



Spina Bifida in Iceland:

Epidemiology, Health and Well-being among Adults

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**Thesis for the degree of Master of Science
In Movement Science
University of Iceland
Faculty of Medicine
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HÁSKÓLI ÍSLANDS

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Abstract

Spina bifida (SB) is one of the most frequent congenital deformities of the neural tube. It is a complex congenital deformity with a variety of complications that require comprehensive multidisciplinary medical care. During the twenty-first century lifestyle-related conditions have been among the leading causes of morbidity and premature death in both developing and developed countries. Because of the limitations and complications associated with SB, individuals with SB are at increased risk for developing lifestyle-related conditions.

Aim: The aim of the study was to perform a descriptive epidemiological investigation of the SB population in Iceland and to assess health and well-being of the adult SB population.

Methods: The first part of the study was a retrospective study which described the incidence and prevalence of SB between 1972 and 2011; and the mobility, cognitive functioning and the comorbidities children with SB had at the age of five years. The second part of the study was a cross-sectional study and assessed the health and well-being of the adult Icelandic SB population currently living in Iceland, born between 1967 and 1996. Twenty-five participants (69%, age 18-47 years, 9 men and 16 women), took part and answered the survey "Research on the health and well-being of Icelanders in 2012". Each participant wore an accelerometer for seven days to measure physical activity and kept a physical activity diary. The waist- and hip-circumferences were measured to evaluate the risk of metabolic/lifestyle complications. In the third part of the study, the results of the questionnaire "health and well-being of Icelanders" were compared with the results from a group of Icelandic participants who answered the survey in 2012 (age 18-47 years, n=2159).

Results: The incidence of SB has markedly declined in Iceland during the last forty years. At five years of age most of the children with SB could walk, had a low borderline or normal intelligence and the comorbidities were mostly orthopedic impairments, impairments affecting the central nervous system and urinary and bowel function. Most participants with SB ($\geq 72\%$) considered their physical and mental health as being good or very good and similar or better than last year. Ninety-two percent of them didn't smoke, 32% didn't drink alcohol and 48% drank less than once a month. Adults with SB did not carry out moderately intense physical activity for 30 min. a day. Most of them had an increased waist circumference. This study also showed that adults with SB drank less alcohol than the comparison group but tended to eat unhealthily.

Conclusion: The incidence of SB has declined in recent years. Most five year old children with SB can walk, however as adults with SB they are at increased risk of developing life-style related conditions. Therefore, education about a healthy lifestyle is of uttermost importance.

Ágrip

Hrygggrauf er einn algengasti meðfæddi gallinn á miðtaugakerfinu. Einkennin eru margbreytileg og fylgikvillar margir sem kallar á þverfaglega nálgun í heilbrigðiskerfinu. Á þessari öld er slæmur lífsstíll meðal helstu orsaka sjúkdóma og ótímabærs dauða í iðnríkjum jafnt sem þróunarlöndum. Vegna hamlana og fylgiraskana eru einstaklingar með hrygggrauf í aukinni hættu á að þróa með sér lífsstílstengda sjúkdóma.

Markmið: Markmið rannsóknarinnar var að framkvæma lýsandi faraldsfræðilega athugun á hrygggrauf og að meta heilsu og líðan fullorðinna einstaklinga með hrygggrauf á Íslandi.

Aðferðir: Fyrsti hluti rannsóknarinnar var afturvirk rannsókn sem lýsti algengi og nýgengi hrygggraufar á árunum 1972 til 2011 meðal Íslendinga. Auk þess var lýst hreyfifærni, vitsmunaproska og viðbótarröskunum sem börn með hrygggrauf voru með þegar þau voru fimm ára. Annar hluti rannsóknarinnar var þversniðsrannsókn og mat heilsu og líðan fullorðinna Íslendinga með hrygggrauf, sem búa núna á Íslandi, fæddir á árunum 1967 til 1996. Tuttugu og fimm einstaklingar (69%, á aldrinum 18-47 ára, 9 karlmenn og 16 konur) tóku þátt og svöruðu könnuninni „Rannsókn á heilsu og líðan Íslendinga árið 2012“. Í þessum hluta rannsóknarinnar voru þeir einnig með hröðunarmæli á sér í sjö daga svo hægt var að mæla hreyfivirkni þeirra. Einnig héldu þau hreyfidagbók. Mittismál og ummál mjaðma voru mæld til að meta áhættu á lífsstílsjúkdómum. Í þriðja hluta rannsóknarinnar voru niðurstöður úr spurningakönnuninni bornar saman við niðurstöður frá Íslendingum sem tóku þátt í sömu könnun á árinu 2012 (á aldrinum 18-47 ára, 2159 þátttakendur).

Niðurstöður: Nýgengi hrygggraufar á Íslandi hefur lækkað verulega á seinustu 40 árum. Við fimm ára aldur gátu flest börn með hrygggrauf gengið. Þau mældust með vitsmunaproska á tornæmistigi eða innan eðlilegra marka og voru með viðbótarraskanir aðallega tengdar stoðkerfi, taugakerfi, nýrum og meltingarfærum. Flestir þátttakendur með hrygggrauf ($\geq 72\%$) mátu líkamlega og andlega heilsu sína sem góða eða mjög góða og svipaða eða betri en árinu áður. Níutíu og tvö prósent reyktu ekki, 32% drukku ekki áfengi og 48% drukku sjaldnar en einu sinni í mánuði. Rannsóknin sýnir einnig að fullorðnir einstaklingar með hrygggrauf eyða miklum tíma í kyrrsetu og stunda ekki 30 mínútna hreyfingu af miðlungs ákefð á dag. Flestir voru með aukið mittismál. Einstaklingar með hrygggrauf drekka minna áfengi en samanburðarhópur en hafa tilhneigingu til að borða óhollan mat.

Ályktanir: Nýgengi hrygggraufar á Íslandi hefur lækkað á undanförunum árum. Flest fimm ára börn með hrygggrauf geta gengið en sem fullorðnir einstaklingar eru þau í aukinni áhættu á að þróa með sér lífsstílstengda sjúkdóma. Fræðsla um heilbrigðan lífsstíl er því afar mikilvæg.

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List of abbreviations

ADL	Activities of Daily Living
BMI	Body Mass Index
cm	Centimeter
CIC	Clean Intermittent Catheterization
CNS	Central Nervous System
COPD	Chronic Obstructive Pulmonary Disease
CPM	Counts per Minute
CSF	Cerebrospinal Fluid
DASS	Depression Anxiety Stress Scales
FSIQ	Full Scale Intelligence Quotient
Hz	Hertz
IPAQ	International Physical Activity Questionnaire
IQ	Intelligence Quotient
MET	Metabolic Equivalent of Task
min	Minutes
mmHg	Millimeter of mercury
MTHFR	5,10-methylene tetrahydrofolate reductase
µg	Microgram
n	Number
NTD	Neural Tube Defects
PA	Physical Activity
PAC	Physical Activity Counts
PIQ	Performance Intelligence Quotient
s	Seconds
SB	Spina Bifida
SD	Standard Deviation
SDCC	State Diagnostic and Counselling Centre
US	United States
VIQ	Verbal Intelligence Quotient
VP	Ventriculoperitoneal
WHO	World Health Organization
y	Years

1 Introduction

1.1 Spina bifida

Spina bifida (SB) is one of the most frequent congenital deformities of the neural tube. SB is a complex congenital deformity of the neural tube with a variety of complications that require comprehensive multidisciplinary medical care (1, 2). Some of the complications are present at birth, like hydrocephalus and Chiari Type II malformation, and others develop later in life, like hypertension and obesity. Difficulties with mobility, bladder and bowel control can lead to poor self-esteem, social isolation, less independence, sexual dysfunction, learned helplessness and feelings of depression (1, 3-5).

1.1.1 Impairments

Neurological impairments associated with SB are motor paralysis, loss of sensation, learning disabilities and the Chiari Type II malformation with associated hydrocephalus. The degree of motor paralysis and loss of sensation depends on the location of the defect in the spinal cord. The higher the level, the more impairment in mobility and sensation. This impairment is not always symmetrical. One side can be more impaired than the other. All individuals with SB have some loss of sensation (5, 6). Children with a high lumbar-thoracic level can walk for short distances using high braces but by early adolescence most of them use a wheelchair for mobility. Children with a low lumbar level can walk with short braces and most of them will use a wheelchair for mobility when reaching adolescence. Children with a high sacral level use braces to stabilize the ankle and foot and usually continue walking through adolescence (5).

Motor paralysis, muscle imbalance and lack of mobility can lead to deformities, even before birth. Children with SB can be born with a clubfoot, dislocated hips, scoliosis or tethered cord but the last three complications can also develop later in life. When the spinal cord becomes attached to the surrounding tissues, instead of hanging loosely in the spinal canal, it is called a tethered cord. It reduces the blood flow to the spinal nerves and can cause damage. A tethered cord can develop as a result of scarring tissue at the site of the initial surgery. Lack of sensation (pain, heat) and mobility can lead to pressure sores or burns (5, 6).

Bladder and bowel dysfunction are present in nearly all individuals with SB because the nerves innervating them leave the spinal cord in the lower sacrum. Many have problems with sexual activities.

Almost all individuals with SB above the sacral level have a Chiari Type II malformation. In this malformation brainstem and cerebellar tissue are displaced downward toward the neck into the foramen magnum. See figure 1. Symptoms of this brainstem and spinal cord compression may include difficulty swallowing, choking, apnea and ophistotonos (5).

