke av for at du samtykker til egen deltakelse i spørreskjemaundersøkelse. Hvis du ønsker at ditt barn skal kunne delta, må du også huke av for at du samtykker til ditt barns deltakelse. Samtykket som gis vedrørende deltakelse gjelder også oppfølgingsstudier etter 2 og 4 år. Ved oppfølgingsstudiene vil det innhentes nytt samtykke fra ditt barn etter at han/hun har fylt 16 år.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Navn og kontaktopplysninger vil erstattes med en kode som lagres på egen navneliste adskilt fra øvrige data. Du og ditt barn vil inneha den samme koden. Navnelisten vil bli oppbevart innelåst i et sikkert skap adskilt fra øvrige data. Det er kun prosjektleder og prosjektets doktorgradsstipendiat som har adgang til navnelisten og som kan finne tilbake til navn. Det er kun prosjektgruppens seks medlemmer som vil ha tilgang til øvrige data.
- Ungdom vil ikke få tilgang til svarene som foresatte gir i spørreundersøkelsen, og omvendt.
- Det vil ikke være mulig å identifisere deg eller ditt barn i resultatene av prosjektet når disse publiseres.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 01.august 2032. Informasjon om deg og ditt barn vil bli anonymisert eller slettet ved prosjektslutt.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,

- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Vi henviser til Start Ung sin egen nettside (https://startung.uia.no) for videre informasjon om forskningsprosjektet. Hvis du har spørsmål til prosjektet, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Universitetet i Agder ved prosjektleder Gudrun E. Rohde, på epost (gudrun.e.rohde@uia.no) eller telefon: 38 14 18 46, eller ved doktorgradsstipendiat Hilde E.T. Mikkelsen på epost (hilde.e.mikkelsen@uia.no) eller telefon: 38 14 13 16.
- Personvernombud v/ UiA: Ina Danielsen, ina.danielsen@uia.no, Tlf: 452 54 401.
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Gudrun E. Rohde
Prosjektleder, professor

Hilde E. Timenes Mikkelsen
Doktorgradsstipendiat

Samtykkeerklæring

- ☐ Jeg har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål.
- ☐ Jeg samtykker til å delta i spørreskjemaundersøkelse
- ☐ Jeg samtykker til at mitt barn kan delta i spørreskjemaundersøkelse

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 01.august 2032.

(Signert av prosjektdeltaker, dato)

Som foresatte til ……. (Fullt navn) samtykker jeg til at han/hun kan delta i forskningsprosjektet «Start Ung – livskvalitet og smerte i generasjoner» og at hans/hennes opplysninger behandles frem til prosjektet er avsluttet, ca. 01.august 2032.

(Signert av prosjektdeltaker, dato)

Kontaktinformasjon

Du har nå samtykket til deltakelse i forskningsprosjektet «Start Ung – livskvalitet og smerte i generasjoner». Vi ber deg derfor om å fylle ut kontaktinformasjon for deg og ditt barn/ungdom. Denne informasjonen vil bli brukt og oppbevart slik det ble skissert i informasjonsskrivet vedrørende deltakelse i forskningsprosjektet.

DIN KONTAKTINFORMASJON

Fornavn …….....
Etternavn ……..…….
Fødselsnummer ……..
E-post …….....
Telefonnummer …….

DITT BARNS KONTAKTINFORMASJON

Fornavn …….....
Etternavn ……..…….
Fødselsnummer ……..
E-post …….....
Telefonnummer ……..
Skole …….....

Appendix 4

Informed consent adolescents (time 2)

Vil du delta i oppfølgingsstudie tilknyttet forskningsprosjektet *Start Ung – livskvalitet og smerte i generasjoner*?

Dette er et spørsmål til deg om å delta i en oppfølgingsstudie tilknyttet et forskningsprosjekt hvor formålet er framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Formålet med Start Ung er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. Bakgrunn for prosjektet er at man i de senere år har sett en negativ utvikling hos ungdom når det gjelder subjektive helseplager og smerter slik som hodepine, magesmerter eller muskel- og skjelett plager. Dette kan påvirke livskvalitet og dagliglivet negativt. Forskningsprosjektet Start Ung vil studere hvilke faktorer som påvirker livskvalitet, smerte og mestring av smerte, samt hvilken sammenheng det er mellom smerter og livskvalitet. Videre ønsker vi å undersøke hvordan for eksempel livsstil, søvn, stress, ensomhet, selvfølelse, tro på egen mestring, venner og familie påvirker smerte og livskvalitet hos ungdom og deres foresatte. Vi vil også undersøke mulige familie- og regionale mønstre samt undersøke hvordan ungdommers og foresattes livskvalitet og smerter utvikler seg over tid.

Hvem er ansvarlig for forskningsprosjektet?
Det er en forskergruppe/prosjektgruppe fra Universitet i Agder (UiA) og OsloMet – storbyuniversitetet som gjennomfører og er ansvarlig for prosjektet. Prosjektet er en doktorgradsstudie. Universitetet i Agder er behandlingsansvarlig institusjon.

Hvorfor får du spørsmål om å delta?
Du blir spurt om å delta fordi du for ca. 2 år siden svarte på en spørreundersøkelse tilknyttet Start Ung. Den gangen samtykket du også til at vi kunne kontakte deg etter 2 år med spørsmål om å delta i en ny spørreundersøkelse. I oppfølgingsstudien nå er det kun de 696 ungdommene og 561 foresatte som for ca.2 år siden svarte på Start Ung sin spørreundersøkelse som får invitasjon til deltakelse.

Hva innebærer det for deg å delta?
Hvis du velger å delta, innebærer det at du fyller ut et spørreskjema. Det vil ta deg ca. 20-30 minutter. Spørreskjemaet inneholder spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, skole, opplevelse av smerter, stress, selvfølelse, tro på egen mestring, helserelatert livskvalitet og søvn. Nytt i oppfølgingsstudien er at du også vil få noen spørsmål som gjelder den pågående corona-epidemien samt spørsmål om hvordan du vurderer din helsekompetanse. Vi har tatt bort noen av spørsmålene du ble stilt forrige gang slik at ikke antall spørsmål er økt. Dine svar fra spørreskjemaet blir registrert elektronisk. Svarene du gir vil bli koblet sammen med svarene fra din foresatte (hvis han/hun deltar/har deltatt) samt svarene du har gitt tidligere for å se om man kan finne noen sammenhenger her.

For å ha mulighet til å se hvordan livskvalitet og smerter utvikler seg gjennom ungdomsårene, vil du få en ny henvendelse om nye to år, med spørsmål om å besvare spørreskjemaet en gang til.

Ved å delta i prosjektet vil du bidra til økt kunnskap omkring ungdommers og deres foresattes opplevelse av smerte og livskvalitet, som på sikt kan brukes til å bedre helsen til ungdom i Norge. Oppfølgingsstudien vil totalt kunne ha ca. 1300 deltakere, og alle deltakere vil bli med i trekning av 20 gavekort á 500kr. Du vil måtte bruke av din fritid i forbindelse med utfylling av spørreskjemaet. Undersøkelsen inneholder noen spørsmål om forhold som kan oppleves sensitive og vekke negative følelser. Ved behov for oppfølging i etterkant anbefaler vi deg å ta kontakt med skolehelsetjenesten ved din skole.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Vi bruker Nettskjema (https://www.uio.no/tjenester/it/adm-app/nettskjema/) for å samle inn data via spørreskjema, og dette er tilkoblet Tjenester for sensitive data (TSD) (https://www.uio.no/tjenester/it/forskning/sensitiv/) som oppfyller lovens strenge krav til behandling og lagring av forskningsdata
- Navnet og kontaktopplysningene dine vil bli erstattet med en kode som lagres på egen navneliste adskilt fra øvrige data. Kun prosjektleder og prosjektets doktorgradsstipendiat har tilgang til listen. Det er kun prosjektgruppens seks medlemmer som vil ha tilgang til øvrige data.
- Ungdom vil ikke få tilgang til svarene som foresatte gir i spørreundersøkelsen, og omvendt.
- Det vil ikke være mulig å identifisere deg eller dine foresatte i resultatene av prosjektet når disse publiseres.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Opplysningene anonymiseres eller slettes når prosjektet avsluttes, noe som etter planen er 01.august 2032.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra UiA har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Vi henviser til Start Ung sin egen nettside (https://startung.uia.no) for videre informasjon om forskningsprosjektet. Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- UiA ved prosjektleder Gudrun E. Rohde (epost: gudrun.e.rohde@uia.no, tlf: 381 41 846) eller ved doktorgradsstipendiat Hilde E.T. Mikkelsen (epost: hilde.e.mikkelsen@uia.no, tlf: 381 41 316)

- Vårt personvernombud: Ina Danielsen (epost: ina.danielsen@uia.no, tlf: 452 54 401)

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Gudrun E. Rohde
Prosjektleder, professor

Hilde E. Timenes Mikkelsen
Doktorgradsstipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. Jeg samtykker til

- ☐ å delta i spørreskjemaundersøkelse

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

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(Signert av prosjektdeltaker, dato)

Appendix 5

Informed consent parents (time 2)

Vil du delta i oppfølgingsstudie tilknyttet forskningsprosjektet

Start Ung – livskvalitet og smerte i generasjoner?

Dette er et spørsmål til deg om å delta i en oppfølgingsstudie tilknyttet et forskningsprosjekt hvor formålet er framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Formålet med Start Ung er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte. Bakgrunn for prosjektet er at man i de senere år har sett en negativ utvikling hos ungdom når det gjelder subjektive helseplager og smerter slik som hodepine, magesmerter eller muskel- og skjelett plager. Dette kan påvirke livskvalitet og dagliglivet negativt. Forskningsprosjektet Start Ung vil studere hvilke faktorer som påvirker livskvalitet, smerte og mestring av smerte, samt hvilken sammenheng det er mellom smerter og livskvalitet. Videre ønsker vi å undersøke hvordan for eksempel livsstil, søvn, stress, ensomhet, selvfølelse, tro på egen mestring, venner og familie påvirker smerte og livskvalitet hos ungdom og deres foresatte. Vi vil også undersøke mulige familie- og regionale mønstre samt undersøke hvordan ungdommers og foresattes livskvalitet og smerter utvikler seg over tid.

Hvem er ansvarlig for forskningsprosjektet?
Det er en forskergruppe/prosjektgruppe fra Universitet i Agder (UiA), fakultet for helse- og idrettsvitenskap, og OsloMet - storbyuniversitetet, fakultet for helsefag, som gjennomfører og er ansvarlig for prosjektet. Prosjektet er en doktorgradsstudie. Universitetet i Agder er behandlingsansvarlig institusjon.

Hvorfor får du spørsmål om å delta?
Du blir spurt om å delta fordi du for ca. 2 år siden svarte på en spørreundersøkelse tilknyttet Start Ung. Den gangen samtykket du også til at vi kunne kontakte deg etter 2 år med spørsmål om å delta i en ny spørreundersøkelse. I oppfølgingsstudien nå er det kun de 696 ungdommene og 561 foresatte som for ca.2 år siden svarte på Start Ung sin spørreundersøkelse som får invitasjon til deltakelse.

Hva innebærer det for deg å delta?
Hvis du velger å delta, innebærer det at du fyller ut et spørreskjema. Det vil ta deg ca. 15-25 minutter. Spørreskjemaet inneholder spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, jobb, opplevelse av smerter, stress, selvfølelse, tro på egen mestring, og helserelatert livskvalitet. Nytt i oppfølgingsstudien er at du også vil få noen spørsmål som gjelder den pågående corona-epidemien samt spørsmål om hvordan du vurderer din helsekompetanse. Vi har tatt bort noen av spørsmålene du ble stilt forrige gang slik at ikke antall spørsmål er økt. Dine svar fra spørreskjemaet blir registrert elektronisk. Svarene du gir vil bli koblet sammen med svarene fra ditt barn (hvis han/hun deltar/har deltatt) samt svarene du har gitt tidligere for å se om man kan finne noen sammenhenger her. Hvis ditt barn velger å delta, vil han/hun også svare på noen spørsmål som gjelder begge foreldre. Det stilles spørsmål vedrørende hvem barnet bor sammen med samt foreldres sivilstand, fødested, arbeidsstatus og foreldres anbefalinger vedrørende bruk av smertestillende medikamenter.

For å ha mulighet til å se hvordan livskvalitet og smerter utvikler seg over tid, vil du få en ny henvendelse om nye to år, med spørsmål om å besvare spørreskjemaet en gang til.

Ved å delta i prosjektet vil du bidra til økt kunnskap omkring ungdommers og deres foresattes opplevelse av smerte og livskvalitet, som på sikt kan brukes til å bedre helsen til ungdom i Norge. Oppfølgingsstudien vil totalt kunne ha ca. 1300 deltakere, og alle deltakere vil bli med i trekning av 20 gavekort á 500kr. Du vil måtte bruke av din fritid i forbindelse med utfylling av spørreskjemaet. Undersøkelsen inneholder noen spørsmål om forhold som kan oppleves sensitive og vekke negative følelser.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Hvis din sønn/datter svarte på spørreundersøkelsen for ca. 2 år siden vil også han/hun få ny invitasjon til deltakelse. Ved denne oppfølgingsstudien er sønnen/datteren din fylt 16 år og kan derfor alene samtykke til egen deltakelse.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Vi bruker Nettskjema (https://www.uio.no/tjenester/it/adm-app/nettskjema/) for å samle inn data via spørreskjema, og dette er tilkoblet Tjenester for sensitive data (TSD) (https://www.uio.no/tjenester/it/forskning/sensitiv/) som oppfyller lovens strenge krav til behandling og lagring av forskningsdata
- Navnet og kontaktopplysningene dine vil bli erstattet med en kode som lagres på egen navneliste adskilt fra øvrige data. Kun prosjektleder og prosjektets doktorgradsstipendiat har tilgang til listen. Det er kun prosjektgruppens seks medlemmer som vil ha tilgang til øvrige data.
- Foresatte vil ikke få tilgang til svarene som ungdommene gir i spørreundersøkelsen, og omvendt.
- Det vil ikke være mulig å identifisere deg eller ditt barn i resultatene av prosjektet når disse publiseres.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Opplysningene anonymiseres eller slettes når prosjektet avsluttes, noe som etter planen er 01.august 2032.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra UiA har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Vi henviser til Start Ung sin egen nettside (https://startung.uia.no) for videre informasjon om forskningsprosjektet. Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- UiA ved prosjektleder Gudrun E. Rohde (epost: gudrun.e.rohde@uia.no, tlf: 381 41 846) eller ved doktorgradsstipendiat Hilde E.T. Mikkelsen (epost: hilde.e.mikkelsen@uia.no, tlf: 381 41 316)
- Vårt personvernombud: Ina Danielsen (epost: ina.danielsen@uia.no, tlf: 452 54 401)

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Gudrun E. Rohde
Prosjektleder, professor

Hilde E. Timenes Mikkelsen
Doktorgradsstipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. Jeg samtykker til

- ☐ å delta i spørreskjemaundersøkelse

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

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(Signert av prosjektdeltaker, dato)

Appendix 6

Decision regarding application to REK

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Leena Heinonen	22845522	25.05.2018	2018/755 REK sør-øst A
			Deres dato:	Deres referanse:
			20.03.2018	

Vår referanse må oppgis ved alle henvendelser

Gudrun Rohde
Universitetet i Agder

2018/755 Start Ung - Livskvalitet og smerte i generasjoner

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 26.04.2018. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig: Universitetet i Agder
Prosjektleder: Gudrun Rohde

Prosjektomtale (revidert av REK):
Formålet med Start Ung er å framskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte samt undersøke potensielle familie- og regionale mønstre. Forskningsprosjektet vil foregå blant 800 tilfeldig valgte ungdom på 9. trinn i Agder og Oslo/Akershus, og deres foresatte. Ungdommer og foresatte vil bli bedt om å svare på en internettbasert spørreundersøkelse som vil bli gjentatt etter 2 og 4 år. I spørreskjemaet vil det blant annet bli stilt spørsmål om sosial og kulturell bakgrunn, forhold til venner og familie, skole/jobb, kroppsbilde, selvrapportert opplevelse av smerter, stress, helserelatert livskvalitet og søvn. Forskningsprosjektet vil gi økt kunnskap om hvordan smerte og helserelatert livskvalitet kan endres i løpet av ungdomsårene, og om eventuelle prediktorer for disse endringene. Videre vil man kunne avsløre potensielle familiemønstre. Basert på funnene, vil man kunne foreslå tiltak for å forbedre helse og livskvalitet og redusere smerte hos ungdom.

Studien er i utgangspunktet en befolkningsstudie med formål å studere forekomsten av smerte opplevelse og livskvalitet i en ungdomspopulasjon. Det ser ikke ut til å være spesifikke helseformål knyttet til gjennomføringen selv om det longitudinelle designet vil kunne gi informasjon om sammenhenger over tid som på sikt kan bidra til utvikling av bedre behandlings og/eller forebyggingstiltak. Studien tar sikte på å rekruttere unge rundt 14 år og selv om noen av temaene kan ansees som noe sensitive i denne gruppen skulle ikke dette være et stort problem.

Vurdering

Etter komiteens vurdering vil ikke prosjektet, slik dets formål er beskrevet i søknad eller protokoll, kunne bringe ny kunnskap om helse eller sykdom, siden studien ikke inneholder helseformål

Hva som er medisinsk og helsefaglig forskning fremgår av helseforskningsloven § 4 bokstav a hvor medisinsk og helsefaglig forskning er definert slik: «virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom».