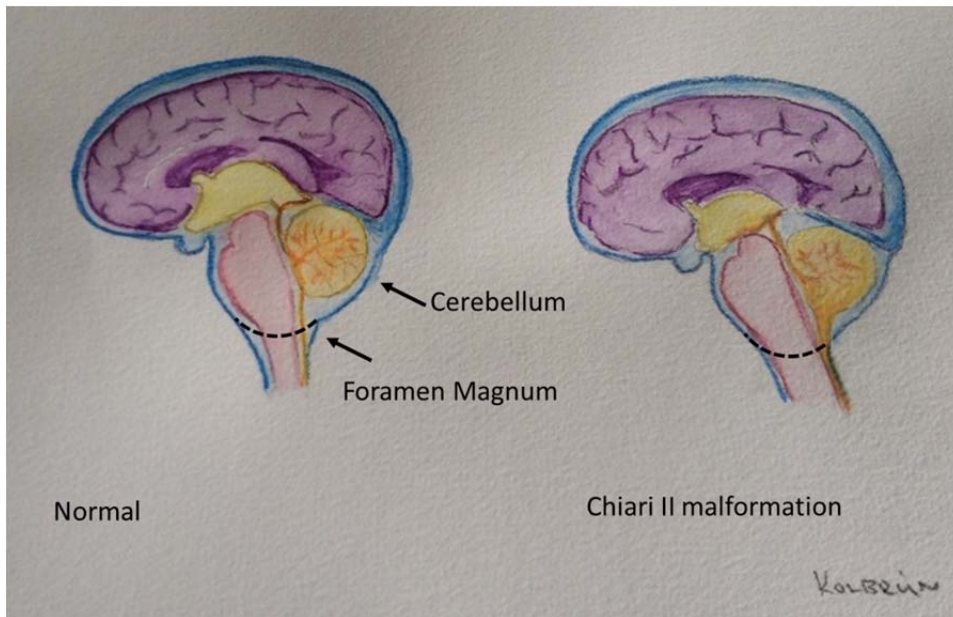


Figure 1. Chiari Type II malformation

Hydrocephalus is often associated with Chiari II malformation and occurs in 60-95% of individuals with SB and is a result of an abnormal cerebrospinal fluid (CSF) flow, resulting in enlargement of the ventricular system of the brain. It is treated by an implanted shunt. The most common is the ventriculoperitoneal (VP) shunt, draining the fluid in the abdominal cavity (5), as shown in figure 2.

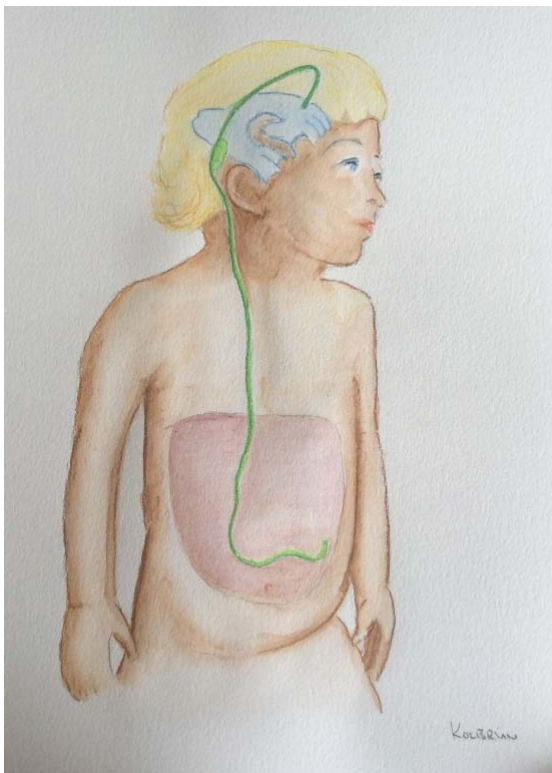


Figure 2. Ventriculoperitoneal shunt

Most of the individuals with SB but without hydrocephalus have an Intelligence Quotient (IQ) in the normal range (85-115), but those with hydrocephalus tend to have more cognitive impairments (7, 8).

Other impairments can develop during life, including hypertension and obesity.

1.1.2 Types of spina bifida

SB is classified into spina bifida occulta and spina bifida aperta. Spina bifida occulta is the most common form with an occurrence of 4.5-10% of the general population (5, 6). There is a split of the vertebral arches but the underlying neural tissue is intact. These individuals were thought not to have any neurologic symptoms but recently tethered cord and urinary tract disorders have been found among them (9, 10). Spina bifida aperta can be divided into meningocele and meningocele. When children are born with a protruding membranous sac containing meninges and cerebrospinal fluid the protruding sac is called a meningocele. The spinal cord itself is not entrapped and these children usually have no symptoms. When the sac is associated with the presence of a malformed spinal cord, the condition is called meningocele or simply spina bifida (5).

Meningocele, myelomeningocele, spina bifida, spina bifida aperta, spina bifida cystica, spinal dysraphism, and myelodysplasia are all synonymous and used interchangeably throughout the world (6). In this thesis the term spina bifida will be used, except when it is necessary to differentiate between meningocele and meningocele. Figure 3 shows the different types of SB.

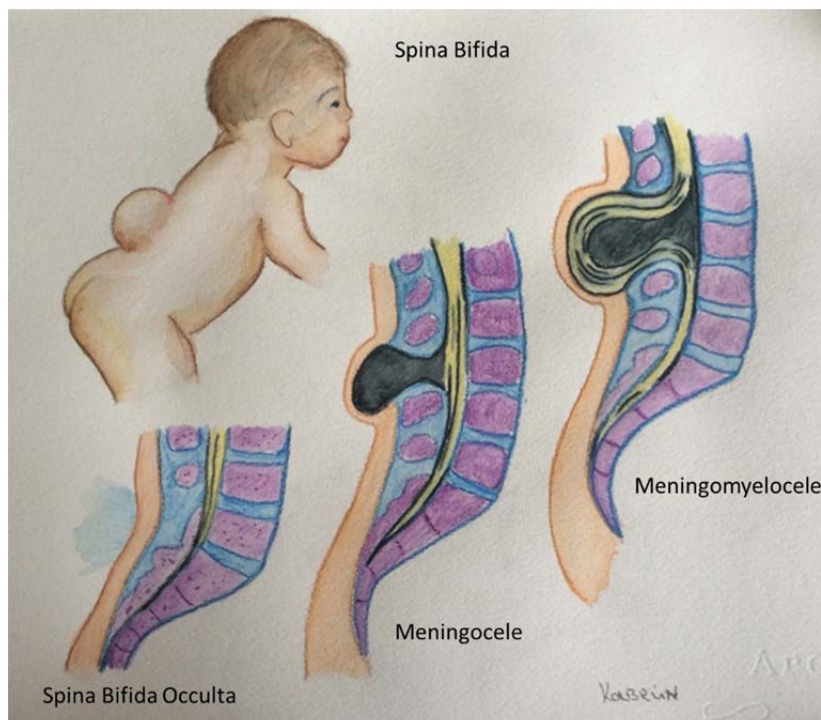


Figure 3. Types of spina bifida

1.1.3 History

Before the 1960s many newborns with SB were not treated surgically because of the poor prognosis. But in the early 1950s Holter and Spitz developed the first working shunt valve for the treatment of hydrocephalus in Philadelphia (11). Clean intermittent catheterization (CIC) was introduced in the

early 1970s by Lapides (12-14). These two innovations increased survival and improved the quality of life (12-14).

1.1.4 Etiology

Neural tube defects (NTD) are a group of malformations of the vertebrae, spinal cord and brain. The mechanism of neural tube closure is not fully understood and the causes remain uncertain. Genetic factors play a role as well as nutritional and environmental factors.

A few genes have been identified that increase the risk of developing NTD. One example is a mutation in the 5,10-methylene tetrahydrofolate reductase (MTHFR) gene, involved in the metabolism of folic acid, that predisposes the development of NTD (5, 6, 14).

Folic acid deficiency prior to conception and during early stages of pregnancy is known to contribute to the development of NTD (5, 6, 14). In the early 1960s, this was increasingly recognized as the major cause of preventable neural tube defects. When dietary modification and supplementation strategies proved inadequate, folic acid food fortification was legally mandated in the US in the late 1990s, which resulted in an abrupt decline (20%-27%) in the prevalence of neural tube defects at birth (15).

Maternal diabetes, obesity, exposure to antiepileptic drugs, hyperthermia (use of hot tubs) and alcohol abuse have been associated with increased risk of NTD (5, 6, 14).

1.1.5 Incidence and prevalence

The worldwide incidence of SB is 1.9 – 8.0 per 10,000 live births (14, 16, 17). Females are more often affected than males, with the male to female ratio 0.76 (18). The prevalence has decreased during the past 20-30 years because of folic acid supplementation and prenatal screening (16). In Iceland the incidence of SB between 1972 and 1976 was 6.4 per 10,000 births including stillborn children and those who died during the first week of life (19).

1.1.6 Prognosis and outcome

Before the use of VP shunts and CIC the survival rate was very poor. In the 1950s the survival to adulthood was less than 10% but had increased in the 1990s to 85% (5). Oakeshott *et al.* did a 40-year follow up with group (n=117) of individuals with SB aperta born between 1963 and 1971 in the UK. Thirty-four percent died before the age of five and 26% during the next 35 years. The death rate between five and 35 years was over 10 times the national cohort born in 1967 (20).

In the same cohort of SB at the age of around 35 about 85% of the survivors had a shunt, 72% an IQ of 80 or higher, 35% could walk 50 meters or more, 20% were fully continent, 56% had pressure sores, 56% were overweight, 41% lived independently, 37% drove a car, 24% were employed and 17% had children (21). Verhoef *et al.* found in a cohort of 142 individuals with SB aperta (age range 16-25 years) in the Netherlands that around 8% had epilepsy, 17% had an IQ of 70 or lower, 25% complained of pain in the head, neck or back, and 58% were sexually active but frequently reported problems with sexual functioning (2).

According to Iddon *et al.*, who studied intellectual and cognitive functioning, adults with hydrocephalus have a significant degree of dysfunction in many areas including memory, attention and executive functioning despite having a normal verbal and emotional intelligence (8). Barnes *et al.* found that adults with SB and hydrocephalus have difficulties with reading and comprehension. The mean Verbal IQ (VIQ) in their study (n=31, age range 18.5-36.3) was 95.4 and the mean Performance IQ (PIQ) 85.2 on the adult Wechsler Adult Intelligence Scale-Revised (22) which are both within the normal range (85-115).

1.2 Lifestyle-related conditions

Currently, lifestyle-related conditions are among the leading causes of morbidity and premature death in developing and developed countries (23, 24). Lifestyle-related conditions include hypertension, type 2 diabetes mellitus, obesity as well as ischemic heart disease, smoking related conditions, stroke, and many cancers (25, 26). The present focus of health care should be on prevention, cure and management of lifestyle conditions. Because of the limitations and complications associated with SB, individuals with SB are at increased risk for developing lifestyle-related conditions. They can have difficulties being physically active and are thus in danger of becoming inactive, which can easily lead to being overweight and therefore being at risk of getting hypertension and type 2 diabetes mellitus.

1.2.1 Spina bifida and lifestyle conditions

1.2.1.1 Obesity

Overweight and obesity are excessive fat accumulation that may impair health. The definition of overweight by the World Health Organization (WHO) is a body mass index (BMI) ≥ 25 and of obesity is a BMI ≥ 30 . BMI is defined as a person's weight in kilograms divided by the square of his height in meters (kg/m^2) (27). There is a large variation among studies in how body composition of individuals with SB is measured. BMI has been calculated in a few studies of SB and the results demonstrated that this group has a high BMI. But some researchers have indicated that a BMI calculation for this group can be falsely high because individuals with SB tend to be shorter, they may have scoliosis, contractures in the lower limbs and hypotrophic legs (28, 29). BMI for individuals with SB is sometimes measured by measuring the height from joint-to joint, or arm span is used instead of height or a supine stadiometer is employed (29). When measuring height from joint to joint the measurement error increases. Some studies use body fat measurements to examine the body composition. Body fat is measured by one of these methods: by measuring waist and extremity circumference, by the use of skin-fold calipers, dual energy x-ray absorptiometry or underwater weighing (29, 30). When using skin-fold measurements the lower limb should be included since individuals with SB may have hypotrophic legs. Dual energy x-ray absorptiometry and underwater weighing are both costly and time consuming methods.

Consensus is needed to form a standardized protocol with norms. WHO recognized the importance of abdominal fat mass which can vary considerably within the BMI and total body fat. There is convincing evidence that waist circumference and waist-hip ratio are useful measures for predicting

disease risk for the general population and may be justified when measuring the waist is easier and more accurate than measuring weight and height (31).

Buffart *et al.* (2008) found an obesity rate of 35% in adolescents and young adults with SB. BMI was measured in this study by measuring the height from joint to joint (32). Dosa *et al.* (2009) stated that obesity rates for adults with SB are slightly higher than the general population (37% compared to 32% in the general population), especially for woman. The height was measured using a standing stadiometer for ambulators and for non-ambulators the arm span length was used (33, 34). Garcia *et al.* found in a retrospective study an obesity rate of 37.5%. In their study self-reported height was used (35).

1.2.1.2 Hypertension

In a study by Buffart *et al.* 20% of young people with SB (aged 16-30) had hypertension, hypertension being defined as blood pressure $\geq 140/90$ millimeter of mercury (mmHg) (36). Liptak *et al.* found 21% of individuals with SB (aged 16-59) had hypertension (hypertension not defined) (37). Garcia *et al.* found in a retrospective study a hypertension rate of 38.3%. Hypertension was defined as having a systolic blood pressure greater than 140 mmHg (35). These three studies were either descriptive or a review and did not include comparison groups. In a study of children with SB (aged 3-18) Mazur *et al.* concluded that children with SB have a significantly higher prevalence of hypertension than children in the general population, 41.5% compared to 3%. Hypertension was defined as a systolic blood pressure or diastolic blood pressure ≥ 95 th percentile for age, gender and height on ≥ 3 occasions (38).

1.2.2 Spina bifida, health and lifestyle

The complications of SB result in an increased risk of developing an inactive lifestyle which may lead to decreased muscle strength and aerobic fitness, an increase in body fat, and a reduction in endurance leading to further inactivity and a lower quality of life (29, 32).

Research on adults with SB concerning health and lifestyle is scanty. A review performed by Crytzer *et al.* concerning physical activity (PA), exercise, and health related measures of fitness showed that adults with SB had an inactive lifestyle, lower aerobic capacity, decreased level of daily physical activities, higher prevalence of obesity, and lower health-related quality of life compared with reference values for other populations of individuals with disabilities (for instance individuals with spinal cord injuries) and without disabilities. The review was limited by the low number of studies (n=18) and the low quality. The studies had small sample sizes with low power (29).

Soe *et al.* examined health risk behaviors among young adults with spina bifida (n=130) and found that, compared to the general population, young adults with SB (aged 16-31) tend to eat less healthy diets, exercise less, and engage in more sedentary activities. On the positive side, they were less likely to use alcohol, tobacco or illegal drugs (39).

Murray *et al.* did a study of young adults (n=50, aged 18-19) and found that young adults reported similar frequencies of cigarette and marijuana use compared with peers but less frequent alcohol use (40).

Edelstein *et al.* studied sleep in children and adults with SB. Both groups reported more sleep problems than the control group. The problems reported by the adults concerned sleep timing and quality (41). Sleep apnea is a symptom related to Chiari Type II malformation of the brain which can be found in most individuals with SB above the sacral level (37).

Mental health is known to impact physical well-being and that optimism is associated with better health outcomes and pessimism with poorer ones. Anxiety and depression influence physical well-being and vice versa as illness and chronic conditions influence mental health (42). Stress is considered a normal part of life; however too much or prolonged stress leads to chronic physical complaints (42). Nearly half of the participants in the study of Soe *et al.* reported mild or major depressive symptoms (39). In a study with 97 adults with SB done by Hayter *et al.* 22% could be classified with severe-to-extremely severe levels of depression, anxiety (23%) and/or stress (16%) (43).

1.2.3 The effect of physical activity on lifestyle-related conditions

Hippocrates already recognized the importance of PA on health in the fifth century BC: *All parts of the body which were made for active use, if moderately used and exercised at the labor to which they are habituated, become healthy, increase in bulk, and bear their age well, but when not used, and when left without exercise, they become diseased, their growth is arrested, and they soon become old* (44). Today there is strong evidence of the health benefits of PA. Increased PA contributes significantly to blood pressure reduction, provides an effective way to delay or avert the development of diabetes mellitus and results in favorable changes in blood lipids. Moderate PA attenuates but does not eliminate the adverse effects of obesity on coronary risk (45, 46). Research has also shown an inverse relationship between physical activity and depression (47). PA should be implemented in daily life both as prevention and as part of a cure.

Physical therapists have a long tradition of using education and therapeutic exercise to work on health, illness, injury, and disability. They can play an important role in promoting positive lifestyle changes. Physical therapists meet their patients or clients over a long period of time and are thus in a position to assess the risks for developing lifestyle conditions and the need for referral to other health care professionals (42, 48). To prevent, cure or manage these disabling and mortal conditions physical therapy needs to include assessment of smoking and smoking cessation, basic nutritional assessment and counseling, recommendations for PA and exercise, stress assessment and basic stress recommendations, and sleep assessment and basic sleep hygiene recommendations (42, 48).

1.2.3.1 The measurement of physical activity

The Directorate of Health of Iceland recommends that adults should do at least 30 minutes (min.) of moderate-intensity PA daily. The total time may be divided into bouts of 10-15 min. Moderate-intensity PA is defined as activity that requires three to six times more energy as at rest, often expressed as 3-6 MET where MET stands for Metabolic Equivalent of Task. With moderate-intensity PA heartbeat and breathing will be faster as usual, but conversation is possible. Examples are brisk walking, gardening, housecleaning, cycling, swimming or jogging (49). Vigorous-intensity PA is defined as being more than 6 METs.

PA can be measured both by using objective methods and subjective methods. Subjective methods are questionnaires or surveys and diaries. These methods are easy and cheap to execute but are limited by recall bias, over- and under-estimation or misinterpretation. Objective methods include, for instance, direct observation of PA, but are time-consuming and therefore not convenient for large-scale studies. The doubly labelled water method in combination with indirect calorimetry is considered the gold standard but is expensive and has many practical problems. Motion sensors can register body motion. Pedometers and accelerometers use motion sensors. Pedometers count steps but are unable to provide information about intensity. Accelerometers can estimate overall PA but like the pedometers are unable to measure correctly upper body activity (like weight lifting) or activities like swimming and cycling (50). The ActivPAL™ physical activity monitor (PAL Technologies Ltd, Glasgow, UK) and the GT3X Activity Monitor (Actigraph, Pensacola FL, USA) are two examples of accelerometers.

Healthy adults take between 4,000 and 18,000 steps a day and 10,000 steps is considered a reasonable number (51). Tudor-Locke *et al.* introduced a graduated step index for healthy adults: 1) <2,500 steps a day (basal activity); 2) 2,500-4,999 steps a day (limited activity); 3) 5,000-7,499 steps a day (low active); 4) 7,500-9,999 steps a day (somewhat active); 5) ≥10,000-12,499 steps a day (active) and 6) ≥12,500 steps a day highly active (51). Special populations average 1,200-8,800 steps a day and these special populations are cancer patients or survivors, adults with chronic obstructive pulmonary disease (COPD), coronary heart diseases, diabetes, knee osteoarthritis, neuromuscular disease or fibromyalgia syndrome (52).

1.2.3.2 *The effect of physical activity on individuals with spina bifida*

Research about the effect of PA on individuals with SB is scanty. Oliveira *et al.* (2014) found in a systematic review three studies analyzing the exercise training effects on physical fitness of individuals with SB. All participants (n= 53, 55% male) were aged between 8 to 17.5 years and it appeared that exercise training is valuable for increasing cardiorespiratory endurance and muscle strength in individuals with SB (17). It is clear that more well-designed randomized control trials are needed to provide stronger evidence about the effects of exercise training on the physical fitness, mobility, independence and health of individuals with SB for all ages, especially for the adult population and to provide recommendations regarding PA.

1.3 Spina bifida in Iceland

1.3.1 Incidence and prevalence

Hreinsdóttir *et al.* investigated the incidence and types of central nervous system (CNS) defects diagnosed in fetuses and newborns over a 20 year period, 1972-1991 in Iceland. Ultrasound screening was organized nationwide in 1984 and as a result the incidence of defects of the CNS decreased in newborn children. As mentioned before, the incidence of SB between 1972 and 1976 was 6.4 per 10,000 births (19).