Det er institusjonens ansvar å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern.

Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2, og kan derfor gjennomføres uten godkjenning av REK.

Klageadgang

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK Sørøst A. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Med vennlig hilsen

Knut Engedal
Professor dr. med.
Leder

Leena Heinonen
rådgiver

Kopi til:gudrun.e.rohde@uia.no
Universitetet i Agder ved øverste administrative ledelse: post@uia.no

Appendix 7

Decision regarding application to FEK

Hilde Elisabeth Timenes Mikkelsen

FEK behandlet 22.06.18. din søknad om etisk godkjenning av vedlagte prosjekt. Søknaden godkjennes under forutsetning av at det gjennomføres som beskrevet i søknaden og godkjenning fra NSD.

Lykke til!

På vegne av FEK

Anne Skisland

Appendix 8

Decision regarding application to NSD

Universitetet i Agder
Att: Hilde E. Timenes Mikkelsen
hilde.e.mikkelsen@uia.no

Vår dato: 30.07.2018 Vår ref: 60981/PEG/LR Deres dato: Deres ref:

VURDERING AV BEHANDLING AV SÆRSKILTE KATEGORIER PERSONOPPLYSNINGER I PROSJEKTET «START UNG - LIVSKVALITET OG SMERTE I GENERASJONER»

Norsk senter for forskningsdata AS (NSD) viser til meldeskjema innsendt 01.06.2018. Meldingen gjelder behandling av personopplysninger til forskningsformål.

Etter avtale med den behandlingsansvarlige, Universitetet i Agder, har NSD foretatt en vurdering av om den planlagte behandlingen er i samsvar med personvernlovgivningen.

Resultat av NSDs vurdering
NSD vurderer at det, ifølge prosjektmeldingen, vil bli behandlet alminnelige personopplysninger i form av navn, fødselsnummer, e-postadresse og telefonnummer og skole, samt særskilte kategorier personopplysninger om helseopplysninger, samt opplysninger om rasemessig eller etnisk opprinnelse, frem til 01.08.2032.

NSDs vurdering er at behandlingen vil være i samsvar med personvernlovgivingen, og at lovlig grunnlag for behandlingen er utvalgets samtykke.

Vår vurdering forutsetter at prosjektansvarlig behandler personopplysninger i tråd med:

- opplysninger gitt i meldeskjema og øvrig dokumentasjon
- dialog med NSD, og vår vurdering (se under)
- Universitetet i Agder sine retningslinjer for datasikkerhet, herunder regler om hvilke tekniske hjelpemidler det er tillatt å bruke:
- Universitetet i Agder sine retningslinjer for bruk av databehandler.

Nærmere begrunnelse for NSDs vurdering:

1. Beskrivelse av den planlagte behandlingen av personopplysninger

Prosjektet er en samarbeidsavtale mellom Universitetet i Agder og OsloMet, hvor Universitetet i Agder er behandlingsansvarlig. Personvernombudet forutsetter at ansvarsforhold, sikring og evt. eierskap av data er avklart mellom de to institusjonene, og anbefaler at forholdet formaliseres.

Formålet med prosjektet er å fremskaffe ny kunnskap om livskvalitet og smerter blant ungdom og deres foresatte, samt undersøke hvordan sosiale sammenhenger påvirker smerte og helserelatert livskvalitet hos ungdom og foresatte. Utvalget består av 800 ungdom på 9. trinn i Agder og i Oslo/Akershus, samt deres foresatte. Totalt antall informanter er rundt 1600. Utvalget trekkes tilfeldig basert på deres skoletilhørighet. Prosjektet formidles ved at en forsker, med skolens godkjennelse, gjester skolen for å gi muntlig informasjon om forskningsprosjektet. Ved tillatelse fra skolen vil det også legges ut link til prosjektets nettside på skolens hjemmeside. Førstegangskontakt oppnås ved informasjonsskriv til ungdommer og foresatte som de får tilgang til via hjemmesiden til prosjektet.

Datamaterialet vil bestå av spørreskjemadata samlet inn via elektronisk spørreskjema. Ungdommene og foreldrene svarer på separate spørreskjema. Begge spørreskjemaene inneholder spørsmål om demografiske data, selvopplevd fysisk og psykisk helse, herunder spørsmål om smerter, sykdom, søvn, selvbilde og generell psykososial trivsel. Det ene spørreskjema etterspør opplysningene om foreldrenes fødeland, noe som, etter Personvernombudets vurdering, kan avsløre opplysninger om rasemessig eller etnisk opprinnelse.

Henholdsvis to og fire år etter første innsamlingsrunde vil utvalget kontaktes på nytt for å gjennomføre oppfølgingsstudier. Oppfølgingsstudiene innebærer å svare på det samme spørreskjemaet på nytt. Formålet er å registrere endringer i svar over tid, og svarene fra de tre rundene vil derfor kobles.

All behandling av personopplysninger i prosjektet er basert på utvalgets informerte samtykke. De foresatte samtykker på egne og ungdommenes vegne, da ungdommene er 13-14 år gamle. Etter hvert som ungdommene blir samtykkekompetente vil det innhentes egne samtykker fra dem. De registrerte har alle rettigheter som etter forordningen får anvendelse når behandlingsgrunnlaget er samtykke (se punkt 4 nedenfor).

Personopplysninger samles inn via den online spørreskjematjeneste SurveyXact (databehandleravtale foreligger). Informasjonssikkerheten ivaretas i henhold til en ROS-analyse (risikoanalyse) utarbeidet av medarbeidere ved forskningsavdelingen og IT-avdelingen ved UiA. Kun prosjektleder og veileder har tilgang til koblingsnøkkel. Prosjektmedarbeidere ved OsloMet får tilgang til datamaterialet i SurveyXact, men får ikke tilgang til koblingsnøkler.

Ifølge meldeskjema skal personopplysninger behandles frem til 01.08.2032, deretter anonymiseres.

2. Personvernprinsipper

NSDs vurdering er at behandlingen følger personvernprinsippene, ved at personopplysninger;

- skal behandles på en lovlig, rettferdig og åpen måte med hensyn til den registrerte (se punkt 3 og 4)
- skal samles inn for spesifikke, uttrykkelig angitte formål og at personopplysningene ikke viderebehandles på en måte som er uforenelig med formålet (se punkt 1 og 3)
- vil være adekvate, relevante og begrenset til det som er nødvendig for formålet de behandles for (se punkt 7)
- skal lagres slik at det ikke er mulig å identifisere de registrerte lengre enn det som er nødvendig for formålet (se punkt 5 og 7)

3. Lovlig grunnlag for å behandle særskilte kategorier av personopplysninger

Det fremgår av meldeskjema vi har fått tilsendt at det vil bli innhentet samtykke fra de registrerte. NSD vurderer at den planlagte behandlingen av personopplysninger er lovlig fordi:

- det skal innhentes uttrykkelig samtykke fra de registrerte og
- forsker har oppfylt den særskilte rådføringsplikten

Personvernforordningen art. 7 stiller krav om at et samtykke skal være dokumenterbart.

Ifølge prosjektmeldingen skal samtykke innhentes ved at foreldre trykker på en påmeldingsknapp på prosjektets nettside, og derved melder på seg selv og sitt barn.

I tillegg skal de foresatte fylle ut en ekstra samtykkeerklæring personopplysninger (med navn, telefonnummer og e-post) på siste side av samtykkeskjemaet. NSD vurderer at utfylling av erklæringen kombinert med avkrysningen av samtykkeboksene vil være tilstrekkelig til å tilfredsstille kravet om et uttrykkelig samtykke, jf. art. 9 nr. 1 bokstav a), og at dokumentasjonsplikten overholdes ved at erklæringene lagres elektronisk. Vi nevner i denne sammenheng at behandling av direkte identifiserende personopplysninger i samtykkeerklæringen anses nødvendig for formålet, og dermed i tråd med dataminimeringsprinsippet, fordi prosjektleder er avhengig av å kunne kontakte utvalget flere ganger i løpet av studien.

Samtykkeerklæringen etterspør også fødselsnummer fra deltakerne. NSD minner om at det ikke skal samles inn flere personopplysninger enn det som er relevant for formålet. Vi kan ikke se at det er nødvendig med fødselsnummer for å kunne følge opp studien, ettersom prosjektleder vil ha tilgang til andre direkte identifiserende personopplysninger som navn, e-postadresse og telefonnummer. I forlengelsen av dette understreker vi at det at forskerne, ved en senere anledning, ser for seg et prosjekt der spørreskjemadata fra dette prosjektet kobles til registerdata, ikke vil legitimere at det innhentes fødselsnummer allerede i dette prosjektet. En slik løsning vil stride mot prinsippet om dataminimering, jf. art. 5.

4. De registrertes rettigheter

NSD finner at informasjonsskrivet datert vil gi de registrerte god informasjon om hva behandlingen innebærer og om hvilke rettigheter de har, og at skrivet oppfyller kravet til et informert samtykke, jf. personvernforordningen art. 4 nr. 11.

De registrerte kan utøve sine rettigheter, herunder trekke tilbake samtykket, ved å ta kontakt med prosjektansvarlig Hilde Timenes Mikkelsen Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har Universitetet i Agder plikt til å svare innen en måned. Vi forutsetter at prosjektansvarlig informerer institusjonen så fort som mulig og at UiAs har rutiner for hvordan henvendelser fra registrerte skal følges opp.

5. Informasjonssikkerhet

I følge meldingen skal personopplysningene behandles ved hjelp av elektronisk spørreskjema (se punkt 1. for nærmere beskrivelse av personopplysningene). Nedenfor følger en beskrivelse av dataflyten:

Spørreskjemadataene innhentes elektronisk via SurveyXact. Utvalget får tilgang til spørreskjema via link på prosjektets hjemmeside. Spørreskjemadataene, samt samtykkeskjemaene, samles inn i SurveyXact, og lastes deretter til en kryptert Excel-fil i Office365 før dataene slettes i SurveyXact.

Dataene i Excel-filen lagres på en stasjonær datamaskin tilknyttet UiAs nettverk, og blir i tillegg synkronisert i UiA sin skybaserte tjeneste for oppbevaring/sikkerhetskopiering (OneDrive/Azure Cloud). Prosjektleder oppretter deretter en koblingsnøkkel i en ny Excel-fil, ved at utvalget tildeles et ID-nummer (ungdom og foresatt tildeles samme ID-nummer). Det er kun prosjektleder og veileder som har tilgang til koblingsnøkkeldokumentet, og innlogging i dokumentet krever to faktor-autentisering. Koblingsnøkkelen overføres deretter til tre USB-pinner og blir skrevet ut i papirform før den slettes fra datamaskinen. Koblingsnøkkelen og samtykkeskjemaene skal oppbevares atskilt fra datamaskinen på et annet egnet sted ved UiA, og kun stipendiaten og veileder skal ha tilgang til den.

Avidentifiserte spørreskjemadata i OneDrive/Azure Cloud vil være tilgjengelig for en prosjektgruppe ved OsloMet. Innlogging skjer kun via prosjektmedarbeidernes Feide-innlogging. Prosjektmedarbeiderne ved OsloMet vil ikke ha tilgang til koblingsnøkkelen.

Ifølge prosjektleder er det gjennomført en ROS-analyse (risikoanalyse) mht. informasjonssikkerheten i prosjektet. ROS-analysen er foretatt av sikkerhetsrådgiver og en senioringeniør ved IT-avdelingen på UiA, samt en seniorrådgiver ved forskningsadministrativ avdeling (personvernkontakt) ved UiA. NSD forutsetter at personopplysningene behandles i tråd med personvernforordningens krav og institusjonens retningslinjer for informasjonssikkerhet.

6. Databehandler

I følge meldingen skal SurveyXact benyttes som databehandler. NSD forutsetter at prosjektansvarlig avklarer bruk av databehandler med UiA, som har ansvar for at bruk av databehandler skjer i samsvar med personvernforordningen art. 28. UiA skal bl.a. foreta en risikovurdering og inngå skriftlig avtale med databehandleren før denne behandler personopplysninger.

7. Varighet

Ifølge meldeskjema skal personopplysninger behandles frem til 01.08.2032 Opplysninger som kan knyttes til en enkeltperson skal da slettes/anonymiseres. De registrerte vil ikke kunne identifiseres i publikasjoner.

Universitetet i Agder må kunne dokumentere at datamaterialet er anonymisert.
Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan bli identifisert. Det gjøres ved å:

- Slette navn, fødselsnummer/andre ID-nummer, adresse, telefonnummer, epostadresse, IP-adresse og andre nettidentifikatorer
- Slette eller grovkategorisere alder, bosted, arbeidssted, institusjon, diagnose, lokaliseringsdata og andre bakgrunnsopplysninger
- Slette eller sladde bilder/videopptak og lydopptak,

Universitetet i Agder må kunne dokumentere at datamaterialet er anonymisert.

Meld fra om endringer
Dersom behandlingen av personopplysninger endrer seg, kan det være nødvending å melde dette til NSD via Min side. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

Informasjon om behandlingen publiseres på Min side, Meldingsarkivet og nettsider
Alle relevante saksopplysninger og dokumenter er tilgjengelig:
- via Min side for forskere, veiledere og studenter
- via Meldingsarkivet for ansatte med internkontrolloppgaver ved (Institusjon).

NSD tar kontakt om status for behandling av personopplysninger
Etter avtale med Universitetet i Agder vil NSD følge opp behandlingen av personopplysninger underveis, og ved planlagt avslutning.

Vi sender da en skriftlig henvendelse til prosjektansvarlig og ber om skriftlig svar på status for behandling av personopplysninger.

Se våre nettsider eller ta kontakt ved spørsmål. Vi ønsker lykke til med behandlingen av personopplysninger.

Med vennlig hilsen,

Marianne Høgetveit Myhren
seksjonsleder

Pernille Ekornrud Grøndal

.....

Lovhenvisninger

NSDs vurdering er at den planlagte behandlingen av personopplysninger:
- er regulert av personopplysingsloven, jf. § 2.
- oppfyller prinsippene i personvernforordningen om:
  - lovlighet, rettferdighet og åpenhet jf. art. 5.1 a)
  - formålsbegrensning jf. art. 5.1 b)
  - dataminimering jf. art. 5.1 c)
  - lagringsbegrensning jf. art. 5.1 e)
- kan finne sted med hjemmel i personvernforordningen art. 9.2 a), jf. personopplysningsloven § 10
- gjennomføres på en måte som ivaretar de registrertes rettigheter personvernforordningen **art. 11-22**

NSD legger til grunn at institusjonen også sørger for at behandlingen gjennomføres i samsvar med personvernforordningen:
- art. 5.1 d) og art. 5.1. f) og art. 32 om sikkerhet
- art. 26-29 ved felles behandlingsansvar med andre institusjoner eller bruk av databehandler
- kapittel 5 ved overføring av personopplysninger til tredjeland/internasjonale organisasjoner

Appendix 9

Notification of change, NSD

Fra: Hilde Elisabeth Timenes Mikkelsen [mailto:hilde.e.mikkelsen@uia.no]
Sendt: 27. august 2018 14:30
Til: personverntjenester@nsd.no
Emne: SV: Melde endring

Hei
Etter avtale per telefon med rådgiver hos personvernombudet i dag, vil jeg herved informere litt mer utdypende om endring i vårt prosjekt med prosjektnummer 60981.

Da vi nå velger å benytte TSD til datalagring medfører dette at vi vil bruke Nettskjema til innhenting av data istedenfor SurveyXact (Rambøll AS) slik det tidligere ble redegjort for i vår søknad til dere. Nettskjema har en sikker overføring av data til TSD. Det vil bli underskrevet en egen databehandleravtale mellom UiA og TSD for vårt prosjekt. Det er IT-avdelingen samt forskningsadministrasjonen ved UiA som har anbefalt at vårt prosjekt benytter seg av denne dataløsningen.

Når vi bruker Nettskjema til innhenting av data vil vi også ha mulighet til å innhente elektronisk samtykke ved at respondenten logger på et Nettskjema med ID-porten for å få tilgang til å signere digitalt. Indirekte medfører dette at man innhenter fødselsnummer til respondentene. Vi ønsker derfor å melde ifra om at vi med den nye dataløsningen vil innhente fødselsnummer til foresatte og ungdom (respondentene) i vårt prosjekt. Dette vil også i større grad sikre at det er de samme respondentene vi følger over tid.

Vennligst ta kontakt ved spørsmål/uklarheter, dersom det er ønsket at denne endringen meldes inn på en annen måte eller dersom dere har innvendinger til vår endring.
Jeg ber også om en bekreftelse på at mailen er mottatt og registrert vedrørende vårt prosjekt.

Vennlig hilsen
Hilde E. Timenes Mikkelsen
Stipendiat
Institutt for helse og sykepleievitenskap

Tlf: 38141316/41107112
hilde.e.mikkelsen@uia.no

UNIVERSITETET I AGDER
FAKULTET FOR HELSE- OG IDRETTSVITENSKAP

Fra: Pernille Ekornrud Grøndal <Pernille.Grondal@nsd.no>
Sendt: mandag 27. august 2018 16:07
Til: Hilde Elisabeth Timenes Mikkelsen <hilde.e.mikkelsen@uia.no>
Kopi: postmottak@nsd.no
Emne: SV: Melde endring

Hei Hilde,

Vi tar endringen til etterretning. Det er ikke nødvendig å sende inn endringsmelding eller lignende.