According to the Directorate of Health (by email, September 2014) food is not fortified by folic acid in Iceland but women who may become pregnant are advised to take 400 µg of folic acid daily and to

consume food rich in folic acid. A brochure with recommendations for the intake of folic acid was first released in 1999 and it is not known if such recommendations had been made before that time (Directorate of Health, by email, January 2015). The incidence and prevalence of SB in Iceland have not been investigated recently.

1.3.2 Services available for individuals with spina bifida

The State Diagnostic and Counselling Centre (SDCC) is a national institution dedicated to improving the lives of children with developmental disabilities and their families. The Centre works in accordance with the Act on the State Diagnostic and Counselling Centre (83/2003) and the aim of this Act is to ensure that children with severe developmental disorders which may result in handicaps are provided with diagnosis, counselling and other remedies aimed at ameliorating the consequences of their disorders, and also to ensure the acquisition, maintenance and dissemination of professional knowledge and skills in this field (53, 54). The SDCC was founded in 1986 and has since been in position to collect data on children with disabilities who were referred to the center. The database also contains data from Kjarvalshús, the predecessor of SDCC. All children with SB should be referred to the SDCC where they are offered long-term follow-up services until they are 18 years old. They attend multi-disciplinary clinics at the center along with their parents once or twice a year. The need for intervention, adaptive equipment and adaptation in their own environment is evaluated and implemented. Before starting primary school at the age of six all children with SB have their physical, cognitive, and communicative skills evaluated at the SDCC in order to inform the schools about the adaptations needed both in the environment and educational plans. At the age of 18 each individual with SB is referred to Grensásdeild, the rehabilitation department of the National University Hospital of Iceland where a team of specialists in adult disabilities provides coordinated care for adults with SB.

1.3.3 Health and well-being

Little is known about the health condition of adults with SB living in Iceland. As far as is known, no study has been done to assess the health and well-being of this population.

However the health and well-being of Icelanders in general has been researched. The survey "Health and well-being of Icelanders" has the purpose of regularly measuring the health, well-being and quality of life of the Icelandic population as well as impact factors like life-style and living conditions. The questionnaire "Research on the health and well-being of Icelanders in 2012" was conducted in 2012 by the Directorate of Health. That was the third time a similar survey had been carried out in Iceland; the first time was in 2007 and the second time in 2009. In 2012 the questionnaire was sent home to 10,162 Icelanders a week after a letter of introduction was sent to them. The final sample in 2012 consisted of 10,093 people aged 18-84 of whom 6,783 (67.2%) answered the survey.

2 Aim

The overall aim of this study was to perform a descriptive epidemiological investigation of the SB population and to assess the health and well-being of the adult SB population in Iceland.

The specific aims were:

1. To perform a descriptive epidemiological investigation of SB in Iceland by:
 - a. Describing the incidence of SB for the last 40 years and the prevalence today.
 - b. Describing the mobility, the intelligence quotients and the comorbidities that individuals with SB had at the age of five years.
2. To assess whether the present adult population with SB is at risk for developing lifestyle related conditions by:
 - a. Investigating and describing some chosen aspects of health and well-being of adults with SB in Iceland.
 - b. Measuring the PA of adults with SB.
 - c. Measuring the body fat distribution by measuring the waist and hip circumferences and calculating the waist-hip-ratio of adults with SB.
3. To compare some chosen aspects of health and well-being of adults with SB in Iceland with the same aspects of the Icelandic population in general.

3 Methods

3.1 Type of study

This study was a population based study divided into three parts. The first part was a descriptive epidemiological investigation of the SB population. It was a retrospective study where the researcher found information from the database of the SDCC, from the National University Hospital of Iceland and from the State Social Security Institute. The State Social Security Institute, as its name implies, supervises the payment of pension insurance and social assistance and is regulated by The Ministry of Welfare.

The second part of the study was a cross-sectional study and assessed the health and well-being of the adults with SB in Iceland, born between 1967 and 1996. Adults with SB answered selected questions from the questionnaire “Health and well-being of Icelanders” and their physical activity was measured. These two cohorts partly overlapped.

The third part was also a cross-sectional study which compared the results from the questionnaire “health and well-being” of adults with SB to the results of a sample of Icelanders which took part in the survey in 2012.

3.2 Epidemiology

3.2.1 Incidence and prevalence of Spina Bifida

A list of names of all people with the diagnosis SB was obtained from the SDCC. As all children with SB should according to law be referred to the center (53) it was thought that the list should contain the complete Icelandic cohort. When the measurements for the second part of the study started it became apparent that the list was incomplete and permission was then obtained to get a list of all people 18 years and older with SB from the State Social Security Institute and the National University Hospital of Iceland. The list from the State Social Security Institute concerned all individuals with the ICD-10 number Q05 and its subgroups, according to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) (55). The National University Hospital of Iceland is the hospital in which almost all children with SB underwent surgery after birth and in addition almost all individuals with SB go for their medical care. Medical records at the National University Hospital of Iceland were used to verify if people were correctly diagnosed with SB. While going through the medical records it was noticed that meningocele and meningomyelocele were used inconsistently. To prevent underestimation of the prevalence and incidence of SB, both individuals with meningocele and meningomyelocele were included in the first part of the study concerning incidence and prevalence. For two individuals it was unclear whether they had meningocele or meningomyelocele. These two individuals were included when calculating the incidence and prevalence. Excluded were those with occipital encephalocele and spina bifida occulta. The total number of births was obtained from Statistics Iceland as well as the size of the total population (56, 57).

3.2.2 Mobility, intelligence and comorbidities at five years

The database of the SDCC was consulted to get information about the mobility status, the intelligence quotients and existence of comorbidities when the individuals with SB were five years old. The mobility status was retrospectively ranked according to "Hoffer's criteria" (community walker, household walker, exercise walker, non-walker). Community walkers walk indoors and outdoors for most of their activities and may need crutches or braces, or both. They use a wheelchair only for long trips out of the community. Household walkers walk only indoors and with equipment. They may use the wheelchair for some indoor activities at home and school and for all activities in the community. Exercise walkers walk only for therapy and use wheelchair for ambulation. Non-walkers depend solely on a wheelchair for ambulation (58, 59).

One of the tests used for testing the cognitive functioning was the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) (60, 61). The test was administered and Verbal IQ (VIQ), Performance IQ (PIQ), and Full Scale IQ (FSIQ) were obtained. The WPPSI has been revised during the years and the norms changed so the results are based on three different versions of the test, the WPPSI (with United States (US) norms) (60), the WPPSI-R (revised, US norms) (61) and the WPPSI-Ris (the validated Icelandic edition of the test) (62). Guðmundsson *et al.* (63) examined the validity of the WPPSI with a group of 70 healthy preschool children (40 boys and 30 girls aged 45-52 months old). Georgsdóttir *et al.* (64) tested Icelandic children born with extremely low birth weight with the WPPSI-R and had a control group of 55 healthy preschool children (aged five years and three months to five years and eight months). The results from Guðmundsson's group (WPPSI) and from Georgsdóttir's control group (WPPSI-R) were used for comparison of the results of the WPPSI and WPPSI-R from the Icelandic children with SB.

3.3 Health and well-being – risk factors for developing lifestyle-related conditions

3.3.1 Participants

For the second and third part of the study concerning health and well-being of the adult SB population, people with occipital encephalocele, spina bifida occulta, meningocele or with severe cognitive limitations were excluded. The two individuals for which it was unclear if they had meningocele or meningomyelocele were excluded since they had had no neurological problems when young. Included were those with meningomyelocele, born in Iceland and ≥ 18 years old. Figure 4 shows the selection procedure.

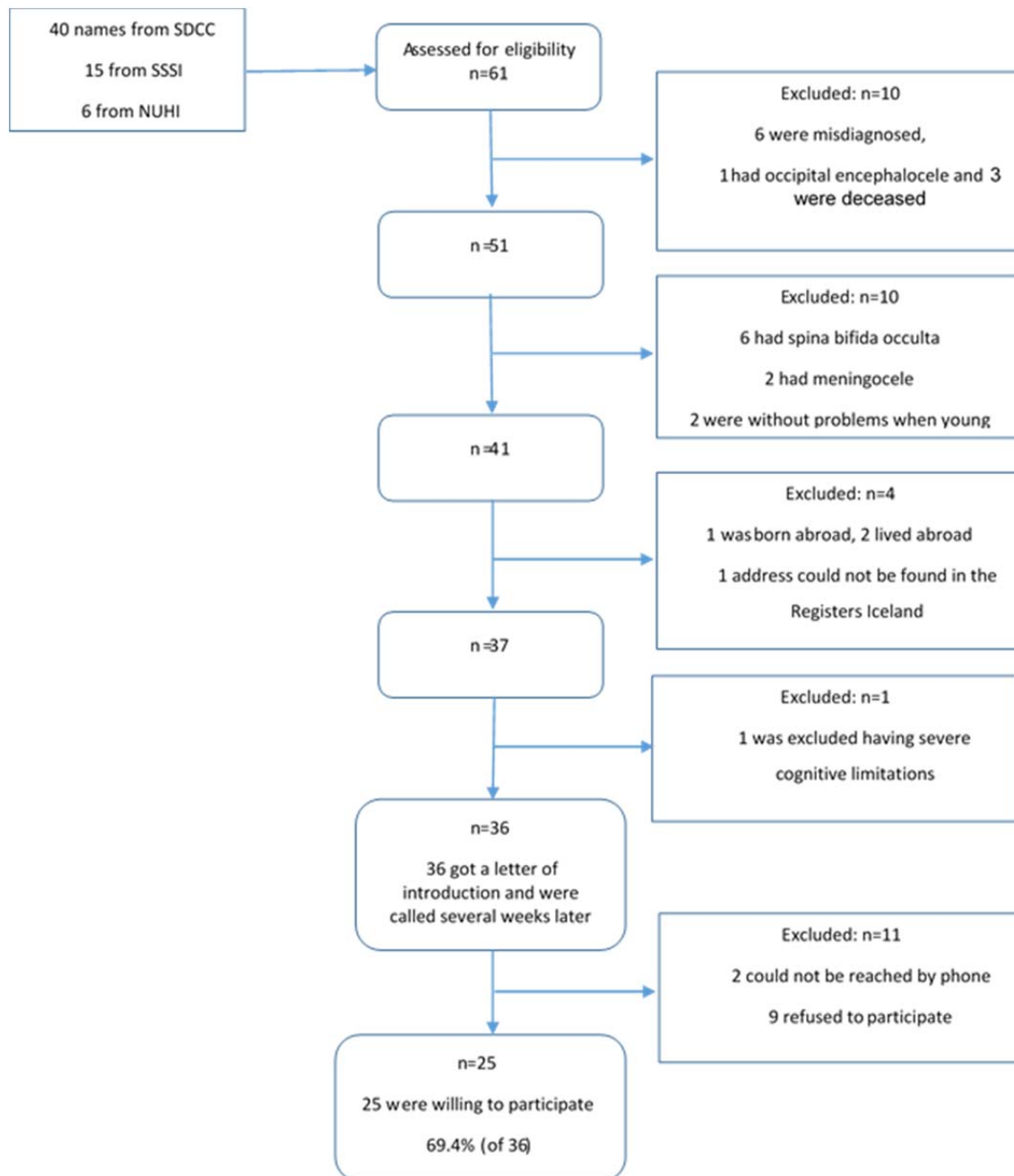


Figure 4. Selection procedure for the second and third parts of the study

SSSI= State Social Security Institute, NUHI=National University Hospital of Iceland