Vennlig hilsen,

Pernille Ekornrud Grøndal
rådgiver | Adviser
Seksjon for personverntjenester | Data Protection Services
T: (+47) 55 58 36 41

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data
Harald Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
postmottak@nsd.no www.nsd.no

Appendix 10

Questionnaire adolescents time 1

Demografiske data Ungdom

1. Er du gutt eller jente?
   - Gutt
   - Jente

2. Hvor gammel er du?
   _____år

3. Hvor høy er du?
   _____cm

4. Hva er din nåværende vekt?
   _____kg

5. Hvilke voksne bor du sammen med nå?

   - Jeg bor sammen med begge foreldrene mine
   - Jeg veksler mellom å bo hos mor og far
   - Jeg bor sammen med den ene av foreldre mine og en stemor/stefar
   - Jeg bor kun sammen med den ene av foreldrene mine
   - Annet _____
     → (oppfølgingsspørsmål)
     Hvis Annet, beskriv hvem du bor sammen med: _____

6. Mine foreldre er
   - Gift eller samboere
   - Ugift
   - Skilt eller separert
   - En eller begge er døde

7. Hvor er foreldrene dine født?
   - Begge er født i Norge
   - Den ene er født i Norge, den andre er født i et annet land
   - Begge er født i et annet land enn Norge

   → (oppfølgingsspørsmål)
   Hvilket land er mor født i? _____
   Hvilket land er far født i? _____

8. Hvor mange søsken har du?
   - Ingen
   - 1
   - 2
   - 3
   - 4
   - 5
   - Mer enn 5

9. Har du flyttet i løpet av de siste 5 årene?
    - Nei
    - Ja, en gang
    - Ja, 2-4 ganger
    - Ja, 5 ganger eller mer

10. Er foreldrene dine i arbeid nå?
    - Ja, begge
    - Ja, én av dem
    - Nei, ingen

    ➔ Er far i jobb nå? (oppfølgingsspørsmål)
        - Ja, heltid
        - Ja, deltid
        - Nei

    ➔ Er mor i jobb nå? (oppfølgingsspørsmål)
        - Ja, heltid
        - Ja, deltid
        - Nei

11. Har du hatt fravær fra skolen i løpet av de siste tre månedene?
    - Ingen fravær
    - 1-4 dager
    - 5-7 dager
    - 8-10 dager
    - Mer enn 10 dager

    ➔ Hva er årsak til fraværet? (oppfølgingsspørsmål)
        - Sykdom
        - Diffuse helseplager (eks. smerte, føler seg sliten)
        - Skulk
        - Skolevegring (fravær på grunn av et emosjonelt/følelsesmessig ubehag)
        - Annet_____
          → (oppfølgingsspørsmål)
          Hvis Annet, beskriv hva som er årsak til fraværet:_____

KIDSCREEN 27

Fysisk aktivitet og helse

1. **Til vanlig, hvordan vil du si at helsen din er**?

- ○ Utmerket
- ○ Veldig bra
- ○ Bra
- ○ Ganske bra
- ○ Dårlig

Når du tenker på den siste uka...

		Ikke I det hele tatt	Litt	Ganske	Veldig	I høy grad
2.	Har du følt deg frisk og sprek?	○	○	○	○	○
3.	Har du vært fysisk aktiv (for eksempel løpt, klatret, syklet)?	○	○	○	○	○
4.	Har du kunne løpe bra?	○	○	○	○	○

Når du tenker på den siste uka...

		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
5.	Har du følt deg full av energi?	○	○	○	○	○

2. Om deg selv, humør og følelser

Når du tenker på den siste uka…

		Ikke I det hele tatt	Litt	ganske	veldig	I høy grad
1.	Har livet ditt vært bra?	○	○	○	○	○

Når du tenker på den siste uka…

		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
2.	Har du vært i godt humør?	○	○	○	○	○
3.	Har du hatt det gøy?	○	○	○	○	○

	Når du tenker på den siste uka…	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
4.	Har du følt deg trist?	○	○	○	○	○
5.	Har du følt deg så ille/elendig at du ikke har villet gjøre noe?	○	○	○	○	○
6.	Har du følt deg ensom?	○	○	○	○	○
7.	Har du vært fornøyd med deg selv slik du er?	○	○	○	○	○

3. Familie og fritid

	Når du tenker på den siste uka…	never	seldom	quite often	very often	always
1.	Har du hatt nok tid for deg selv?	○	○	○	○	○
2.	Har du kunnet gjøre de tingene du ønsker i fritiden din?	○	○	○	○	○
3.	Har moren/faren din hatt nok tid til deg?	○	○	○	○	○
4.	Har moren/faren din behandlet deg rettferdig?	○	○	○	○	○
5.	Har du kunnet snakke med moren/faren din når du har lyst?	○	○	○	○	○
6.	Har du hatt nok penger til å gjøre de samme tingene som vennene dine?	○	○	○	○	○
7.	Har du hatt nok penger til utgiftene dine?	○	○	○	○	○

4. Venner

Når du tenker på den siste uka…

		never	seldom	quite often	very often	always
1.	Har du vært sammen med vennene dine?	○	○	○	○	○
2.	Har du hatt det gøy sammen med vennene dine?	○	○	○	○	○
3.	Har du og vennene dine hjulpet hverandre?	○	○	○	○	○
4.	Har du kunnet stole på vennene dine?	○	○	○	○	○

5. Skole og læring

Når du tenker på den siste uka…

		Ikke I det hele tatt	Litt	Ganske	Veldig	I høy grad
1.	Har du vært glad på skolen?	○	○	○	○	○
2.	Har du klart deg bra på skolen?	○	○	○	○	○

Når du tenker på den siste uka…..

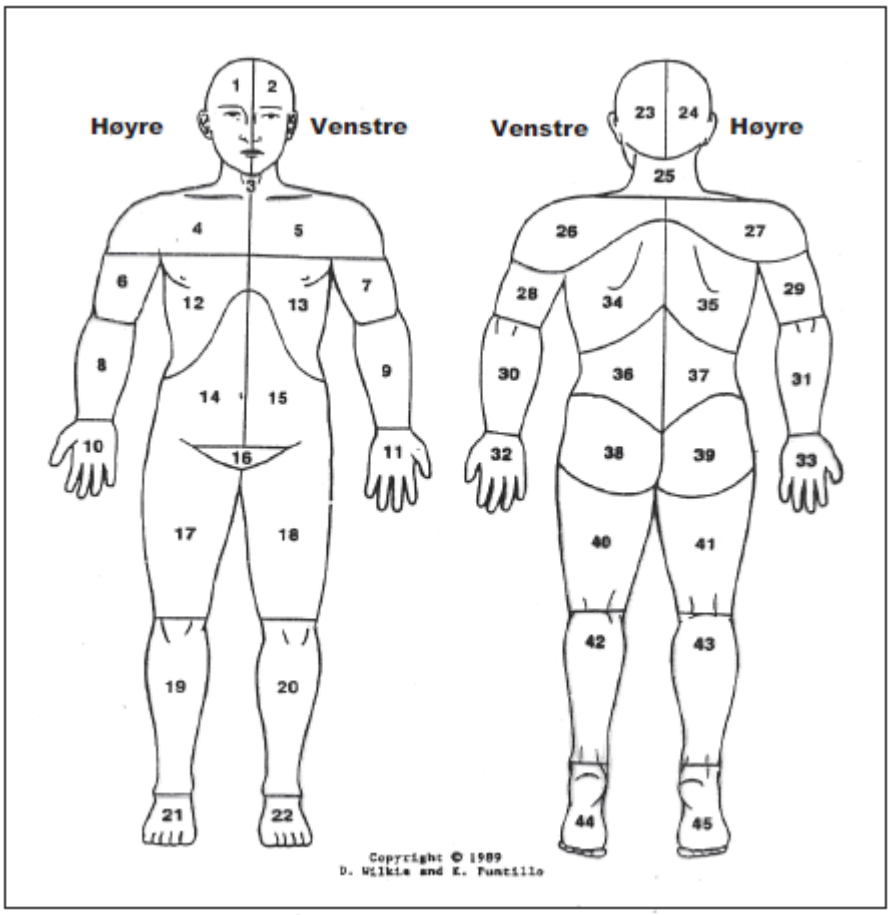
		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
3.	Har du klart å følge med på skolen?	○	○	○	○	○
4.	Har du kommet godt ut av det med lærerne dine?	○	○	○	○	○

Brief Pain Inventory (BPI)

1.	Gjennom livet har de fleste av oss hatt smerter fra tid til annen (som lett hodepine, forstuelser eller tannpine). Har du i dag hatt smerter av et annet slag enn slike dagligdagse smerter?

1. Ja 2. Nei

2.	Vil du skravere de områdene på kroppen hvor du har smerter. Marker med et kryss der du har mest vondt.



3.	Vennligst sett en ring rundt det tallet som best beskriver de sterkeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

4.	Vennligst sett en ring rundt det tallet som best beskriver de svakeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

5. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har i gjennomsnitt.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

6. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har akkurat nå.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

7. Hvilken behandling eller medisiner får du for å lindre smertene dine?

---

8. I hvor stor grad har behandling eller medisiner lindret smertene dine den siste uka? Vennligst sett en ring rundt det prosenttallet som best viser hvor stor smertelindring du har fått.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Ingen lindring										Fullstendig lindring

9. Sett en ring rundt det tallet som for den siste uka best beskriver hvor mye smertene har virket inn på:

A. Daglig aktivitet

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

B. Humør

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

C. Evne til å gå

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

D. Vanlig arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

E. Forhold til andre mennesker

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

F. Søvn

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

G. Livsglede

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

The Lübeck Pain-Screening questionnaire (LPQ) (utvalgte spørsmål)

4. **Hvor lenge har du hatt vondt på denne måten?**

Bare en gang.	○	Mer enn 3 måneder	○
Mindre enn en måned	○	Mer enn 6 måneder	○
Mellom 1 og 3 måneder	○	Mer enn 12 måneder	○

5 **Hvor ofte har du hatt denne smerten (hatt vondt på denne måten) de tre siste månedene?**

Mindre enn èn gang i måneden	○	1 gang i uka	○
1 gang i måneden	○	Flere ganger i uka	○
2-3 ganger i måneden	○	Hver dag	○

8 **Hva tror du selv er årsaken til disse smertene (grunnen til at du har vondt)?**

Værskifte	○	Bråk/høy musikk	○
Irritasjon/krangling	○	Familiesituasjonen	○
Skolesituasjonen	○	Skjermtid (TV/nettbrett/PC/mobil)	○
Opphisselse	○	Skolearbeidet	○
Tristhet	○	Ikke noe spesielt	○
For lite søvn	○	En ny situasjon	○
Forkjølelse	○	Fysisk anstrengelse/ sport	○
Sosiale media	○	Mat/søtsaker	○
Ensomhet/følte meg alene	○	For jenter: *Menstruasjon*	○
Vet ikke	○	Annet_____	○

9 **Når fikk du disse smertene for første gang?**

Etter en skade/ et uhell	○	Etter å ha byttet skole	(
Etter en medisinsk behandling/operasjon	○	Etter skilsmisse/separasjon hos foreldre	(
Etter et dødsfall I familien	○	Hos jenter: I forbindelse med menstruasjon	(
Etter en flytting	○	Vet ikke	(
Etter en sykdom/i forbindelse med en sykdom	○	Etter noe annet	(
Etter fysisk anstrengelse/sport	○	_____ *(hva?)*	

10. **Finnes det en årsak og/eller medisinsk diagnose til smertene dine?**

Nei ○ Vet ikke ○ Ja ○ _____ *(hvilken?)*

11. **Har du en eller flere kroniske sykdommer?** for eksempel diabetes, astma)

12. **Er det noen i familien din som har ofte smerter, eller alltid smerter?**

'Nei ○ Vet ikke ○ Ja ○ _____ *(hvem?)*

Spørsmål vedrørende bruk av smertestillende

(hentet fra «Smerte, ungdom og selvmedisinering (SUS)» studien)

(Utvalgte spørsmål)

Smertetilstander:

4.0 Har du eller har du hatt noen av de nevnte plager i løpet av siste 4 uker?
(*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Tannreguleringssmerter
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____

Ingen

Bruker du eller har du brukt smertestillende medisin (for eksempel Paracet eller Ibux) i løpet av siste 4 uker?

Ja □

Nei ☐

Bruk av smertestillende:

5.0 Bruker du eller har du brukt smertestillende medisin for noen av de nevnte plagene i løpet av siste 4 uker? (*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett til moderat hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Tannreguleringssmerter
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____

Mengde smertestillende medisin:

6.0 Hvis du har tatt smertestillende siste 4 uker, hvor ofte har du da tatt slik medisin? (*sett bare ett kryss*)

- ☐ Daglig
- ☐ Hver uke, men ikke daglig
- ☐ Sjeldnere enn hver uke
- ☐ Ikke tatt siste 4 uker

Tilgang på smertestillende og informasjon

17.0 Tilgang på reseptfri smertestillende medisin: (*sett ingen, ett eller flere kryss*)

- ☐ Jeg har smertestillende hjemme som jeg kan ta selv
- ☐ Jeg får smertestillende hjemme hvis jeg spør en av de voksne
- ☐ Vi har ikke smertestillende hjemme
- ☐ Jeg har fått smertestillende av en venn eller venninne
- ☐ Jeg har fått smertestillende av idretts trener
- ☐ Jeg har kjøpt smertestillende til meg selv på apotek
- ☐ Jeg har kjøpt smertestillende til meg selv på bensinstasjon, i matbutikken
- ☐ Jeg passer på å ha smertestillende med meg (i lommebok, veske, skolesekk)

18.0 Hvor har du fått informasjon om bruk av smertestillende?
(*sett ett eller flere kryss*)

- ☐ Av mor, far eller annen voksen hjemme
- ☐ Av søsken
- ☐ Av apotekpersonalet
- ☐ Ved å lese pakningsvedlegget
- ☐ Av venner/venninner
- ☐ Ved informasjonsprogram på TV
- ☐ Ved reklame på TV eller i blader
- ☐ Av lærer
- ☐ Av helsesøster
- ☐ Av lege
- ☐ Av idretts trener
- ☐ Annet, spesifiser: _____
- ☐ Ingen informasjon

19.0 Hvis du forteller at du har smerter, hva anbefaler dine foreldre?
(*sett bare ett kryss*)

- ☐ At du tar smertestillende medikamenter
- ☐ At du venter og håper at det går over
- ☐ At du hviler deg
- ☐ Annet, spesifiser: _____

20.0 Hvis du bruker smertestillende medisiner
(*sett bare ett kryss*)

- ☐ Forteller du det ikke til andre
- ☐ Forteller du det kun til dine foreldre
- ☐ Forteller du det kun til dine nærmeste venner
- ☐ Bruker du smertestillende medisiner åpenlyst

22.0 Hva er ditt syn på bruk av smertestillende medisiner?
(*sett bare ett kryss*)

- ☐ Bør brukes ved opplevelse av smerter
- ☐ Bør brukes i situasjoner hvor smerte kan oppstå
- ☐ Et middel som ikke bør brukes

General Self-efficacy

Sett kryss for de utsagnene som passer best for deg:

	Helt galt	Nokså galt	Nokså riktig	Helt riktig
Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil	☐	☐	☐	☐
Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte	☐	☐	☐	☐
Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det	☐	☐	☐	☐
Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min	☐	☐	☐	☐
Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det	☐	☐	☐	☐
Hvis jeg er i knipe, så finner jeg vanligvis en vei ut	☐	☐	☐	☐
Samme hva som hender så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

Søvnspørsmål for ungdom

(Spørsmålene er tilpasset fra School Sleep Habits Survey)

1. Når går du vanligvis til sengs på skoledager/hverdager?
   Svar med ett tidspunkt i hele 24 timer – slik at 10 om kvelden angis som kl. 22.00.
   Klokken: _____

2. Når våkner du vanligvis opp på skoledager/hverdager?
   Klokken: _____

3. Når går du vanligvis til sengs i helgene?
   Svar med ett tidspunkt i hele 24 timer – slik at 10 om kvelden angis som kl. 22.00.
   Klokken: _____

4. Når våkner du vanligvis opp i helgene?
   Klokken: _____

5. Noen personer våkner opp om natten. Andre gjør det aldri. Hvor mange ganger våkner du vanligvis opp om natten?
   - Aldri
   - En gang
   - 2 eller 3 ganger
   - Mer enn 3 ganger
   - Vet ikke

6. Noen mennesker føler seg søvnige om dagen. Når du holder på med aktiviteter om dagen, hvor stort problem har du da med søvnighet (føle seg søvnig, vanskelig å holde seg våken)?
   - Ikke noen problem i det hele tatt
   - Et lite problem
   - Mer enn et lite problem
   - Et stort problem
   - Et veldig stort problem

7.Hvor ofte får du nok søvn?

   - Alltid
   - Vanligvis
   - Av og til
   - Sjelden
   - Aldri

Revised UCLA Loneliness scale (ULS-8)

De neste setningene beskriver hvordan man noen ganger har det.

Kryss av for hvor ofte du har det slik som det beskrives i setningene nedenfor.
Sett ett kryss for hver setning.