The study was approved by the Faculty of Medicine at the University of Iceland. Ethical approval was obtained from The National Bioethics Committee (VSNb2014060004/03.07) and The Data Protection Authority (2014060893TS/--). Permission was obtained from the Directorate of Health to use a selected part of the questionnaire “Research on the health and well-being of Icelanders in 2012” and to get the results from the Icelandic population from 2012 to the same questions. Permission was obtained from the State Social Security Institute to get the list of names of all individuals with the diagnosis SB who were 18 years and older from their database and from the National University Hospital of Iceland to get access to their database. And permission was also obtained from the SDCC

to get access to their database. Written informed consent was collected from the participants who took part in the second part of the study (Appendix 2).

3.3.2 Procedure

Several weeks after the potential participants had received a letter with information about the study (Appendix 1) they were called by phone to ask if they wanted to take part. Those who agreed to participate were invited to come to the SDCC where the measurements took place. Two persons were measured in the north of Iceland, at Bjarg, the Rehabilitation Centre of Sjúkshöfðin in Akureyri, and one was measured at home. The measurements took place from September 2014 to March 2015.

3.3.3 Measurements

The participants were asked to fill in part of the questionnaire “Research on the health and well-being of Icelanders in 2012” (65) (Appendix 3). The second measurement is a measure of the physical activity. Since some of the participants were ambulatory and others used wheelchairs two methods were used. For the third and last measurement, the waist and hip circumference were measured and the waist-hip-ratio was calculated. In addition to the questionnaire the group answered four questions focusing on aspects of SB (level of lesion, ambulatory status according to Hoffer’s criteria and the presence of a shunt) and independence in activities of daily living (ADL) (Appendix 4).

3.3.3.1 *Assessment of health and well-being*

To measure certain aspects of health and well-being the questionnaire “Health and well-being of Icelanders (2012)” was used. The questionnaire consisted of 123 questions divided into 21 subcategories. Examples of these subcategories are general health, illness, PA and sitting, smoking, sun and sunbathing and income and financial position.

Many questions in the survey have been adopted from recognized measurements or scales while other questions are original (see appendix 3). To give some examples, the questions about PA nos. 52 and 53 are based on a shorter version of the International Physical Activity Questionnaire (IPAQ), no. 54 is a question from the IPAQ and questions nos. 55-60 are original. Among the questions about well-being and the quality of life is the shorter version of the Depression Anxiety Stress Scales (DASS) (questions nos. 68 and 69). Question no. 63 about happiness is standardized and has been used in many studies, like the European Social Survey. And a question about sleep (no. 76) is based on the RHINE questionnaire about sleep (66, 67).

The answers were rated on a nominal scale (Do you smoke? Yes, no), an ordinal scale (I felt down-hearted and blue: never, sometimes, often, almost always) and on a ratio scale (What is your height?). Most questions were on an ordinal scale.

For this study the participants with SB were asked to answer 52 questions from 10 subcategories (general health, smoking habits, use of alcohol, nutrition, height and weight, common activities, PA and sitting, well-being and quality of life, social participation and sleep). Some completed the survey when they came to the SDCC for measurements but most participants filled out the survey at home. Several participants needed some assistance with a few questions. The results from the participants from this study were used to assess certain aspects of health and well-being.

3.3.3.2 *Physical Activity*

The physical activity of those who were ambulatory were measured by the ActivPAL accelerometer. The ActivPAL is a small lightweight device worn on the thigh (shown in figure 5). The ActivPAL is a single unit device, requiring no calibration that records step numbers and instantaneous cadence for each period of walking. In addition, the monitor identifies episodes of walking, sitting and standing in real time (68). The ActivPAL has been shown to be a valid and reliable device for measuring step numbers and cadence in a healthy adult population (68, 69). There are a limited number of studies providing promising evidence that the ActivPAL may be a valid tool for the assessment of sedentary behavior in adults (69). The device is worn on the subject's thigh for up to a week at a time. The pattern (sedentary, standing and stepping) and intensity of a subject's activities can be captured and analyzed using custom designed software. The resultant evidence may then be downloaded as clear graphs and spreadsheets. The ActivPAL was put in a waterproofed flexible sleeve, attached to the thigh (mid front) with OPSITE[®] FLEXIFIX[®] transparent film (Smith & Nephew Medical Ltd, Hull, England) and initialized for seven days. The ActivPAL measured the sitting-lying time, standing time, stepping time and counted the number of steps taken. Fourteen participants (56%) wore the ActivPAL during seven days. Two of them were ambulatory but wheelchair users as well and also wore an Actigraph around the wrist. A third person did get both the ActivPAL and the Actigraph but did not like the feeling of the ActivPAL on his leg so he only used the Actigraph.



Figure 5. ActivPAL and Actigraph accelerometers

The wheelchair users among the participants wore the GT3X Actigraph accelerometer (shown in figure 5). The GT3X Activity Monitor delivers objective 24 hour physical activity and sleep/wake measurements including raw acceleration, activity counts, energy expenditure, physical activity intensity, body position, and amount of sleep, while a light sensor provides valuable information about the subject environment. The Actigraph measures accelerations which are converted into physical activity counts (PAC). The Freedson Adult vector magnitude count value for PA at moderate intensity is from 2,691-6,166 counts per minute (CPM) (70). Actigraphy is suitable as a measurement of activity for people with spinal cord injury and other wheelchair users (71). In a study with twenty participants with spinal injury Garcia-Massó *et al.* found that the non-dominant wrist was the best placement for the device (72).

Thirteen participants (52%) wore the Actigraph during seven days. Two of them who were also ambulatory wore an ActivPAL as well. In this study the Actigraph was placed on the non-dominant

wrist and was initialized for seven days of measurement using 1-second (s) epochs (a sampling frequency of 60 Hertz (Hz)). A participant removed the device when he/she went swimming, took a shower or bath or went to bed. The PACs were summated in 60-s epochs. The Freedson adult cut-off points for PA at moderate intensity (2,691-6,166 CPM) were determined in a study where participants wore the Actigraph on the hip and can therefore not be used by participants in a wheelchair. Results from the study by Nightingale *et al.* (71) were used to calculate cut-off points for wheelchair users.

Self-reported physical activity: since both the ActivPAL and Actigraph have their limitations, as mentioned before, the participants were also asked to keep a PA diary to especially write down the PA not measured by the ActivPAL or Actigraph. During the 7 days they wore the ActivPAL and/or Actigraph the participants got an email to remind them to keep the PA diary and to ask if everything was all right or if there were any problems. After the seven days the devices and diaries were picked up at their home (those living in the capital area) or sent back by mail (those living in the country).

3.3.3.3 *Waist Circumference and Waist-Hip Ratio*

After considering various ways of measuring body composition it was decided to measure the waist circumference and the hip circumference to be able to calculate the waist-hip ratio. Measuring the waist and hip circumference is an easy and cheap measurement which can be done by all physical therapists in their practice.

The waist and hip circumference measurement protocol from the WHO was used (31). The participant stood upright during the measurement, with arms relaxed at the side, feet evenly spread apart and body weight evenly distributed. The waist circumference was measured at the end of several consecutive natural breaths, at a level parallel to the floor, midpoint between the top of the iliac crest and the lower margin of the last palpable rib in the mid axillary line. The hip circumference was measured at a level parallel to the floor, at the largest circumference of the buttocks. Both measurements were made with Figure Finder® Tape Measure (Novel Products, Inc. Rockton, IL, USA) a stretch-resistant tape providing consistent and repeatable 4 oz. of tension, which was wrapped snugly around the participant. The tape was kept level and parallel to the floor at the point of measurement. There is no protocol from WHO for measuring the waist and hip circumference measurement by people who are not able to stand. Therefore those who were able to stand were measured both standing and lying down to see if there was a difference between these two measurements. Those participants who were not able to stand were measured while lying supine. Since it was not always clear where the largest circumference of the buttocks was while supine, it was decided to measure at the femoral trochanter level. The waist-hip ratio was calculated by dividing the waist circumference by the hip circumference.

As there are no specific cut-off points for individuals with SB the WHO cut-off points (table 1) were used to see if the participants are at increased risk of metabolic complications (31).

Table 1. World Health Organization cut-off points and risk of metabolic complications

Indicator	Cut-off points	Risk of metabolic complications
Waist circumference	>94 cm (M); >80 cm (W)	Increased
Waist circumference	>102 cm (M); >88 cm (W)	Substantially increased
Waist-hip ratio	≥0.90 (M); ≥0.85 (W)	Substantially increased

M= men; W= women; cm= centimeter

3.4 Health and well-being - comparison of aspects of health and well-being between Icelanders with Spina Bifida and Icelanders without Spina Bifida

The answers of the Icelandic participants who took part in the survey from 2012 were obtained from the Directorate of Health to be able to compare those answers with the answers of the adults with SB in Iceland taking part in the current study. Of the 6,783 people who had answered the questionnaire only the answers from the same age group as the participants with SB in the current study were used (n=2159, age 18-47).

3.5 All the participants in the study

Figure 6 shows all the participants in the study.

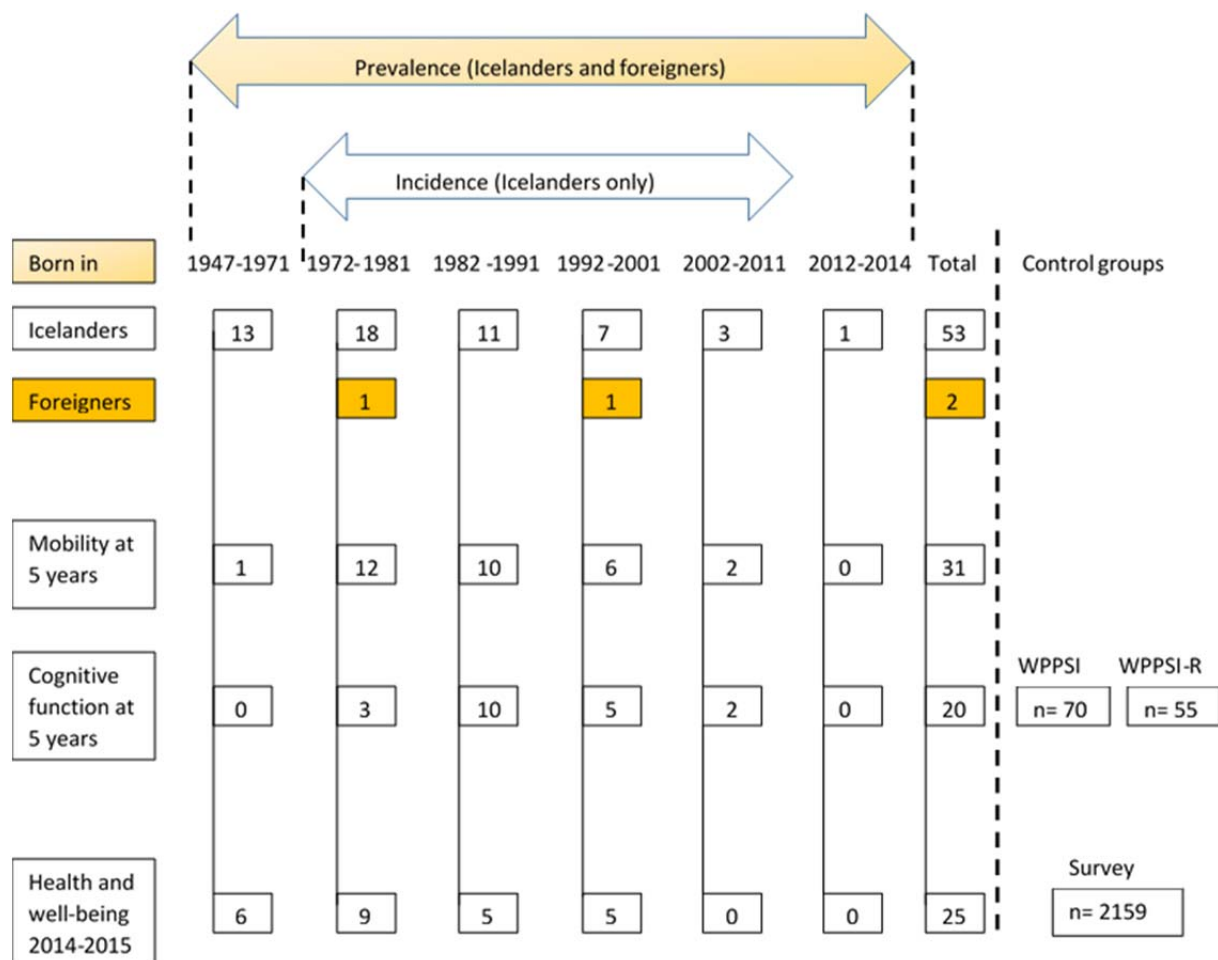


Figure 6. The participants in the study

3.6 Statistical analysis

Excel 2013 (© 2013, Microsoft, Redmond WA, USA) and SAS Enterprise Guide 6.1 (©2013, SAS Institute Inc., Cary NC, USA) were used for calculations and statistical analysis. The significance level in all tests was set at $p < 0.05$.

Descriptive statistics were used for analysis of the whole group with SB in Iceland and the subgroup who took part in the second part of the study. Inferential statistics were used to explore the relationship and differences in the group and between the group with SB and the different comparison groups.

The number of individuals born with SB (incidence) for each decade was calculated and also the prevalence of SB today. The two-sided chi square trend test was used to analyze the change in incidence rate over a forty year period.

The mobility status was retrospectively ranked according "Hoffer's criteria" (community walker, household walker, exercise walker, non-walker) and the frequency distribution with percentage in each category was calculated. Information on the cognitive status that had been measured when the participants were 5 years old was compared to the normative criteria of the cognitive tests. The one sided t-test was used for comparison of the mean of cognitive outcomes between the group of children with SB and two control groups with healthy children from the studies done by Guðmundsson *et al.* and Georgsdóttir *et al.* (63, 64) respectively. The frequency distribution in percentage for hydrocephalus, shunt, breech presentation and Arnold Chiari malformation was calculated.

The frequency distribution in percentage for each question in the survey was calculated. The results from question 68 and 69 (the shorter version of the DASS) were scored according to the DASS and the frequency distribution in percentage was calculated.

The ActivPAL measured the time in sitting-lying, standing and stepping. It also counted the number of steps taken. Sitting time was calculated by subtracting the self-reported lying time of the sitting-lying time. For each participant the average was calculated by adding the results for all valid days and dividing by the number of valid days. The participants were classified according to the step-index by Tudor-Locke *et al.* (51) and the frequency distribution in percentage was calculated for each category.

Cut-off points for moderate PA for the Actigraph users in this study were calculated by using the results of a study by Nightingale *et al.* (71). They found 8,192 counts per minute (CPM) equivalent for 2.3 METs, 11,712 CPM equivalent for 3.5 METs, 17,105 CPM for 4.7 METs and 25,599 CPM for 6.4 METs when the participants wore the Actigraph on the wrist. These numbers were used to calculate the CPM for 3 METs (=10,245 CPM) and for 6 METs (=23,600 CPM). The number of each 10 min. epochs of moderate PA was calculated as well as the total time spent in moderate PA or in vigorous PA (>6 METs) and the total number of counts per day. For each participant the average was calculated by adding the results for all valid days and dividing the sum by the number of valid days. Then the average for the whole group was calculated.

The waist-hip ratio for each individual was calculated by dividing the waist circumference by the hip circumference and the frequency distribution in percentage was calculated for the group.

The chi square test was used for comparison of health aspects between the group of people with SB and the Icelandic population without SB that participated in the survey "Research on the health and well-being of Icelanders in 2012". Because of the small number of participants with SB the answers to the questions with many answers were grouped together to reduce the number of answers in order to be able to use the chi square test. For instance, in the question about nutrition the seven answers were reduced to three: never, less than once a week, and once a week became \leq once a week, two to three times a week, and four to six times a week became two to six times a week and once a day, and twice or more often a day became \geq once a day.

4 Results

4.1 Epidemiology

4.1.1 Incidence and prevalence of Spina Bifida

The cohort consisted of 55 individuals with meningocele and meningomyelocele, aged 2-71 years old (91% of the Icelandic cohort born in 1967 or later). The male to female ratio in the Icelandic population of individuals with SB was 0.77. Table 2 shows the incidence of SB in Iceland between 1972 and 2011. The year 1972 was chosen because that was the year birth registration started (19). The two-sided chi square trend test demonstrated a significant decline ($p < 0.001$) over a 40 year period. Those who were stillborn, died in the first week or where the pregnancy was terminated were not included.

Table 2. Incidence of Spina Bifida in Iceland

Time period	Number of SB cases	Number of live births	Incidence per 10,000 live births
1972-1981	18	43,731	4.1
1982-1991	11	43,285	2.5
1992-2001	7	43,118	1.6
2002-2011	3	44,941	0.7

Number of live births: Statistics Iceland (56)

The prevalence of Spina Bifida in Iceland on Jan 1, 2014, was 1.5 per 10,000 inhabitants, 50 individuals in a population of 325,671 (57) with a male to female ratio of 0.92.

4.1.2 Mobility at five years

Information about mobility at the age of five years was found for 31 individuals. From the data available it wasn't clear for 11 individuals if they were community walkers or household walkers and for two it wasn't clear if they were exercise walkers or non-walkers. Therefore the whole group was also classified as walkers (community walkers and household walkers) or non-walkers (exercise walker and non-walker). The results are shown in table 3.

Table 3. Mobility at five years of age

	n (%)
Community walker	16 (51.6)
Household walker	0 (0)
Community or household walker	11 (35.5)
Exercise walker	1 (3.2)
Non-walker	1 (3.2)
Exercise walker or non-walker	2 (6.5)
Total	31 (100)
Walker	27 (87.1)
Non-walker	4 (12.9)
Total	31 (100)

4.1.3 Cognitive function at five years

Twenty participants with SB underwent a neuropsychological evaluation at the State Diagnostic and Counselling Centre (SDCC) and at Kjarvalshús, when they were five years of age (range from four years and four months to six years and four months). Eight children were evaluated between 1983 and 1993 with the WPPSI (60) (US norms), 9 children were evaluated between 1993 and 1999 with WPPSI-R (61) (revised, US norms) and 3 children were evaluated between 2004 and 2012 with WPPSI-R^{IS} (62) (the validated Icelandic edition of the test). The results are shown in table 4. Eleven children (55%) had normal intelligence (FSIQ > 85), six children (30%) had sub-average intelligence (FSIQ 70-84) and three children (15%) were diagnosed with mild intellectual impairment (FSIQ 50-69). The average FSIQ for all children with hydrocephalus (n=18) was 81.9 (SD 20.4). The one sided t-test showed a significant difference ($p<0.05$) between the mean of cognitive outcomes between the group of individuals with SB and the two groups from Guðmundsson *et al.* and Georgsdóttir *et al.* (63, 64) respectively, for the VIQ, PIQ and FSIQ.