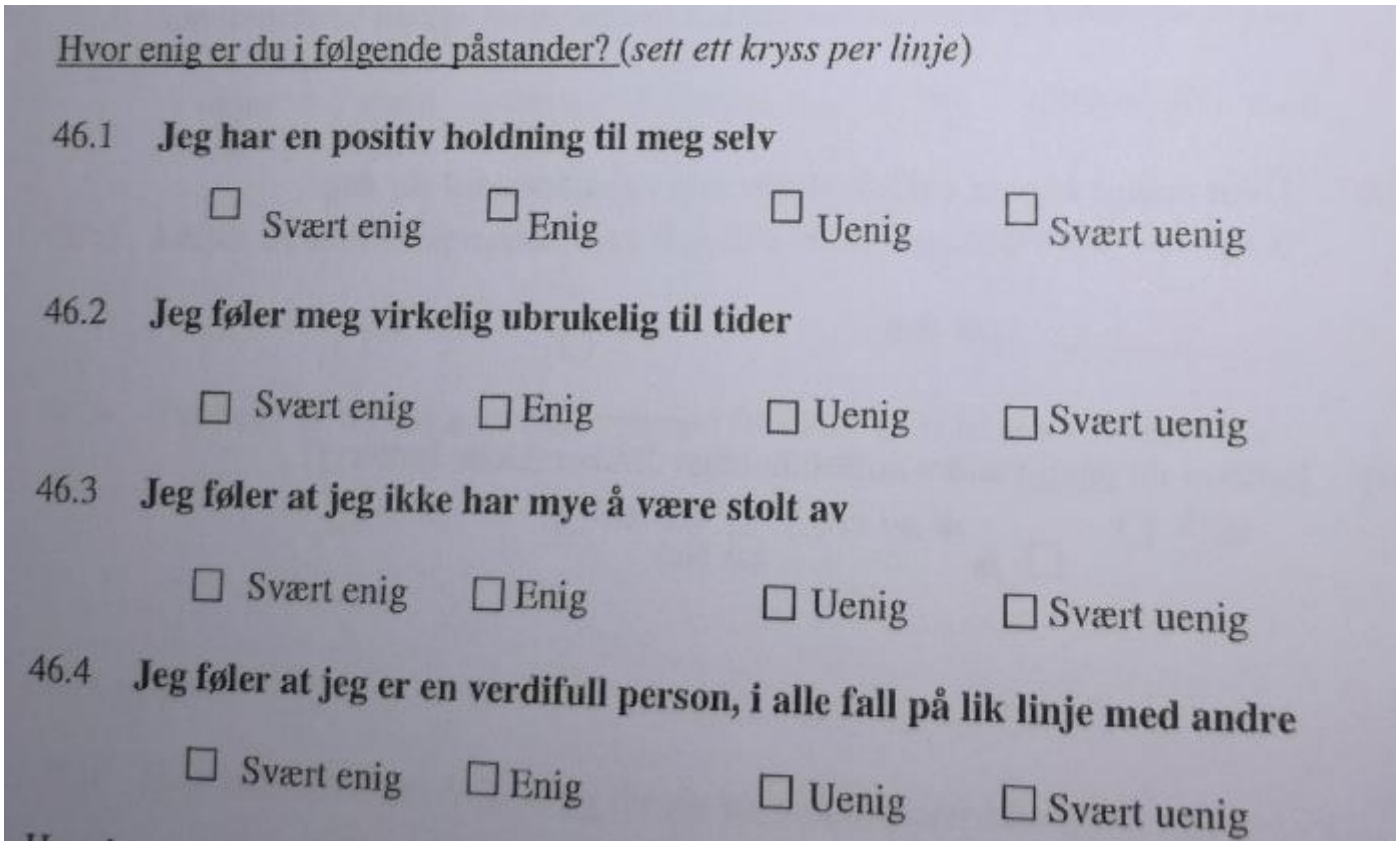
	Setning	Aldri	Sjeldent	Noen ganger	Ofte
1.	Jeg mangler noen (venner) å være sammen med	1	2	3	4
2.	Det er ingen jeg kan snakke med	1	2	3	4
3.	Jeg er en sosial / utadvendt person	1	2	3	4
4.	Jeg føler meg utenfor	1	2	3	4
5.	Jeg føler meg isolert fra andre	1	2	3	4
6.	Jeg kan finne noen (venner) å være sammen med når jeg ønsker det	1	2	3	4
7.	Når jeg er alene, synes jeg det er leit	1	2	3	4
8.	Folk er rundt meg, men ikke sammen med meg	1	2	3	4

Perceived Stress Questionaire (PSQ)

Sett ring rundt tallet som beskriver hvordan det er eller har vært for deg *den siste måneden*. Gjør dette raskt uten å sjekke svarene nøye og merk at det skal gjelde *den siste måneden*.

	Nesten aldri	Av og til	Ofte	Vanligvis
1. Du føler deg uthvilt	1	2	3	4
2. Du føler at du får for mange krav stilt til deg	1	2	3	4
3. Du er irritabel og gretten	1	2	3	4
4. Du har for mye å gjøre	1	2	3	4
5. Du føler deg ensom og isolert	1	2	3	4
6. Du opplever å være i konfliktsituasjoner	1	2	3	4
7. Du føler at du gjør ting som du virkelig liker	1	2	3	4
8. Du kjenner deg trøtt	1	2	3	4
9. Du frykter at du kanskje ikke klarer å nå målene dine	1	2	3	4
10. Du føler deg rolig	1	2	3	4
11. Du har for mange avgjørelser å ta	1	2	3	4
12. Du føler deg frustrert	1	2	3	4
13. Du er full av energi	1	2	3	4
14. Du føler deg anspent	1	2	3	4
15. Problemene dine virker til å hope seg opp	1	2	3	4
16. Du føler at du har det travelt	1	2	3	4
17. Du føler deg trygg og beskyttet	1	2	3	4
18. Du har mange bekymringer	1	2	3	4
19. Du er under press fra andre mennesker	1	2	3	4
20. Du føler deg motløs	1	2	3	4
21. Du har det hyggelig	1	2	3	4
22. Du er redd for fremtiden	1	2	3	4
23. Du føler at du gjør ting fordi du må, ikke fordi du vil	1	2	3	4
24. Du føler deg kritisert eller bedømt	1	2	3	4
25. Du er munter	1	2	3	4
26. Du føler deg mentalt utmattet	1	2	3	4
27. Du har problemer med å slappe av	1	2	3	4
28. Du føler deg tynget av ansvar	1	2	3	4
29. Du har nok tid til deg selv	1	2	3	4
30. Du føler deg presset av tidsfrister	1	2	3	4

Rosenberg self-esteem scale (RSES)



Hvor enig er du i følgende påstander? (*sett ett kryss per linje*)

46.1 **Jeg har en positiv holdning til meg selv**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.2 **Jeg føler meg virkelig ubrukelig til tider**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.3 **Jeg føler at jeg ikke har mye å være stolt av**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.4 **Jeg føler at jeg er en verdifull person, i alle fall på lik linje med andre**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

Appendix 11

Questionnaire parents time 1

Demografiske data foreldre

1. Er du mann eller kvinne?
   - Mann
   - Kvinne

2. Hvem fyller ut spørreskjemaet?
   - Mor
   - Far
   - Stemor/fars partner
   - Stefar/mors partner
   - Andre _____

3. Hvor gammel er du?
   _____år

4. Hvor høy er du?
   _____cm

5. Hva er din nåværende vekt?
   _____kg

6. Hva er din sivilstand?
   - Gift eller samboer
   - Enslig
   - Skilt eller separert
   - Enke/enkemann

7. Hvor lenge har du bodd der du bor nå?
   _____år

8. Har du flyttet i løpet av de siste 5 årene?
   - Nei
   - Ja, en gang
   - Ja, 2-4 ganger
   - Ja, 5 ganger eller mer

9. Hvilken utdanning er den høyeste du har du fullført?
   (sett ett kryss)
   - Grunnskole nivå (barne- og ungdomsskole, framhaldsskole, folkehøyskole)
   - 1-2 årig videregående skole
   - 3 år i videregående skole
   - Fagbrev eller svennebrev
   - Høyskole/universitet, mindre enn 4 år
   - Høyskole/universitet, 4 år eller mer

10. Er du i arbeid nå?
    - Ja, fulltid
    - Ja, deltid
    - Nei, jeg er ikke i arbeid

    ➔ Hvis du ikke er i heltids arbeid, er det på grunn av: (oppfølgingsspørsmål)
    - Studier
    - Ønsker selv å jobbe redusert/ikke være i arbeid
    - Svangerskaps-/fødselspermisjon
    - Arbeidsløshet, permittering
    - Uføretrygd/Delvis uføretrygd
    - Sykemelding
    - Alderspensjon
    - Annet_____

11. Har du hatt fravær fra jobb i løpet av de siste tre månedene?
    - Ingen fravær
    - 1-4 dager
    - 5-7 dager
    - 8-10 dager
    - Mer enn 10 dager

    ➔ Hva er årsak til fraværet? (oppfølgingsspørsmål)
    - Sykdom
    - Diffuse helseplager (eks. smerte, føler seg sliten)
    - Arbeidsmiljø (fravær på grunn av et emosjonelt/følelsesmessig ubehag)
    - Annet_____

12. Hva er din husstands samlede inntekt siste år (brutto-inntekt)?
    Ta med alle inntekter fra arbeid, trygder, sosialhjelp og lignende. (Sett ett kryss)
    - Under 250.000kr
    - 250.000kr – 450.000kr
    - 451.000kr – 750.000kr
    - 751.000kr – 1.000.000kr
    - Over 1.000.000kr

RAND 36

RAND-36 Din helse

Spørsmålene under handler om hvordan du oppfatter helsen din. Disse opplysningene vil hjelpe oss til å forstå hvordan du føler deg og hvor godt du er i stand til å utføre dine vanlige aktiviteter.

Hvert spørsmål skal besvares ved å sette et kryss (X) i den boksen som passer best for deg.

1. Stort sett, vil du si at helsen din er:

Utmerket	Veldig god	God	Nokså god	Dårlig
☐	☐	☐	☐	☐

2. Sammenlignet med for ett år siden, hvordan vil du si at helsen din stort sett er nå?

Mye bedre nå enn for ett år siden	Litt bedre nå enn for ett år siden	Omtrent som for ett år siden	Litt dårligere nå enn for ett år siden	Mye dårligere nå enn for ett år siden
☐	☐	☐	☐	☐

3. De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er helsen din slik at den begrenser deg i utførelsen av disse aktivitetene nå? Hvis ja, hvor mye? [Kryss (X) en boks på hver linje.]

		Ja, begrenser meg mye	Ja, begrenser meg litt	Nei, begrenser meg ikke i det hele tatt
a	**Anstrengende aktiviteter** som å løpe, løfte tunge gjenstander, delta i anstrengende idrett	☐	☐	☐
b	**Moderate aktiviteter** som å flytte et bord, støvsuge, gå en spasertur eller drive med hagearbeid	☐	☐	☐
c	Løfte eller bære poser med dagligvarer	☐	☐	☐
d	Gå opp trappen **flere** etasjer	☐	☐	☐
e	Gå opp trappen **én** etasje	☐	☐	☐
f	Bøye deg eller gå ned på kne	☐	☐	☐
g	Gå **mer enn to kilometer**	☐	☐	☐
h	Gå **flere hundre meter**	☐	☐	☐
i	Gå **hundre meter**	☐	☐	☐
j	Dusje eller kle på deg	☐	☐	☐

4. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av din fysiske helse?**

		Ja	Nei
a	Kuttet ned på **hvor mye tid** du brukte på arbeid eller andre aktiviteter	☐	☐
b	**Fått gjort mindre** enn du ønsket	☐	☐
c	Vært begrenset i type **arbeidsoppgaver** eller andre aktiviteter	☐	☐
d	Hatt **problemer** med å utføre arbeidet eller andre aktiviteter (for eksempel at det krevde en ekstra innsats av deg)	☐	☐

5. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av følelsesmessige problemer (som å føle seg engstelig eller deprimert)?**

		Ja	Nei
a	Kuttet ned på **hvor mye tid** du brukte på arbeid eller andre aktiviteter	☐	☐
b	**Fått gjort mindre** enn du ønsket	☐	☐
c	Utført arbeid eller andre aktiviteter **mindre grundig** enn vanlig	☐	☐

6. **I løpet av de siste fire ukene, i hvilken grad har den fysiske helsen din eller følelsesmessige problemer påvirket dine vanlige sosiale aktiviteter med familie, venner, naboer eller andre grupper mennesker?**

Ikke i det hele tatt	Litt	Moderat	Ganske mye	Ekstremt mye
☐	☐	☐	☐	☐

7. **Hvor mye kroppslige smerter har du hatt i løpet av de siste fire ukene?**

Ingen	Veldig svake	Svake	Moderate	Sterke	Veldig sterke
☐	☐	☐	☐	☐	☐

8. **I løpet av de siste fire ukene, hvor mye har smerter påvirket det vanlige arbeidet ditt (gjelder både arbeid utenfor hjemmet og husarbeid)?**

Ikke i det hele tatt	Litt	Moderat	Ganske mye	Ekstremt mye
☐	☐	☐	☐	☐

9. **De neste spørsmålene handler om hvordan du føler deg og hvordan du har hatt det i løpet av de siste fire ukene. For hvert spørsmål, ber vi deg velge det svaret som best beskriver hvordan du har følt deg.**

Hvor ofte i løpet av de siste fire ukene:

		Hele tiden	Mesteparten av tiden	En god del av tiden	Noe av tiden	Litt av tiden	Aldri
a	Har du følt deg full av liv?	☐	☐	☐	☐	☐	☐
b	Har du vært veldig nervøs?	☐	☐	☐	☐	☐	☐
c	Har du følt deg så langt nede at ingenting kunne gjøre deg glad?	☐	☐	☐	☐	☐	☐
d	Har du følt deg rolig og avslappet?	☐	☐	☐	☐	☐	☐
e	Har du hatt mye overskudd?	☐	☐	☐	☐	☐	☐
f	Har du følt deg nedfor og deprimert?	☐	☐	☐	☐	☐	☐
g	Har du følt deg utslitt	☐	☐	☐	☐	☐	☐
h	Har du følt deg glad?	☐	☐	☐	☐	☐	☐
i	Har du følt deg sliten?	☐	☐	☐	☐	☐	☐

10. **I løpet av de siste fire ukene, hvor mye av tiden har den fysiske helsen din eller følelsesmessige problemer påvirket dine sosiale aktiviteter (som å besøke venner, slektninger osv.)?**

Hele tiden	Mesteparten av tiden	En del av tiden	Litt av tiden	Aldri
☐	☐	☐	☐	☐

11. Hvor RIKTIG eller GAL er hver av de følgende påstandene for deg?

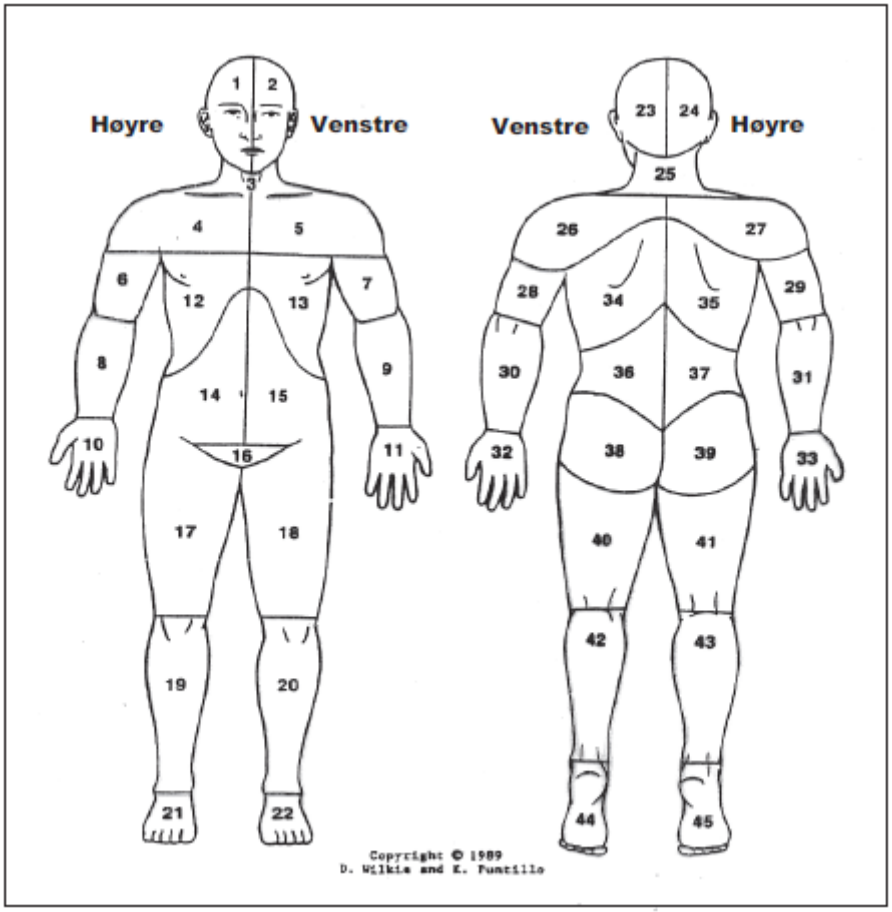
		Helt riktig	Stort sett riktig	Vet ikke	Stort sett galt	Helt galt
a	Det virker som om jeg blir syk litt lettere enn andre	☐	☐	☐	☐	☐
b	Jeg er like frisk som de fleste jeg kjenner	☐	☐	☐	☐	☐
c	Jeg regner med at helsen min blir dårligere	☐	☐	☐	☐	☐
d	Helsen min er utmerket	☐	☐	☐	☐	☐

Brief Pain Inventory (BPI)

1.	Gjennom livet har de fleste av oss hatt smerter fra tid til annen (som lett hodepine, forstuelser eller tannpine). Har du i dag hatt smerter av et annet slag enn slike dagligdagse smerter?