Table 4. Results of the WPPSI (performance, verbal and full-scale IQ)

Test	n	IQ	Mean	SD	range
WPPSI	8	PIQ	78.4	16.2	48-94
		VIQ	80.3	15.3	62-101
		FSIQ	77.3	16.3	51-97
WPPSI-R	9	PIQ	90.2	10.8	76-110
		VIQ	90.7	7.7	81-106
		FSIQ	89.1	8.9	77-101
WPPSI-R ^{IS}	3	PIQ	90.3	12.2	77-101
		VIQ	79.0	4.4	76-84
		FSIQ	82.3	7.2	74-87

4.1.4 Comorbidities at five years

4.1.4.1 *Hydrocephalus and a shunt*

Table 5 shows the presence of hydrocephalus and insertion of a shunt at birth in the whole group and the presence of shunt in the participants in the second part of the study.

Table 5. Hydrocephalus and a shunt in Icelandic people with Spina Bifida

	Hydrocephalus and a shunt at birth (%)	Shunt in 2014/2015 (%)
Yes	33 (62)	19 (76)
No	3 (6)	6 (24) ^a
Missing information	17 (32)	
Total number	53	25

a. Two of them had a shunt when they were younger but it was removed when they grew up.

4.1.4.2 *Breech presentation*

In the database of the SDCC a breech presentation was reported for 8 of 23 children (34.8%).

4.1.4.3 *Arnold Chiari malformation type 2*

In the database of the SDCC information about the presence of the Arnold Chiari malformation type 2 could be found for 16 individuals. Ten of those 16 (62.5%) did have the malformation and six (37.5%) did not have the malformation.

4.1.4.4 *Other comorbidities*

When going through the database of the SDCC it was noticed that the amount of information about the children varied: for some children who had come just a few times to the center there was little information while for other children who had come regularly for many years there was a lot of information. So it was decided to just list the other comorbidities, without giving information on the number of children who had those comorbidities to prevent underestimating the incidence of these comorbidities. At the age of five years children with SB had been diagnosed with orthopedic impairments like scoliosis, kyphosis, hip luxation, equino-varus deformity, calcaneus deformity and fractures and impairments affecting the central nervous system like a blocked shunt, shunt malfunctioning, tethered cord, central cerebral hernia, seizures and secondary brain injury after a seizure or shunt malfunctioning. Impairments in urinary and bowel function included neurogenic bladder, urinary tract infections, cystitis, vesicoureteral reflux and neurogenic bowel. Other impairments were inguinal hernia, iron deficiency anemia, blindness and skin sores.

4.2 Health and well-being – risk factors for developing lifestyle-related conditions

4.2.1 Participants

Twenty five (69%) agreed to take part in the second and third parts of the study concerning health and well-being. The participants' characteristics are presented in table 6.

Table 6. Characteristics of participants

Characteristics		n (%)
Sex	Male	9 (36) ^a
	Female	16 (64) ^a
Age (y)	18-27	8 (32)
	28-37	7 (28)
	38-47	10 (40)
Ambulatory status	Community walker	11 (44)
	Household walker	4 (16)
	Exercise walker	2 (8)
	Non-walker	8 (32)
ADL independency	Independent	23 (92)
	Assistance from family	2 (8)
	Assistance from services	0
Self-reported level of the lesion ^b	Thoracic	1 (4)
	Lumbar	6 (24)
	Sacral	5 (20)
	Did not know	13 (52)

a. 69% of the invited men took part in the study and 70% of the invited women

b. Only 3 were able to name the level exactly: L2-3, L4-5 and S2-3

4.2.2 Survey

Table 7 shows the results of the 25 SB participants answering selected questions of the questionnaire "Health and well-being of Icelanders in 2012" (the column marked SB) as well as the results from the Icelandic comparison group (who took part in the Directorate of Health's survey in 2012) to the same questions (the column marked control). The results from the chi square test are also shown in the same table.

Table 7. Aspects of health and well-being - comparison between participants with SB and the group of Icelanders who took part in a study conducted by the Directorate of Health in 2012.

		SB (%) (n=25)	Control (%) (n=2159)	P value*
Physical health	Good or very good	76	80	0.59
	Reasonable or poor	24	20	
	Similar or better than last year	88	88	0.98
	Worse than last year	12	12	
Mental health	Good or very good	72	82	0.18
	Reasonable or poor	28	18	
	Similar or better than last year	96	90	0.34
	Worse than last year	4	10	
Smoking	Yes	8	18	0.18
	No	92	82	
Alcohol	Have used alcohol	76	97	<0.001*
	Have never used alcohol	24	3	
Frequency	Drink daily to once a month	20	22	<0.001*
	Drink less than once a month	48	68	
	Never drink	32	10	
Drinking ≥ 5 drinks the last 12 months	Daily to once a month	8	4	0.001*
	Less than once a month	32	67	
	Did not drink the last 12 months	60	29	
Number of drinks each time	0-3	87	57	0.16
	3.5-6	11	29	
	>6	2	15	
Nutrition	How often eaten			
Fruit	≥ 1 x a day	36	40	0.01*
	2-6 x a week	28	45	
	≤ 1 x a week	36	15	
Vegetables	≥ 1 x a day	28	42	0.004*
	2-6 x a week	44	49	
	≤ 1 x a week	28	9	

Fish	≥ 2 x a week	44	49	0.64
	< 2 x a week	56	51	
Milk or milk products	≥ 1 x a day	28	43	0.048*
	2-6 x a week	32	36	
	≤ 1 x a week	40	20	
Whole grain products	≥ 1 x a day	24	27	0.55
	2-6 x a week	40	47	
	≤ 1 x a week	36	26	
Fast food	≥ 1 x a day	0	0	0.34
	2-6 x a week	24	14	
	≤ 1 x a week	76	86	
Sweetened soda	≥ 1 x a day	28	11	0.004*
	2-6 x a week	4	26	
	≤ 1 x a week	68	63	
Cod-liver oil	≥ 1 x a day	36	35	0.85
	2-6 x a week	12	16	
	≤ 1 x a week	52	49	
Vitamins and minerals	≥ 1 x a day	44	31	0.37
	2-6 x a week	12	15	
	≤ 1 x a week	44	54	
I try to eat healthy food	Applies very well or rather well to me	80	80	0.95
	Neither nor	16	15	
	Applies poorly or very poorly to me	4	5	
Self-reported BMI	≥ 25	68	60	0.41
	< 25	32	40	
How satisfied are you with your weight	Very or rather satisfied	36	40	0.68
	Neither nor	24	17	
	Very or rather unsatisfied	40	43	
Have you been trying to lose or gain weight the last 12 months	I am/was trying to lose weight	60	59	0.33

	Neither losing nor gaining	28	36	
	I am/was trying to gain weight	12	6	
PA in leisure time the last 7 days	Sitting or moderate active	75	78	0.74
	Vigorous activity for at least 4 hours	25	22	
Sitting time the last 5 workdays	≤ 7 hours a day	21	61	<0.001*
	≥ 8 hours a day	79	39	
How is your physical endurance compared to your peers	Some or much more	12	30	<0.001*
	The same	28	46	
	Some or much less	60	25	
How is your physical strength compared to your peers	Some or much more	20	34	0.04*
	The same	44	49	
	Some or much less	36	17	
I've been looking optimistically to the future	Never or seldom	16	6	0.14
	Sometimes	24	21	
	Often or always	60	72	
I felt useful	Never or seldom	16	4	0.04*
	Sometimes	20	18	
	Often or always	64	78	
Happiness on a scale 0-10 (10= very happy)	Score 1-4	8	5	0.76
	Score 5-7	32	28	
	Score 8-10	60	66	
I felt down-hearted and blue	Never or sometimes	80	88	0.19
	Often or almost always	20	12	
I was aware of dryness of my mouth	Never or sometimes	88	94	0.20
	Often or almost always	12	6	
I couldn't seem to experience	Never or sometimes	96	95	0.83

any positive feeling at all				
	Often or almost always	4	5	
I'm happy with the way I look	I agree or rather agree	64	60	0.77
	Neither nor	12	18	
	I disagree or rather disagree	24	22	
My body is sexually attractive	I agree or rather agree	17	36	0.001*
	Neither nor	25	38	
	I disagree or rather disagree	58	25	
I'm physically unattractive	I agree or rather agree	21	48	0.02*
	Neither nor	42	22	
	I disagree or rather disagree	38	30	
I was unable to become enthusiastic about anything	Never or sometimes	92	92	0.96
	Often or almost always	8	8	
Difficulties falling asleep	Never or seldom	56	59	0.91
	Sometimes	28	24	
	Often or always	16	17	
Waking up and then having difficulties falling asleep again	Never or seldom	68	62	0.30
	Sometimes	12	24	
	Often or always	20	14	
Waking up well rested	Never or seldom	16	31	0.27
	Sometimes	32	26	
	Often or always	52	43	
Waking up several times during the night	Never or seldom	56	43	0.31
	Sometimes	28	28	
	Often or always	16	29	

*Statistically significant $p < 0.05$

The results from the survey show that most participants with SB ($\geq 72\%$) considered their physical and mental health as being good or very good and similar or better than last year. Ninety-two percent of them didn't smoke, 32% didn't drink alcohol and 48% drank less than once a month. The results also show that most of the participants were quite happy, were happy with the way they look but didn't think

they were sexually attractive. The majority of the participants with SB did not report problems with sleep.

When the results from questions 68 and 69 (the shorter version of the DASS) from the participants with SB were scored according to the DASS (73, 74), 84% of the participants got a score of normal or mild for depression while 16% scored moderate to severe depression. Eighty-four percent got a score of normal or mild for anxiety and 16% got a score of moderate, while 96% scored normal or mild on stress compared to only 4% scored as having severe stress. The results are shown in table 8.