1. Ja 2. Nei

2.	Vil du skravere de områdene på kroppen hvor du har smerter. Marker med et kryss der du har mest vondt.



3.	Vennligst sett en ring rundt det tallet som best beskriver de sterkeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

4.	Vennligst sett en ring rundt det tallet som best beskriver de svakeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

5. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har i gjennomsnitt.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

6. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har akkurat nå.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

7. Hvilken behandling eller medisiner får du for å lindre smertene dine?

---

8. I hvor stor grad har behandling eller medisiner lindret smertene dine den siste uka? Vennligst sett en ring rundt det prosenttallet som best viser hvor stor smertelindring du har fått.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Ingen lindring										Fullstendig lindring

9. Sett en ring rundt det tallet som for den siste uka best beskriver hvor mye smertene har virket inn på:

A. Daglig aktivitet

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

B. Humør

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

C. Evne til å gå

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

D. Vanlig arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

E. Forhold til andre mennesker

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

F. Søvn

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

G. Livsglede

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

The Lübeck Pain-Screening questionnaire (LPQ) (utvalgte spørsmål)

4. **Hvor lenge har du hatt vondt på denne måten?**

Bare en gang.	○	Mer enn 3 måneder	○
Mindre enn en måned	○	Mer enn 6 måneder	○
Mellom 1 og 3 måneder	○	Mer enn 12 måneder	○

5 **Hvor ofte har du hatt denne smerten (hatt vondt på denne måten) de tre siste månedene?**

Mindre enn èn gang i måneden	○	1 gang i uka	○
1 gang i måneden	○	Flere ganger i uka	○
2-3 ganger I måneden	○	Hver dag	○

8 **Hva tror du selv er årsaken til disse smertene (grunnen til at du har vondt)?**

Værskifte	○	Bråk/høy musikk	○
Irritasjon/krangling	○	Familiesituasjonen	○
Arbeidsmiljø	○	Skjermtid (TV/nettbrett/PC/mobil)	○
Opphisselse	○	Arbeidsmengde på jobb	○
Tristhet	○	Ikke noe spesielt	○
For lite søvn	○	En ny situasjon	○
Forkjølelse	○	Fysisk anstrengelse/ sport	○
Sosiale media	○	Mat/søtsaker	○
Ensomhet/følte meg alene	○	For kvinner: menstruasjon	○
Vet ikke	○	Annet_____	○

9 **Når fikk du disse smertene for første gang?**

Etter en skade/ et uhell	○	Etter å ha byttet jobb	(
Etter en medisinsk behandling/operasjon	○	Etter samlivsbrudd	(
Etter et dødsfall I familien	○	Hos kvinner: i forbindelse med menstruasjon	(
Etter en flytting	○	Vet ikke	(
Etter en sykdom/i forbindelse med en sykdom	○	Etter noe annet	(
Etter fysisk anstrengelse/sport	○	_____ (hva?)	

10. **Finnes det en årsak og/eller medisinsk diagnose til smertene dine?**

Nei ○ Vet ikke ○ Ja ○ _____ (hvilken?)

11. **Har du en eller flere kroniske sykdommer?** for eksempel diabetes, astma)

12. **Er det noen i familien din som har ofte smerter, eller alltid smerter?**

'Nei ○ Vet ikke ○ Ja ○ _____ (hvem?)

Spørsmål vedrørende bruk av smertestillende

(hentet fra «Smerte, ungdom og selvmedisinering (SUS)» studien)

(Utvalgte spørsmål. Spørsmålene er tilpasset voksne)

Smertetilstander:

4.0 Har du eller har du hatt noen av de nevnte plager i løpet av siste 4 uker?
(*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____
- ☐ Ingen

Bruker du eller har du brukt smertestillende medisin (for eksempel Paracet eller Ibux) i løpet av siste 4 uker?

Ja ☐

Nei ☐

Bruk av smertestillende:

5.0 Bruker du eller har du brukt smertestillende medisin for noen av de nevnte plagene i løpet av siste 4 uker? (*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett til moderat hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Magesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____
- ☐ Ingen

Mengde smertestillende medisin:

6.0 Hvis du har tatt smertestillende siste 4 uker, hvor ofte har du da tatt slik medisin? (*sett bare ett kryss*)

- ☐ Daglig
- ☐ Hver uke, men ikke daglig
- ☐ Sjeldnere enn hver uke
- ☐ Ikke tatt siste 4 uker

Tilgang på smertestillende og informasjon

17.0 Tilgang på reseptfri smertestillende medisin: (*sett ingen, ett eller flere kryss*)

☐ Jeg har smertestillende hjemme

☐ Jeg har ikke smertestillende hjemme

☐ Jeg har fått smertestillende av en venn eller venninne

☐ Jeg har kjøpt smertestillende på apotek

☐ Jeg har kjøpt smertestillende på bensinstasjon, i matbutikken

☐ Jeg passer på å ha smertestillende med meg (i lommebok, veske, sekk)

18.0 Hvor har du fått informasjon om bruk av smertestillende?
(*sett ett eller flere kryss*)

☐ Av familie

☐ Av apotekpersonalet

☐ Ved å lese pakningsvedlegget

☐ Av venner/venninner

☐ Ved informasjonsprogram på TV

☐ Ved reklame på TV eller i blader

☐ Av lege

☐ Annet, spesifiser: _____

☐ Ingen informasjon

19.0 Hvis ditt barn forteller at han/hun har smerter, hva anbefaler du?
(*sett bare ett kryss*)

- ☐ At han/hun tar smertestillende medikamenter
- ☐ At han/hun venter og håper at det går over
- ☐ At han/hun hviler seg
- ☐ Annet, spesifiser: _____

20.0 Hvis du bruker smertestillende medisiner
(*sett bare ett kryss*)

- ☐ Forteller du det ikke til andre
- ☐ Forteller du det kun til din partner
- ☐ Forteller du det kun til dine nærmeste venner
- ☐ Bruker du smertestillende medisiner åpenlyst

22.0 Hva er ditt syn på bruk av smertestillende medisiner?
(*sett bare ett kryss*)

- ☐ Bør brukes ved opplevelse av smerter
- ☐ Bør brukes i situasjoner hvor smerte kan oppstå
- ☐ Et middel som ikke bør brukes

General Self-efficacy

Sett kryss for de utsagnene som passer best for deg:

	Helt galt	Nokså galt	Nokså riktig	Helt riktig
Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil	☐	☐	☐	☐
Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte	☐	☐	☐	☐
Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det	☐	☐	☐	☐
Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min	☐	☐	☐	☐
Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det	☐	☐	☐	☐
Hvis jeg er i knipe, så finner jeg vanligvis en vei ut	☐	☐	☐	☐
Samme hva som hender så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

Pittsburgh Sleep Quality Index (PSQI)

Instruksjoner: Følgende spørsmål har med ditt vanlige søvnmønster *den siste måneden* å gjøre. Du skal svare på hva som er mest riktig for *de fleste* dager og netter den siste måneden. Vennligst svar på alle spørsmål.

1. I løpet av den siste måneden, når har du vanligvis lagt deg om kvelden?
   VANLIG LEGGETID_____
2. I løpet av den siste måneden, hvor lang tid (i minutter) har det vanligvis tatt deg å sovne om kvelden?
   ANTALL MINUTTER_____
3. I løpet av den siste måneden, når har du vanligvis stått opp om morgenen?
   VANLIGVIS STÅTT OPP KL_____
4. I løpet av den siste måneden, hvor mange timer søvn har du *faktisk* fått om natten? (Dette kan være forskjellig fra hvor mange timer du oppholdt deg i sengen.)
   ANTALL TIMER SØVN HVER NATT _____

For hvert av de følgende spørsmål, kryss av for det beste svar. Vennligst svar på *alle* spørsmålene.

5. I løpet av den siste måneden, hvor ofte har du hatt problemer med søvnen fordi du…

(a) Ikke klarer å sovne i løpet av 30 minutter

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(b) Våkner opp midt på natten eller tidlig om morgenen

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(c) Må opp for å gå på toalettet

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(d) Ikke klarer å puste ordentlig

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(e) Hoster eller snorker høyt

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(f) Føler deg for kald

Ikke i løpet av den s iste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(g) Føler deg for varm

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(h) Har vonde drømmer

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(i) Har smerter

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

(j) Andre grunner, vennligst beskriv_____

_____

Hvor ofte, i løpet av den siste måneden, har du hatt problemer med søvnen på grunn av dette

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

6. I løpet av den siste måneden, hvordan vil du bedømme søvnkvaliteten din totalt sett?
   - Veldig bra _____
   - Ganske bra _____
   - Ganske dårlig _____
   - Veldig dårlig _____

7. I løpet av den siste måneden, hvor ofte har du tatt medisin (med eller uten resept) som hjelp til å sove?

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

8. I løpet av den siste måneden, hvor ofte har du hatt problemer med å holde deg våken under bilkjøring, måltider eller når du holder på med sosiale aktiviteter?

Ikke i løpet av den siste måneden___	Mindre enn en gang i uken___	En eller to ganger i uken___	Tre eller flere ganger i uken___

9. I løpet av den siste måneden, hvor stort problem har det vært for deg å ha overskudd nok til å få ting gjort?
   - Ikke noe problem i det hele tatt _____
   - Bare et lite problem _____
   - Et visst problem _____
   - Et stort problem _____

Revised UCLA Loneliness scale (ULS-8)

De neste setningene beskriver hvordan man noen ganger har det.

Kryss av for hvor ofte du har det slik som det beskrives i setningene nedenfor.
Sett ett kryss for hver setning.

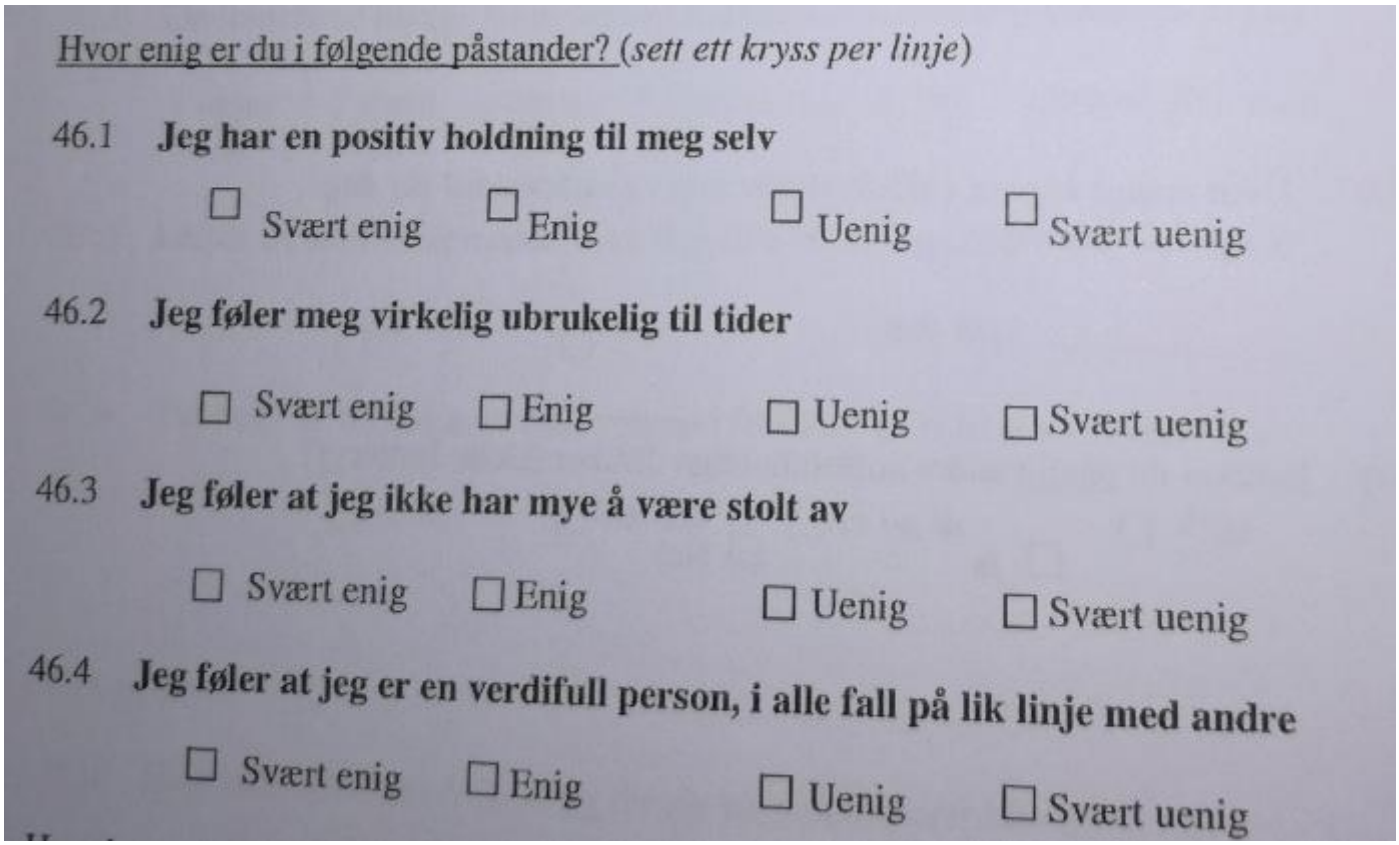
	Setning	Aldri	Sjeldent	Noen ganger	Ofte
1.	Jeg mangler noen (venner) å være sammen med	1	2	3	4
2.	Det er ingen jeg kan snakke med	1	2	3	4
3.	Jeg er en sosial / utadvendt person	1	2	3	4
4.	Jeg føler meg utenfor	1	2	3	4
5.	Jeg føler meg isolert fra andre	1	2	3	4
6.	Jeg kan finne noen (venner) å være sammen med når jeg ønsker det	1	2	3	4
7.	Når jeg er alene, synes jeg det er leit	1	2	3	4
8.	Folk er rundt meg, men ikke sammen med meg	1	2	3	4

Perceived Stress Questionaire (PSQ)

Sett ring rundt tallet som beskriver hvordan det er eller har vært for deg *den siste måneden*. Gjør dette raskt uten å sjekke svarene nøye og merk at det skal gjelde *den siste måneden*.

	Nesten aldri	Av og til	Ofte	Vanligvis
1. Du føler deg uthvilt	1	2	3	4
2. Du føler at du får for mange krav stilt til deg	1	2	3	4
3. Du er irritabel og gretten	1	2	3	4
4. Du har for mye å gjøre	1	2	3	4
5. Du føler deg ensom og isolert	1	2	3	4
6. Du opplever å være i konfliktsituasjoner	1	2	3	4
7. Du føler at du gjør ting som du virkelig liker	1	2	3	4
8. Du kjenner deg trøtt	1	2	3	4
9. Du frykter at du kanskje ikke klarer å nå målene dine	1	2	3	4
10. Du føler deg rolig	1	2	3	4
11. Du har for mange avgjørelser å ta	1	2	3	4
12. Du føler deg frustrert	1	2	3	4
13. Du er full av energi	1	2	3	4
14. Du føler deg anspent	1	2	3	4
15. Problemene dine virker til å hope seg opp	1	2	3	4
16. Du føler at du har det travelt	1	2	3	4
17. Du føler deg trygg og beskyttet	1	2	3	4
18. Du har mange bekymringer	1	2	3	4
19. Du er under press fra andre mennesker	1	2	3	4
20. Du føler deg motløs	1	2	3	4
21. Du har det hyggelig	1	2	3	4
22. Du er redd for fremtiden	1	2	3	4
23. Du føler at du gjør ting fordi du må, ikke fordi du vil	1	2	3	4
24. Du føler deg kritisert eller bedømt	1	2	3	4
25. Du er munter	1	2	3	4
26. Du føler deg mentalt utmattet	1	2	3	4
27. Du har problemer med å slappe av	1	2	3	4
28. Du føler deg tynget av ansvar	1	2	3	4
29. Du har nok tid til deg selv	1	2	3	4
30. Du føler deg presset av tidsfrister	1	2	3	4

Rosenberg self-esteem scale (RSES)



Hvor enig er du i følgende påstander? (*sett ett kryss per linje*)

46.1 **Jeg har en positiv holdning til meg selv**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.2 **Jeg føler meg virkelig ubrukelig til tider**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.3 **Jeg føler at jeg ikke har mye å være stolt av**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.4 **Jeg føler at jeg er en verdifull person, i alle fall på lik linje med andre**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

Appendix 12

Questionnaire adolescents time 2

SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om spørreskjemaundersøkelsen tilknyttet forskningsprosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. *

Jeg samtykker til å delta i spørreskjemaundersøkelsen og til at mine opplysninger behandles frem til prosjektet er avsluttet *

- ○ Ja
- ○ Nei

Hva heter du (fornavn og etternavn)? *

Hva er ditt mobilnummer? *

Dette nummeret fylles automatisk ut da det er dette mobilnummeret som har mottatt link til spørreskjema.

Demografiske data Ungdom

1. Er du gutt eller jente?
   - Gutt
   - Jente

2. Hvor gammel er du?
   _____år

3. Hvilke voksne bor du sammen med nå?

   - Jeg bor sammen med begge foreldrene mine
   - Jeg veksler mellom å bo hos mor og far
   - Jeg bor sammen med den ene av foreldre mine og en stemor/stefar
   - Jeg bor kun sammen med den ene av foreldrene mine
   - Annet _____
     → (oppfølgingsspørsmål)
     Hvis Annet, beskriv hvem du bor sammen med: _____

4. Mine foreldre er
   - Gift eller samboere
   - Ugift
   - Skilt eller separert
   - En eller begge er døde

5. Hvor er foreldrene dine født?
   - Begge er født i Norge
   - Den ene er født i Norge, den andre er født i et annet land
   - Begge er født i et annet land enn Norge

   → (oppfølgingsspørsmål)
   Hvilket land er mor født i? _____
   Hvilket land er far født i? _____

6. Har du flyttet i løpet av de siste 5 årene?
   - Nei
   - Ja, en gang
   - Ja, 2-4 ganger
   - Ja, 5 ganger eller mer

7. Er foreldrene dine i arbeid nå?
   - Ja, begge
   - Ja, én av dem
   - Nei, ingen
   - Vet ikke

   ➔ Er far i jobb nå? (oppfølgingsspørsmål)

- Ja, heltid
- Ja, deltid
- Nei

➔ Er mor i jobb nå? (oppfølgingsspørsmål)

- Ja, heltid
- Ja, deltid
- Nei

8. Har du hatt fravær fra skolen i løpet av de siste tre månedene?
   - Ingen fravær
   - 1-4 dager
   - 5-7 dager
   - 8-10 dager
   - Mer enn 10 dager

   ➔ Hva er årsak til fraværet? (oppfølgingsspørsmål)
   - Sykdom
   - Diffuse helseplager (eks. smerte, føler seg sliten)
   - Skulk
   - Skolevegring (fravær på grunn av et emosjonelt/følelsesmessig ubehag)
   - Annet_____
     → (oppfølgingsspørsmål)
     Hvis Annet, beskriv hva som er årsak til fraværet:_____

KIDSCREEN 27

Fysisk aktivitet og helse

Til vanlig, hvordan vil du si at helsen din er?

1. ○ Utmerket
   ○ Veldig bra
   ○ Bra
   ○ Ganske bra
   ○ Dårlig

Når du tenker på den siste uka...

		Ikke I det hele tatt	Litt	Ganske	Veldig	I høy grad
2.	Har du følt deg frisk og sprek?	○	○	○	○	○
3.	Har du vært fysisk aktiv (for eksempel løpt, klatret, syklet)?	○	○	○	○	○
4.	Har du kunne løpe bra?	○	○	○	○	○

Når du tenker på den siste uka...

		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
5.	Har du følt deg full av energi?	○	○	○	○	○

2. Om deg selv, humør og følelser

Når du tenker på den siste uka…

		Ikke I det hele tatt	Litt	ganske	veldig	I høy grad
1.	Har livet ditt vært bra?	○	○	○	○	○

Når du tenker på den siste uka…

		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
2.	Har du vært i godt humør?	○	○	○	○	○
3.	Har du hatt det gøy?	○	○	○	○	○

	Når du tenker på den siste uka…	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
4.	Har du følt deg trist?	○	○	○	○	○
5.	Har du følt deg så ille/elendig at du ikke har villet gjøre noe?	○	○	○	○	○
6.	Har du følt deg ensom?	○	○	○	○	○
7.	Har du vært fornøyd med deg selv slik du er?	○	○	○	○	○

3. Familie og fritid

	Når du tenker på den siste uka…	never	seldom	quite often	very often	always
1.	Har du hatt nok tid for deg selv?	○	○	○	○	○
2.	Har du kunnet gjøre de tingene du ønsker i fritiden din?	○	○	○	○	○
3.	Har moren/faren din hatt nok tid til deg?	○	○	○	○	○
4.	Har moren/faren din behandlet deg rettferdig?	○	○	○	○	○
5.	Har du kunnet snakke med moren/faren din når du har lyst?	○	○	○	○	○
6.	Har du hatt nok penger til å gjøre de samme tingene som vennene dine?	○	○	○	○	○
7.	Har du hatt nok penger til utgiftene dine?	○	○	○	○	○

4. Venner

Når du tenker på den siste uka…

		never	seldom	quite often	very often	always
1.	Har du vært sammen med vennene dine?	○	○	○	○	○
2.	Har du hatt det gøy sammen med vennene dine?	○	○	○	○	○
3.	Har du og vennene dine hjulpet hverandre?	○	○	○	○	○
4.	Har du kunnet stole på vennene dine?	○	○	○	○	○

5. Skole og læring

Når du tenker på den siste uka…

		Ikke I det hele tatt	Litt	Ganske	Veldig	I høy grad
1.	Har du vært glad på skolen?	○	○	○	○	○
2.	Har du klart deg bra på skolen?	○	○	○	○	○

Når du tenker på den siste uka…..

		Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
3.	Har du klart å følge med på skolen?	○	○	○	○	○
4.	Har du kommet godt ut av det med lærerne dine?	○	○	○	○	○

Har det skjedd en stor endring i livet ditt i løpet av de to siste årene som har påvirket din livskvalitet?»

- Ja
- Nei

➔ Hvis ja, beskriv hvilken endring som har skjedd (oppfølgingsspørsmål): _____

Brief Pain Inventory (BPI)

3.	Vennligst sett en ring rundt det tallet som best beskriver de sterkeste smertene du har hatt i løpet av den siste uka.									
	0	1	2	3	4	5	6	7	8	9	10
	Ingen smerter										Verst tenkelige smerter
4.	Vennligst sett en ring rundt det tallet som best beskriver de svakeste smertene du har hatt i løpet av den siste uka.									
	0	1	2	3	4	5	6	7	8	9	10
	Ingen smerter										Verst tenkelige smerter
5.	Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har i gjennomsnitt.									
	0	1	2	3	4	5	6	7	8	9	10
	Ingen smerter										Verst tenkelige smerter
6.	Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har akkurat nå.									
	0	1	2	3	4	5	6	7	8	9	10
	Ingen smerter										Verst tenkelige smerter

7. Hvilken behandling eller medisiner får du for å lindre smertene dine?

8.	I hvor stor grad har behandling eller medisiner lindret smertene dine den siste uka? Vennligst sett en ring rundt det prosenttallet som best viser hvor stor smertelindring du har fått.									
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
	Ingen lindring										Fullstendig lindring

9. Sett en ring rundt det tallet som for den siste uka best beskriver hvor mye smertene har virket inn på:

A. Daglig aktivitet

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

B. Humør

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

C. Evne til å gå

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

D. Vanlig arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

E. Forhold til andre mennesker

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

F. Søvn

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

G. Livsglede

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

The Lübeck Pain-Screening questionnaire (LPQ) (utvalgte spørsmål)

4. **Hvor lenge har du hatt vondt på denne måten?**

Bare en gang.	○	Mer enn 3 måneder	○
Mindre enn en måned	○	Mer enn 6 måneder	○
Mellom 1 og 3 måneder	○	Mer enn 12 måneder	○

5 **Hvor ofte har du hatt denne smerten (hatt vondt på denne måten) de tre siste månedene?**

Mindre enn èn gang i måneden	○	1 gang i uka	○
1 gang i måneden	○	Flere ganger i uka	○
2-3 ganger i måneden	○	Hver dag	○

8 **Hva tror du selv er årsaken til disse smertene (grunnen til at du har vondt)?**

Værskifte	○	Bråk/høy musikk	○
Irritasjon/krangling	○	Familiesituasjonen	○
Skolesituasjonen	○	Skjermtid (TV/nettbrett/PC/mobil)	○
Opphisselse	○	Skolearbeidet	○
Tristhet	○	Ikke noe spesielt	○
For lite søvn	○	En ny situasjon	○
Forkjølelse	○	Fysisk anstrengelse/ sport	○
Sosiale media	○	Mat/søtsaker	○
Ensomhet/følte meg alene	○	For jenter: *Menstruasjon*	○
Vet ikke	○	Annet_____	○

10. **Finnes det en årsak og/eller medisinsk diagnose til smertene dine?**

Nei ○ Vet ikke ○ Ja ○ _____ *(hvilken?)*

11. **Har du en eller flere kroniske sykdommer?** for eksempel diabetes, astma)

12. **Er det noen i familien din som har ofte smerter, eller alltid smerter?**

'Nei ○ Vet ikke ○ Ja ○ _____ *(hvem?)*

Spørsmål vedrørende bruk av smertestillende

(hentet fra «Smerte, ungdom og selvmedisinering (SUS)» studien)

(Utvalgte spørsmål)

Smertetilstander:

4.0 Har du eller har du hatt noen av de nevnte plager i løpet av siste 4 uker?
(*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Tannreguleringssmerter
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____

Ingen

Bruker du eller har du brukt smertestillende medisin (for eksempel Paracet eller Ibux) i løpet av siste 4 uker?

Ja ☐

Nei ☐

Bruk av smertestillende:

5.0 Bruker du eller har du brukt smertestillende medisin for noen av de nevnte plagene i løpet av siste 4 uker? (*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett til moderat hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Tannreguleringssmerter
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____

Mengde smertestillende medisin:

6.0 Hvis du har tatt smertestillende siste 4 uker, hvor ofte har du da tatt slik medisin? (*sett bare ett kryss*)

- ☐ Daglig
- ☐ Hver uke, men ikke daglig
- ☐ Sjeldnere enn hver uke
- ☐ Ikke tatt siste 4 uker

Tilgang på smertestillende og informasjon

17.0 Tilgang på reseptfri smertestillende medisin: (*sett ingen, ett eller flere kryss*)

- ☐ Jeg har smertestillende hjemme som jeg kan ta selv
- ☐ Jeg får smertestillende hjemme hvis jeg spør en av de voksne
- ☐ Vi har ikke smertestillende hjemme
- ☐ Jeg har fått smertestillende av en venn eller venninne
- ☐ Jeg har fått smertestillende av idretts trener
- ☐ Jeg har kjøpt smertestillende til meg selv på apotek
- ☐ Jeg har kjøpt smertestillende til meg selv på bensinstasjon, i matbutikken
- ☐ Jeg passer på å ha smertestillende med meg (i lommebok, veske, skolesekk)

18.0 Hvor har du fått informasjon om bruk av smertestillende?
(*sett ett eller flere kryss*)

- ☐ Av mor, far eller annen voksen hjemme
- ☐ Av søsken
- ☐ Av apotekpersonalet
- ☐ Ved å lese pakningsvedlegget
- ☐ Av venner/venninner
- ☐ Ved informasjonsprogram på TV
- ☐ Ved reklame på TV eller i blader
- ☐ Av lærer
- ☐ Av helsesøster
- ☐ Av lege
- ☐ Av idretts trener
- ☐ Annet, spesifiser: _____
- ☐ Ingen informasjon

19.0 Hvis du forteller at du har smerter, hva anbefaler dine foreldre?
(*sett bare ett kryss*)

- ☐ At du tar smertestillende medikamenter
- ☐ At du venter og håper at det går over
- ☐ At du hviler deg
- ☐ Annet, spesifiser: _____

20.0 Hvis du bruker smertestillende medisiner
(*sett bare ett kryss*)

- ☐ Forteller du det ikke til andre
- ☐ Forteller du det kun til dine foreldre
- ☐ Forteller du det kun til dine nærmeste venner
- ☐ Bruker du smertestillende medisiner åpenlyst

General Self-efficacy

Sett kryss for de utsagnene som passer best for deg:

	Helt galt	Nokså galt	Nokså riktig	Helt riktig
Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil	☐	☐	☐	☐
Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte	☐	☐	☐	☐
Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det	☐	☐	☐	☐
Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min	☐	☐	☐	☐
Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det	☐	☐	☐	☐
Hvis jeg er i knipe, så finner jeg vanligvis en vei ut	☐	☐	☐	☐
Samme hva som hender så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

Søvnspørsmål for ungdom

(Spørsmålene er tilpasset fra School Sleep Habits Survey)

1. Når går du vanligvis til sengs på skoledager/hverdager?
   Svar med ett tidspunkt i hele 24 timer – slik at 10 om kvelden angis som kl. 22.00.
   Klokken: _____

2. Når våkner du vanligvis opp på skoledager/hverdager?
   Klokken: _____

3. Når går du vanligvis til sengs i helgene?
   Svar med ett tidspunkt i hele 24 timer – slik at 10 om kvelden angis som kl. 22.00.
   Klokken: _____

4. Når våkner du vanligvis opp i helgene?
   Klokken: _____

5. Noen personer våkner opp om natten. Andre gjør det aldri. Hvor mange ganger våkner du vanligvis opp om natten?
   - Aldri
   - En gang
   - 2 eller 3 ganger
   - Mer enn 3 ganger
   - Vet ikke

6. Noen mennesker føler seg søvnige om dagen. Når du holder på med aktiviteter om dagen, hvor stort problem har du da med søvnighet (føle seg søvnig, vanskelig å holde seg våken)?
   - Ikke noen problem i det hele tatt
   - Et lite problem
   - Mer enn et lite problem
   - Et stort problem
   - Et veldig stort problem

7.Hvor ofte får du nok søvn?

   - Alltid
   - Vanligvis
   - Av og til
   - Sjelden
   - Aldri

Revised UCLA Loneliness scale (ULS-8)

De neste setningene beskriver hvordan man noen ganger har det.

Kryss av for hvor ofte du har det slik som det beskrives i setningene nedenfor.
Sett ett kryss for hver setning.

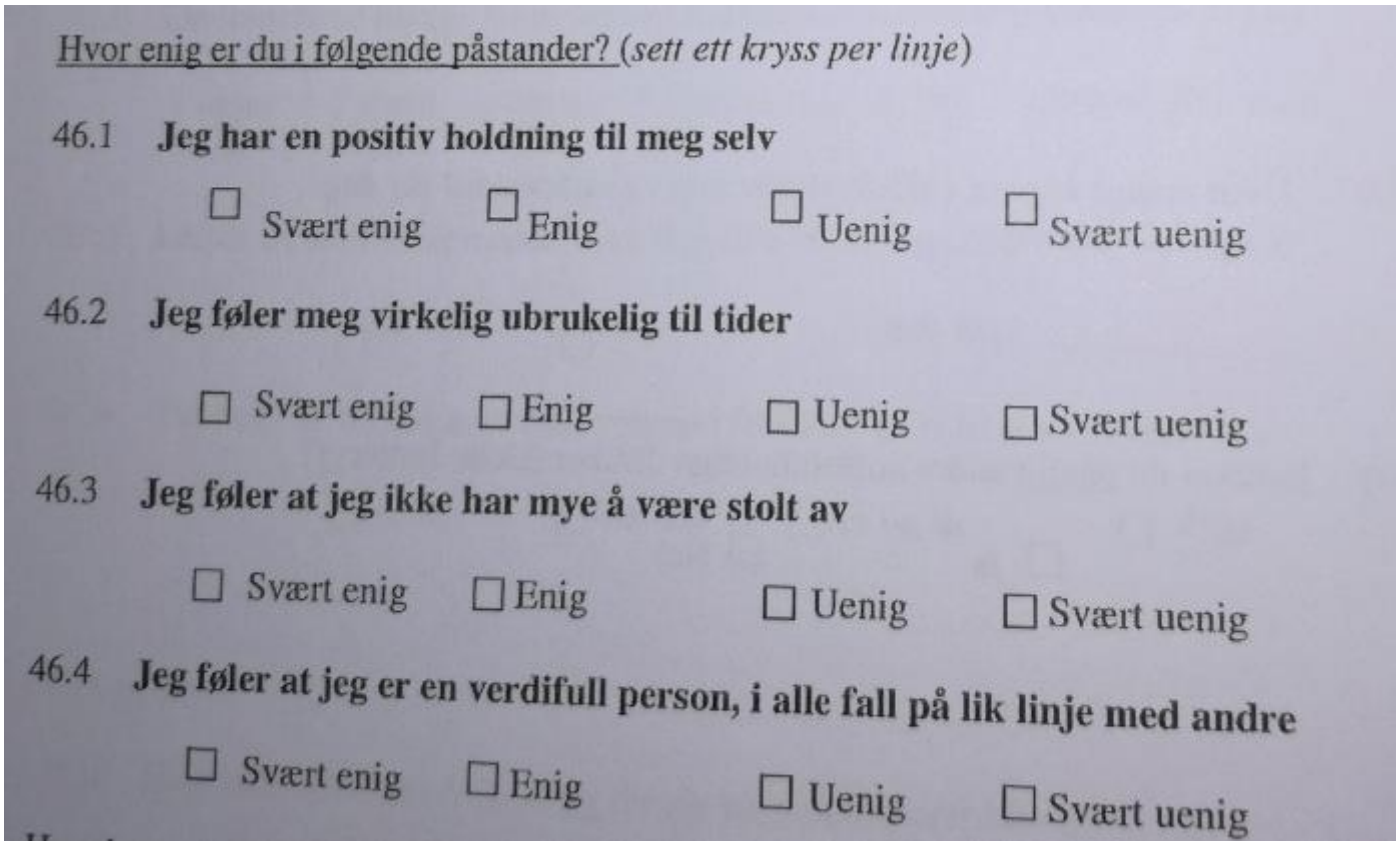
	Setning	Aldri	Sjeldent	Noen ganger	Ofte
1.	Jeg mangler noen (venner) å være sammen med	1	2	3	4
2.	Det er ingen jeg kan snakke med	1	2	3	4
3.	Jeg er en sosial / utadvendt person	1	2	3	4
4.	Jeg føler meg utenfor	1	2	3	4
5.	Jeg føler meg isolert fra andre	1	2	3	4
6.	Jeg kan finne noen (venner) å være sammen med når jeg ønsker det	1	2	3	4
7.	Når jeg er alene, synes jeg det er leit	1	2	3	4
8.	Folk er rundt meg, men ikke sammen med meg	1	2	3	4

Perceived Stress Questionaire (PSQ)

Sett ring rundt tallet som beskriver hvordan det er eller har vært for deg *den siste måneden*. Gjør dette raskt uten å sjekke svarene nøye og merk at det skal gjelde *den siste måneden*.

	Nesten aldri	Av og til	Ofte	Vanligvis
1. Du føler deg uthvilt	1	2	3	4
2. Du føler at du får for mange krav stilt til deg	1	2	3	4
3. Du er irritabel og gretten	1	2	3	4
4. Du har for mye å gjøre	1	2	3	4
5. Du føler deg ensom og isolert	1	2	3	4
6. Du opplever å være i konfliktsituasjoner	1	2	3	4
7. Du føler at du gjør ting som du virkelig liker	1	2	3	4
8. Du kjenner deg trøtt	1	2	3	4
9. Du frykter at du kanskje ikke klarer å nå målene dine	1	2	3	4
10. Du føler deg rolig	1	2	3	4
11. Du har for mange avgjørelser å ta	1	2	3	4
12. Du føler deg frustrert	1	2	3	4
13. Du er full av energi	1	2	3	4
14. Du føler deg anspent	1	2	3	4
15. Problemene dine virker til å hope seg opp	1	2	3	4
16. Du føler at du har det travelt	1	2	3	4
17. Du føler deg trygg og beskyttet	1	2	3	4
18. Du har mange bekymringer	1	2	3	4
19. Du er under press fra andre mennesker	1	2	3	4
20. Du føler deg motløs	1	2	3	4
21. Du har det hyggelig	1	2	3	4
22. Du er redd for fremtiden	1	2	3	4
23. Du føler at du gjør ting fordi du må, ikke fordi du vil	1	2	3	4
24. Du føler deg kritisert eller bedømt	1	2	3	4
25. Du er munter	1	2	3	4
26. Du føler deg mentalt utmattet	1	2	3	4
27. Du har problemer med å slappe av	1	2	3	4
28. Du føler deg tynget av ansvar	1	2	3	4
29. Du har nok tid til deg selv	1	2	3	4
30. Du føler deg presset av tidsfrister	1	2	3	4

Rosenberg self-esteem scale (RSES)



Hvor enig er du i følgende påstander? (*sett ett kryss per linje*)

46.1 **Jeg har en positiv holdning til meg selv**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.2 **Jeg føler meg virkelig ubrukelig til tider**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.3 **Jeg føler at jeg ikke har mye å være stolt av**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.4 **Jeg føler at jeg er en verdifull person, i alle fall på lik linje med andre**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

Helsekompetanse (HLSAC)

Paakkari O, Torppa M, Kannas L, Paakkari L. Subjective health literacy: Development of a brief instrument for school-aged children. Scand J Public Health. 2016;44(8):751-7.

Jeg er sikker på at jeg…

1…har kunnskap om helse

2…ved behov kan komme med forslag til hvordan helsesituasjonen i omgivelsene mine kan forbedres (f.eks venner, familie og i nærmiljøet)

3…kan vurdere helserelatert informasjon fra ulike kilder

4…kan følge instruksjoner gitt av helsepersonell (f.eks sykepleier og lege)

5…enkelt kan gi eksempler på ting som er viktig for god helse

6…kan vurdere hvordan handlingene mine påvirker miljøet

7…kan finne forståelig informasjon om helse når jeg trenger det

8…kan vurdere hvordan handlingene mine påvirker helsen min

9…vanligvis kan avgjøre om helserelatert informasjon er rett eller feil

10…kan begrunne valg jeg tar når det gjelder helsen min

(**svaralternativer**: Helt feil Litt feil Litt riktig Helt riktig)

Spørsmål vedrørende Covid-19

Hentet fra undersøkelsen "Oslo-ungdom i koronatiden» (OsloMet)

6/43 Korona-epidemiens påvirkning på livet ditt

DU VIL NÅ FÅ SPØRSMÅL OM HVORDAN KORONA-EPIDEMIEN HAR PÅVIRKET LIVET DITT. SVAR SÅ GODT DU KAN.

Har korona-epidemien påvirket livet ditt i negativ retning?
☐ Nei, ikke i det hele tatt
☐ Ja, litt
☐ Ja, en del
☐ Ja, mye
☐ Ja, veldig mye

Har korona-epidemien påvirket livet ditt i positiv retning?
☐ Nei, ikke i det hele tatt
☐ Ja, litt
☐ Ja, en del
☐ Ja, mye
☐ Ja, veldig mye

11/43

Hvor bekymret er du for at ...	Ikke bekymret i det hele tatt	Litt bekymret	Ganske bekymret	Veldig bekymret
.. du selv skal bli syk av koronaviruset?	☐	☐	☐	☐
.. du skal smitte andre med koronaviruset?	☐	☐	☐	☐
.. venner eller noen i familien din skal bli syk av koronaviruset?	☐	☐	☐	☐

12/43

Har korona-epidemien gjort deg bekymret...	Ikke bekymret i det hele tatt	Litt bekymret	Ganske bekymret	Veldig bekymret
.. for hvordan det vil gå med karakterene dine?	☐	☐	☐	☐
.. for hvordan det vil gå med økonomien i familien din?	☐	☐	☐	☐
.. for hvordan det vil gå med økonomien i Norge?	☐	☐	☐	☐

Appendix 13

Questionnaire parents time 2

SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om spørreskjemaundersøkelsen tilknyttet forskningsprosjektet «Start Ung – livskvalitet og smerte i generasjoner», og har fått anledning til å stille spørsmål. *

Jeg samtykker til å delta i spørreskjemaundersøkelsen og til at mine opplysninger behandles frem til prosjektet er avsluttet *

- ○ Ja
- ○ Nei

Hva heter du (fornavn og etternavn)? *

Hva er ditt mobilnummer? *

Dette nummeret fylles automatisk ut da det er dette mobilnummeret som har mottatt link til spørreskjema.

Demografiske data foreldre

1. Er du mann eller kvinne?
   - Mann
   - Kvinne

2. Hvem fyller ut spørreskjemaet?
   - Mor
   - Far
   - Stemor/fars partner
   - Stefar/mors partner
   - Andre _____

3. Hvor gammel er du?
   _____år

4. Hva er din sivilstand?
   - Gift eller samboer
   - Enslig
   - Skilt eller separert
   - Enke/enkemann

5. Hvilken utdanning er den høyeste du har du fullført?
   (sett ett kryss)
   - Grunnskole nivå (barne- og ungdomsskole, framhaldsskole, folkehøyskole)
   - 1-2 årig videregående skole
   - 3 år i videregående skole
   - Fagbrev eller svennebrev
   - Høyskole/universitet, mindre enn 4 år
   - Høyskole/universitet, 4 år eller mer

6. Er du i arbeid nå?
   - Ja, fulltid
   - Ja, deltid
   - Nei, jeg er ikke i arbeid

   ➔ Hvis du ikke er i heltids arbeid, er det på grunn av: (oppfølgingsspørsmål)
   - Studier
   - Ønsker selv å jobbe redusert/ikke være i arbeid
   - Svangerskaps-/fødselspermisjon
   - Arbeidsløshet, permittering
   - Uføretrygd/Delvis uføretrygd
   - Sykemelding
   - Alderspensjon
   - Annet_____

7. Har du hatt fravær fra jobb i løpet av de siste tre månedene?
    - Ingen fravær
    - 1-4 dager
    - 5-7 dager
    - 8-10 dager
    - Mer enn 10 dager

    ➔ Hva er årsak til fraværet? (oppfølgingsspørsmål)
        - Sykdom
        - Diffuse helseplager (eks. smerte, føler seg sliten)
        - Arbeidsmiljø (fravær på grunn av et emosjonelt/følelsesmessig ubehag)
        - Annet_____

8. Hva er din husstands samlede inntekt siste år (brutto-inntekt)?
   Ta med alle inntekter fra arbeid, trygder, sosialhjelp og lignende. (Sett ett kryss)
    - Under 250.000kr
    - 250.000kr – 450.000kr
    - 451.000kr – 750.000kr
    - 751.000kr – 1.000.000kr
    - Over 1.000.000kr

RAND 36

RAND-36 Din helse

Spørsmålene under handler om hvordan du oppfatter helsen din. Disse opplysningene vil hjelpe oss til å forstå hvordan du føler deg og hvor godt du er i stand til å utføre dine vanlige aktiviteter.

Hvert spørsmål skal besvares ved å sette et kryss (X) i den boksen som passer best for deg.

1. Stort sett, vil du si at helsen din er:

Utmerket	Veldig god	God	Nokså god	Dårlig
☐	☐	☐	☐	☐

2. Sammenlignet med for ett år siden, hvordan vil du si at helsen din stort sett er nå?

Mye bedre nå enn for ett år siden	Litt bedre nå enn for ett år siden	Omtrent som for ett år siden	Litt dårligere nå enn for ett år siden	Mye dårligere nå enn for ett år siden
☐	☐	☐	☐	☐

3. De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er helsen din slik at den begrenser deg i utførelsen av disse aktivitetene nå? Hvis ja, hvor mye? [Kryss (X) en boks på hver linje.]

		Ja, begrenser meg mye	Ja, begrenser meg litt	Nei, begrenser meg ikke i det hele tatt
a	**Anstrengende aktiviteter** som å løpe, løfte tunge gjenstander, delta i anstrengende idrett	☐	☐	☐
b	**Moderate aktiviteter** som å flytte et bord, støvsuge, gå en spasertur eller drive med hagearbeid	☐	☐	☐
c	Løfte eller bære poser med dagligvarer	☐	☐	☐
d	Gå opp trappen **flere** etasjer	☐	☐	☐
e	Gå opp trappen **én** etasje	☐	☐	☐
f	Bøye deg eller gå ned på kne	☐	☐	☐
g	Gå **mer enn to kilometer**	☐	☐	☐
h	Gå **flere hundre meter**	☐	☐	☐
i	Gå **hundre meter**	☐	☐	☐
j	Dusje eller kle på deg	☐	☐	☐

4. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av din fysiske helse?**

		Ja	Nei
a	Kuttet ned på **hvor mye tid** du brukte på arbeid eller andre aktiviteter	☐	☐
b	**Fått gjort mindre** enn du ønsket	☐	☐
c	Vært begrenset i type **arbeidsoppgaver** eller andre aktiviteter	☐	☐
d	Hatt **problemer** med å utføre arbeidet eller andre aktiviteter (for eksempel at det krevde en ekstra innsats av deg)	☐	☐

5. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av følelsesmessige problemer (som å føle seg engstelig eller deprimert)?**

		Ja	Nei
a	Kuttet ned på **hvor mye tid** du brukte på arbeid eller andre aktiviteter	☐	☐
b	**Fått gjort mindre** enn du ønsket	☐	☐
c	Utført arbeid eller andre aktiviteter **mindre grundig** enn vanlig	☐	☐

6. **I løpet av de siste fire ukene, i hvilken grad har den fysiske helsen din eller følelsesmessige problemer påvirket dine vanlige sosiale aktiviteter med familie, venner, naboer eller andre grupper mennesker?**

Ikke i det hele tatt	Litt	Moderat	Ganske mye	Ekstremt mye
☐	☐	☐	☐	☐

7. **Hvor mye kroppslige smerter har du hatt i løpet av de siste fire ukene?**

Ingen	Veldig svake	Svake	Moderate	Sterke	Veldig sterke
☐	☐	☐	☐	☐	☐

8. **I løpet av de siste fire ukene, hvor mye har smerter påvirket det vanlige arbeidet ditt (gjelder både arbeid utenfor hjemmet og husarbeid)?**

Ikke i det hele tatt	Litt	Moderat	Ganske mye	Ekstremt mye
☐	☐	☐	☐	☐

9. **De neste spørsmålene handler om hvordan du føler deg og hvordan du har hatt det i løpet av de siste fire ukene. For hvert spørsmål, ber vi deg velge det svaret som best beskriver hvordan du har følt deg.**

Hvor ofte i løpet av de siste fire ukene:

		Hele tiden	Mesteparten av tiden	En god del av tiden	Noe av tiden	Litt av tiden	Aldri
a	Har du følt deg full av liv?	☐	☐	☐	☐	☐	☐
b	Har du vært veldig nervøs?	☐	☐	☐	☐	☐	☐
c	Har du følt deg så langt nede at ingenting kunne gjøre deg glad?	☐	☐	☐	☐	☐	☐
d	Har du følt deg rolig og avslappet?	☐	☐	☐	☐	☐	☐
e	Har du hatt mye overskudd?	☐	☐	☐	☐	☐	☐
f	Har du følt deg nedfor og deprimert?	☐	☐	☐	☐	☐	☐
g	Har du følt deg utslitt	☐	☐	☐	☐	☐	☐
h	Har du følt deg glad?	☐	☐	☐	☐	☐	☐
i	Har du følt deg sliten?	☐	☐	☐	☐	☐	☐

10. **I løpet av de siste fire ukene, hvor mye av tiden har den fysiske helsen din eller følelsesmessige problemer påvirket dine sosiale aktiviteter (som å besøke venner, slektninger osv.)?**

Hele tiden	Mesteparten av tiden	En del av tiden	Litt av tiden	Aldri
☐	☐	☐	☐	☐

11. Hvor RIKTIG eller GAL er hver av de følgende påstandene for deg?

		Helt riktig	Stort sett riktig	Vet ikke	Stort sett galt	Helt galt
a	Det virker som om jeg blir syk litt lettere enn andre	☐	☐	☐	☐	☐
b	Jeg er like frisk som de fleste jeg kjenner	☐	☐	☐	☐	☐
c	Jeg regner med at helsen min blir dårligere	☐	☐	☐	☐	☐
d	Helsen min er utmerket	☐	☐	☐	☐	☐

Har det skjedd en stor endring i livet ditt i løpet av de to siste årene som har påvirket din livskvalitet?»

- Ja
- Nei

➔ Hvis ja, beskriv hvilken endring som har skjedd (oppfølgingsspørsmål): _____

Brief Pain Inventory (BPI)

3. Vennligst sett en ring rundt det tallet som best beskriver de sterkeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

4. Vennligst sett en ring rundt det tallet som best beskriver de svakeste smertene du har hatt i løpet av den siste uka.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

5. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har i gjennomsnitt.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

6. Vennligst sett en ring rundt det tallet som best angir hvor sterke smerter du har akkurat nå.

0	1	2	3	4	5	6	7	8	9	10
Ingen smerter										Verst tenkelige smerter

7. Hvilken behandling eller medisiner får du for å lindre smertene dine?

---

8. I hvor stor grad har behandling eller medisiner lindret smertene dine den siste uka? Vennligst sett en ring rundt det prosenttallet som best viser hvor stor smertelindring du har fått.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Ingen lindring										Fullstendig lindring

9. Sett en ring rundt det tallet som for den siste uka best beskriver hvor mye smertene har virket inn på:

A. Daglig aktivitet

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

B. Humør

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

C. Evne til å gå

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

D. Vanlig arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

E. Forhold til andre mennesker

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

F. Søvn

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

G. Livsglede

0	1	2	3	4	5	6	7	8	9	10
Ikke påvirket										Fullstendig påvirket

The Lübeck Pain-Screening questionnaire (LPQ) (utvalgte spørsmål)

4. **Hvor lenge har du hatt vondt på denne måten?**

Bare en gang.	○	Mer enn 3 måneder	○
Mindre enn en måned	○	Mer enn 6 måneder	○
Mellom 1 og 3 måneder	○	Mer enn 12 måneder	○

5 **Hvor ofte har du hatt denne smerten (hatt vondt på denne måten) de tre siste månedene?**

Mindre enn èn gang i måneden	○	1 gang i uka	○
1 gang i måneden	○	Flere ganger i uka	○
2-3 ganger I måneden	○	Hver dag	○

8 **Hva tror du selv er årsaken til disse smertene (grunnen til at du har vondt)?**

Værskifte	○	Bråk/høy musikk	○
Irritasjon/krangling	○	Familiesituasjonen	○
Arbeidsmiljø	○	Skjermtid (TV/nettbrett/PC/mobil)	○
Opphisselse	○	Arbeidsmengde på jobb	○
Tristhet	○	Ikke noe spesielt	○
For lite søvn	○	En ny situasjon	○
Forkjølelse	○	Fysisk anstrengelse/ sport	○
Sosiale media	○	Mat/søtsaker	○
Ensomhet/følte meg alene	○	For kvinner: menstruasjon	○
Vet ikke	○	Annet_____	○

10. **Finnes det en årsak og/eller medisinsk diagnose til smertene dine?**

Nei ○ Vet ikke ○ Ja ○ _____

(hvilken?)

11. **Har du en eller flere kroniske sykdommer?** for eksempel diabetes, astma)

12. **Er det noen i familien din som har ofte smerter, eller alltid smerter?**

'Nei ○ Vet ikke ○ Ja ○ _____ *(hvem?)*

Spørsmål vedrørende bruk av smertestillende

(hentet fra «Smerte, ungdom og selvmedisinering (SUS)» studien)

(Utvalgte spørsmål. Spørsmålene er tilpasset voksne)

Smertetilstander:

4.0 Har du eller har du hatt noen av de nevnte plager i løpet av siste 4 uker?
(*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Mavesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre **årsaker**, spesifiser: _____
- ☐ Ingen

Bruker du eller har du brukt smertestillende medisin (for eksempel Paracet eller Ibux) i løpet av siste 4 uker?

Ja ☐

Nei ☐

Bruk av smertestillende:

5.0 Bruker du eller har du brukt smertestillende medisin for noen av de nevnte plagene i løpet av siste 4 uker? (*sett ett eller flere kryss*)

- ☐ Vondt i øret/øreverk
- ☐ Menstruasjonssmerter
- ☐ Vondt i ryggen
- ☐ Vondt i halsen
- ☐ Lett til moderat hodepine
- ☐ Sterk hodepine/migrene
- ☐ Tannverk
- ☐ Feber
- ☐ Vondt i nakke/skuldre
- ☐ Magesmerter/knip/krampe
- ☐ Vondt i hele kroppen
- ☐ Idrettsskade (forstuing o.l.)
- ☐ Andre årsaker, spesifiser: _____
- ☐ Ingen

Mengde smertestillende medisin:

6.0 Hvis du har tatt smertestillende siste 4 uker, hvor ofte har du da tatt slik medisin? (*sett bare ett kryss*)

- ☐ Daglig
- ☐ Hver uke, men ikke daglig
- ☐ Sjeldnere enn hver uke
- ☐ Ikke tatt siste 4 uker

Tilgang på smertestillende og informasjon

17.0 Tilgang på reseptfri smertestillende medisin: (*sett ingen, ett eller flere kryss*)

☐ Jeg har smertestillende hjemme

☐ Jeg har ikke smertestillende hjemme

☐ Jeg har fått smertestillende av en venn eller venninne

☐ Jeg har kjøpt smertestillende på apotek

☐ Jeg har kjøpt smertestillende på bensinstasjon, i matbutikken

☐ Jeg passer på å ha smertestillende med meg (i lommebok, veske, sekk)

18.0 Hvor har du fått informasjon om bruk av smertestillende?
(*sett ett eller flere kryss*)

☐ Av familie

☐ Av apotekpersonalet

☐ Ved å lese pakningsvedlegget

☐ Av venner/venninner

☐ Ved informasjonsprogram på TV

☐ Ved reklame på TV eller i blader

☐ Av lege

☐ Annet, spesifiser: _____

☐ Ingen informasjon

19.0 Hvis ditt barn forteller at han/hun har smerter, hva anbefaler du?
(*sett bare ett kryss*)

- ☐ At han/hun tar smertestillende medikamenter
- ☐ At han/hun venter og håper at det går over
- ☐ At han/hun hviler seg
- ☐ Annet, spesifiser: _____

20.0 Hvis du bruker smertestillende medisiner
(*sett bare ett kryss*)

- ☐ Forteller du det ikke til andre
- ☐ Forteller du det kun til din partner
- ☐ Forteller du det kun til dine nærmeste venner
- ☐ Bruker du smertestillende medisiner åpenlyst

General Self-efficacy

Sett kryss for de utsagnene som passer best for deg:

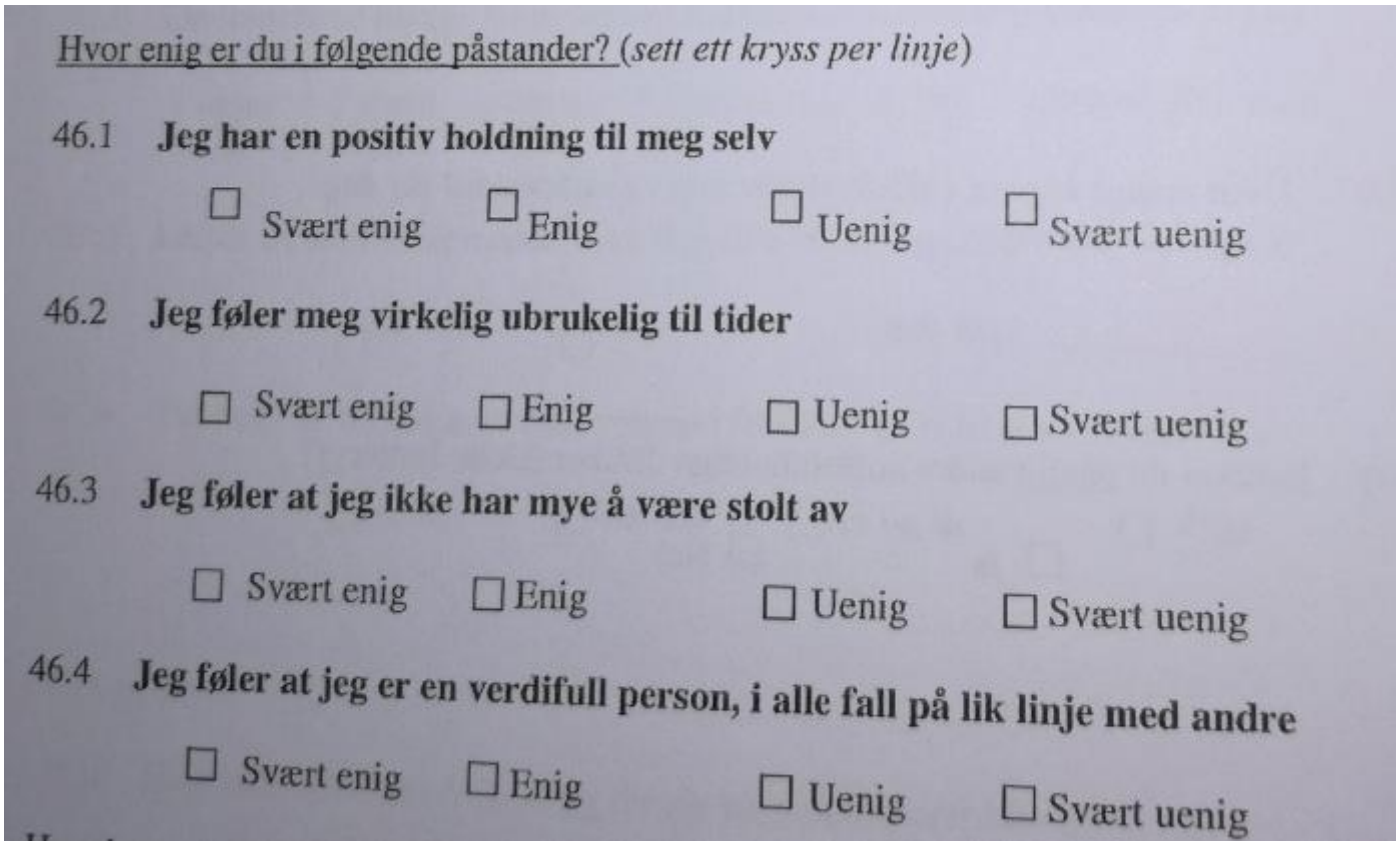
	Helt galt	Nokså galt	Nokså riktig	Helt riktig
Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil	☐	☐	☐	☐
Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte	☐	☐	☐	☐
Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det	☐	☐	☐	☐
Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min	☐	☐	☐	☐
Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det	☐	☐	☐	☐
Hvis jeg er i knipe, så finner jeg vanligvis en vei ut	☐	☐	☐	☐
Samme hva som hender så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

Perceived Stress Questionaire (PSQ)

Sett ring rundt tallet som beskriver hvordan det er eller har vært for deg *den siste måneden*. Gjør dette raskt uten å sjekke svarene nøye og merk at det skal gjelde *den siste måneden*.

	Nesten aldri	Av og til	Ofte	Vanligvis
1. Du føler deg uthvilt	1	2	3	4
2. Du føler at du får for mange krav stilt til deg	1	2	3	4
3. Du er irritabel og gretten	1	2	3	4
4. Du har for mye å gjøre	1	2	3	4
5. Du føler deg ensom og isolert	1	2	3	4
6. Du opplever å være i konfliktsituasjoner	1	2	3	4
7. Du føler at du gjør ting som du virkelig liker	1	2	3	4
8. Du kjenner deg trøtt	1	2	3	4
9. Du frykter at du kanskje ikke klarer å nå målene dine	1	2	3	4
10. Du føler deg rolig	1	2	3	4
11. Du har for mange avgjørelser å ta	1	2	3	4
12. Du føler deg frustrert	1	2	3	4
13. Du er full av energi	1	2	3	4
14. Du føler deg anspent	1	2	3	4
15. Problemene dine virker til å hope seg opp	1	2	3	4
16. Du føler at du har det travelt	1	2	3	4
17. Du føler deg trygg og beskyttet	1	2	3	4
18. Du har mange bekymringer	1	2	3	4
19. Du er under press fra andre mennesker	1	2	3	4
20. Du føler deg motløs	1	2	3	4
21. Du har det hyggelig	1	2	3	4
22. Du er redd for fremtiden	1	2	3	4
23. Du føler at du gjør ting fordi du må, ikke fordi du vil	1	2	3	4
24. Du føler deg kritisert eller bedømt	1	2	3	4
25. Du er munter	1	2	3	4
26. Du føler deg mentalt utmattet	1	2	3	4
27. Du har problemer med å slappe av	1	2	3	4
28. Du føler deg tynget av ansvar	1	2	3	4
29. Du har nok tid til deg selv	1	2	3	4
30. Du føler deg presset av tidsfrister	1	2	3	4

Rosenberg self-esteem scale (RSES)



Hvor enig er du i følgende påstander? (*sett ett kryss per linje*)

46.1 **Jeg har en positiv holdning til meg selv**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.2 **Jeg føler meg virkelig ubrukelig til tider**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.3 **Jeg føler at jeg ikke har mye å være stolt av**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

46.4 **Jeg føler at jeg er en verdifull person, i alle fall på lik linje med andre**

☐ Svært enig ☐ Enig ☐ Uenig ☐ Svært uenig

The Health Literacy Questionnaire (HLQ)

Kryss av i en av boksene på denne måten: ☒

		Veldig uenig	Uenig	Enig	Veldig enig
1	Jeg synes jeg har god informasjon om helse	☐	☐	☐	☐
2	Jeg har minst én helsearbeider som kjenner meg godt	☐	☐	☐	☐
3	Jeg har mange jeg kan kontakte som forstår og støtter meg	☐	☐	☐	☐
4	Jeg sammenligner helseinformasjon fra ulike kilder	☐	☐	☐	☐
5	Når jeg føler meg syk forstår virkelig folk rundt meg hva jeg gjennomgår	☐	☐	☐	☐
6	Jeg bruker ganske mye tid på aktivt å ta vare på helsen min	☐	☐	☐	☐
7	Når jeg kommer over ny informasjon om helse sjekker jeg om det er sant eller ikke	☐	☐	☐	☐

		Veldig uenig	Uenig	Enig	Veldig e
8	Jeg har minst én helsearbeider som jeg kan diskutere helseproblemene mine med	☐	☐	☐	☐
9	Jeg legger planer for hva jeg trenger å gjøre for å ha god helse	☐	☐	☐	☐
10	Jeg har nok informasjon til å ta hånd om helseproblemene mine	☐	☐	☐	☐
11	Hvis jeg trenger hjelp har jeg mange mennesker jeg kan stole på	☐	☐	☐	☐
12	Jeg sammenligner alltid helseinformasjon fra ulike kilder og avgjør hva som er best for meg	☐	☐	☐	☐
13	Til tross for andre ting som skjer i livet mitt, setter jeg av tid til å ta vare på helsen	☐	☐	☐	☐
14	Jeg er sikker på at jeg har all den informasjonen jeg trenger for å ta vare på helsen min på en god måte	☐	☐	☐	☐
15	Jeg har minst én person som kan bli med meg når jeg har avtaler hos helsepersonell	☐	☐	☐	☐
16	Jeg vet hvordan jeg skal finne ut om den helseinformasjonen jeg får er riktig eller ikke	☐	☐	☐	☐
17	Jeg har de helsearbeiderne jeg trenger til å hjelpe meg å finne ut hva jeg trenger å gjøre	☐	☐	☐	☐
18	Jeg setter mine egne mål for å opprettholde helse	☐	☐	☐	☐
19	Jeg har stor støtte fra familie eller venner	☐	☐	☐	☐
20	Jeg spør helsearbeidere om kvaliteten på den helseinformasjonen jeg finner	☐	☐	☐	☐
21	Det er ting jeg gjør regelmessig for å bli sunnere	☐	☐	☐	☐
22	Jeg kan stole på minst én helsearbeider	☐	☐	☐	☐
23	Jeg har all den informasjonen jeg trenger for å ta vare på helsen min	☐	☐	☐	☐

Kryss av i en av boksene på denne måten: ☒

		Klarer ikke å gjøre det eller alltid vanskelig	Vanligvis vanskelig	Av og til vanskelig	Vanligvis lett	Alltid lett
1	Finne den riktige helsehjelpen	☐	☐	☐	☐	☐
2	Forsikre deg om at helsearbeiderne forstår problemene dine ordentlig	☐	☐	☐	☐	☐
3	Finne informasjon om helseproblemer	☐	☐	☐	☐	☐
4	Føle at du kan diskutere dine helsebekymringer med en helsearbeider	☐	☐	☐	☐	☐
5	Fylle ut skjema med helseopplysninger på en riktig måte	☐	☐	☐	☐	☐
6	Finne helseinformasjon fra flere ulike steder	☐	☐	☐	☐	☐
7	Ha gode diskusjoner om helsen din med leger	☐	☐	☐	☐	☐
8	Få treffe de helsearbeiderne jeg trenger	☐	☐	☐	☐	☐
9	Følge instruksjoner fra helsearbeidere nøye	☐	☐	☐	☐	☐
10	Få informasjon om helse slik at du er oppdatert med den beste informasjonen	☐	☐	☐	☐	☐
11	Bestemme hvilken helsearbeider du trenger å treffe	☐	☐	☐	☐	☐
12	Lese og forstå skriftlig helseinformasjon	☐	☐	☐	☐	☐
13	Være sikker på at du finner det rette stedet for å få den helsehjelpen du trenger	☐	☐	☐	☐	☐

		Klarer ikke å gjøre det eller alltid vanskelig	*Vanligvis vanskelig*	*Av og til vanskelig*	*Vanligvis lett*	*Alltid lett*
14	Få helseinformasjon med ord du forstår	☐	☐	☐	☐	☐
15	Diskutere ting med helsearbeidere til du forstår det du trenger	☐	☐	☐	☐	☐
16	Finne ut av hvilke helsetjenester du har krav på	☐	☐	☐	☐	☐
17	Lese og forstå all informasjon på medisinforpakninger	☐	☐	☐	☐	☐
18	Få tak i helseinformasjon på egenhånd	☐	☐	☐	☐	☐
19	Finne ut av hvilken helsehjelp som er best for deg	☐	☐	☐	☐	☐
20	Stille spørsmål til helsearbeidere for å få den helseinformasjonen du trenger	☐	☐	☐	☐	☐
21	Forstå hva helsearbeidere vil at du skal gjøre	☐	☐	☐	☐	☐

Spørsmål vedrørende Covid-19

Hentet fra undersøkelsen "Oslo-ungdom i koronatiden» (OsloMet)

6/43 Korona-epidemiens påvirkning på livet ditt

DU VIL NÅ FÅ SPØRSMÅL OM HVORDAN KORONA-EPIDEMIEN HAR PÅVIRKET LIVET DITT. SVAR SÅ GODT DU KAN.

Har korona-epidemien påvirket livet ditt i negativ retning?
☐ Nei, ikke i det hele tatt
☐ Ja, litt
☐ Ja, en del
☐ Ja, mye
☐ Ja, veldig mye

Har korona-epidemien påvirket livet ditt i positiv retning?
☐ Nei, ikke i det hele tatt
☐ Ja, litt
☐ Ja, en del
☐ Ja, mye
☐ Ja, veldig mye

11/43

Hvor bekymret er du for at ...	Ikke bekymret i det hele tatt	Litt bekymret	Ganske bekymret	Veldig bekymret
.. du selv skal bli syk av koronaviruset?	☐	☐	☐	☐
.. du skal smitte andre med koronaviruset?	☐	☐	☐	☐
.. venner eller noen i familien din skal bli syk av koronaviruset?	☐	☐	☐	☐

12/43

Har korona-epidemien gjort deg bekymret...	Ikke bekymret i det hele tatt	Litt bekymret	Ganske bekymret	Veldig bekymret
.. for hvordan det vil gå med jobben din?	☐	☐	☐	☐
.. for hvordan det vil gå med økonomien i familien din?	☐	☐	☐	☐
.. for hvordan det vil gå med økonomien i Norge?	☐	☐	☐	☐