Table 8. The results according the Depression Anxiety Stress Scales

	Depression	n (%)	Anxiety	n (%)	Stress	n(%)
Normal	0-9	17 (68)	0-7	20 (80)	0-14	22 (88)
Mild	10-13	4 (16)	8-9	1 (4)	15-18	2 (8)
Moderate	14-20	2 (8)	10-14	4 (16)	19-25	
Severe	21-27	2 (8)	15-19		26-33	1 (4)
Extremely severe	28+		20+		34+	
Total		25 (100)		25 (100)		25 (100)

4.2.3 Physical Activity

Only three people commented about the weather. One participant wearing the ActivPAL, reported after wearing the device for seven days that the weather had not been good during the weekend and therefore the participant had walked less than usual. Two of the wheelchair users commented that it would have been better to do the study in the summer as they were outdoors self-propelling their wheelchair much more often.

4.2.3.1 *ActivPAL accelerometer*

One person was sick during one day; the results from that day were therefore removed from the total results and those results were divided by six to get the average. One person had apparently put the ActivPAL upside down one day, because the results from that day did clearly not agree with that person's PA diary and were not comparable with the other days. In this case the results from that day were also removed from the total results which were then divided by six to get the average. At that time it wasn't known that the waterproof sleeve was latex free so the ActivPAL was only attached with transparent film (without the sleeve) and removed before going swimming or taking a shower. None of the participants walked for 30 min. (or 30 min. in 10 min. bouts) each day; only one participant managed that during one day.

Figure 7 is an example and shows the results for the whole week for two different participants and figure 8 shows the results for two different days for those same two participants. In figure 7 the time is in hour/day, in figure 8 in min/hour. Table 9 shows the time spent in sitting, standing and stepping and how many steps were taken a day on average. The average number of steps a day the participants

took ranged from 1,173 to 11,654 steps a day. In table 10 the participants are classified according to the step Tudor–Locke *et al.* step index (51).

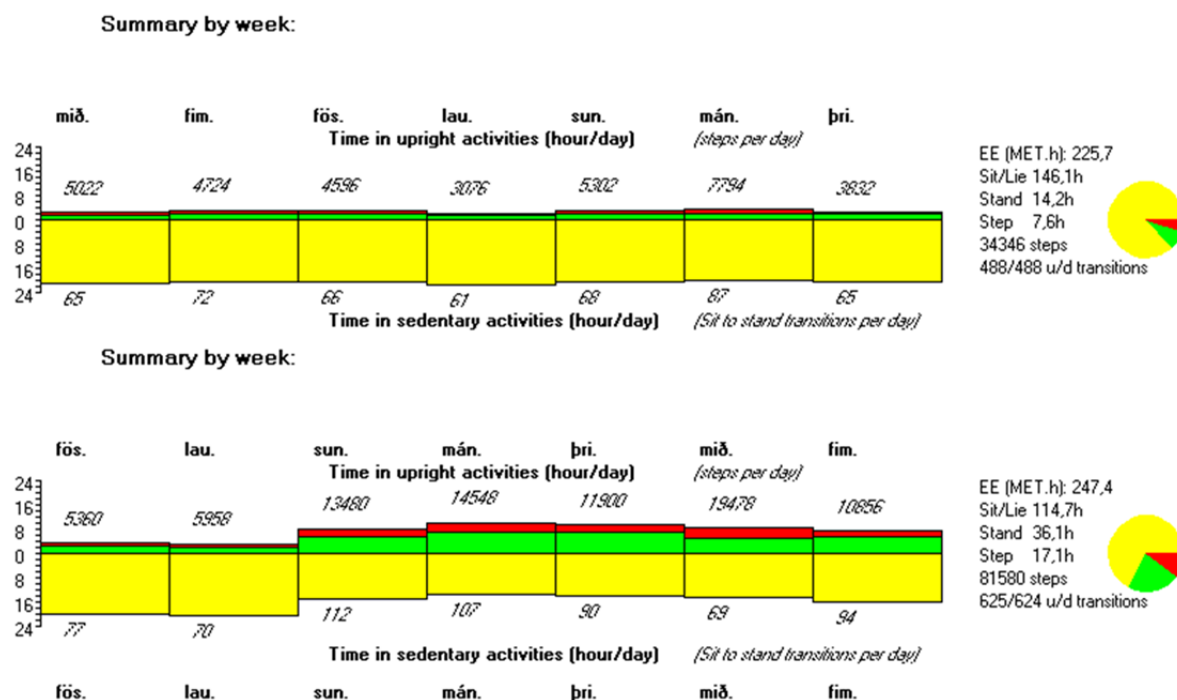


Figure 7. ActivPAL accelerometer, summary by week

Yellow means time spent in sedentary activities (sitting/lying), green shows time spent in standing and red the time spent in stepping.

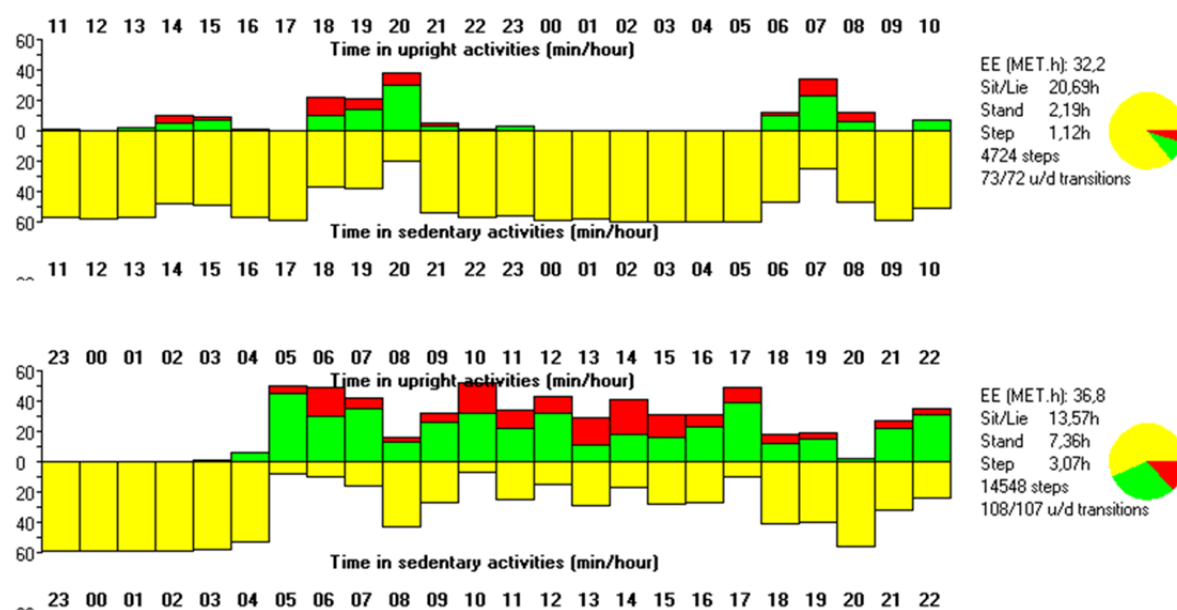


Figure 8. ActivPAL accelerometer, summary by day

Table 9. Results from the ActivPAL accelerometers

Subjects (n)	Sitting (range) ^(b)	Standing (range) ^(b)	Stepping (range) ^(b)	Steps (range) ^(c)
14 ^(a)	12.1 (9.2-15.2)	3.1 (0.7-6.2)	1.1 (0.3-2.4)	4688 (1173-11,654)
12 ^(a)	11.6 (9.2-14.5)	3.5 (1.7-6.2)	1.2 (0.3-2.4)	5252 (1173-11,654)

a. n= 14 are the results from the whole group, n= 12 are the results without the wheelchair users

b. mean time in hours per day

c. mean number of steps taken per day

Table 10. Distribution of participants in Step index

Subjects (n) (%)	Step index (steps a day)
4 (29)	<2500 (basal activity)
5 (36)	2500-4999 (limited activity)
2 (14)	5000-7499 (low active)
2 (14)	7500-9999 (somewhat active)
1 (7)	≥10000-12499 (active)
0	≥12500 (highly active)

The results for every hour for each participant were examined to see if the participants walked for 30 min. each day (or 30 min. in 10 min. bouts). One participant walked for over 40 min. on one day but none of the others walked 30 min. on any day. Many participants walked for 10 min. or longer but none of them did so for 30 min. in a day.

4.2.3.2 Actigraph accelerometer

Three participants were sick for a day, one got sick after two days and quit participation and one forgot to put the Actigraph on for two days. Those days were not counted in the results. The device did not function on two occasions so two participants were asked to do the measurements again. Two persons had used the device less than five hours during a total of three days. The results from those days were excluded. Only results from participants who used the Actigraph for at least five days for at least five hours each day were used for the calculations. Measurements from 12 participants were considered valid. According to the measurements of the Actigraph in this study none of the participants did 30 min. of moderate-intensity PA daily. Most of the participants did some moderate-intensity PA but only four of the 12 (33%) in bouts of 10 min. or longer. Only one person on two days carried out ≥ 45 min. of moderate-intensity PA and that happened on the days he was practicing wheelchair handball and wheelchair basketball. None of the others did 30 min. of moderate-intensity PA in a single day. The results are shown in table 11.

Table 11. Results from the Actigraph accelerometers

	n=12 (a) Mean (SD)	n=12 (a) Range	n=9 (a) Mean (SD)	n=9 (a) Range
Total counts per day (x 1000)	1,615 (504)	644 - 2363	1,756 (390)	1,125-2,363
N of valid days	6.3 (0.8)	5 - 7	6.3 (0.9)	5 - 7
Wear time (hours a day)	15.1 (2.7)	11.1 - 22.8	15.1 (3.2)	11.1 - 22.8
Moderate PA (min/day)	8.3 (6.8)	0.1 – 20.5	8.5 (5.7)	1.2 – 15.0
10 min. bouts of moderate PA (min/day)	2.2 (4.6)	0 – 15.5	1.0 (2.1)	0 – 5.3
Vigorous PA (min/day)	0.2 (0.4)	0 – 1.1	0.2 (0.4)	0 – 1.1

SD = standard deviation

a. n=12 are the results from the whole group, n=9 are the results without the participants who could walk

4.2.3.3 Self-reported physical activity

Of the 25 participants nine (36%) reported no other PA than walking or wheelchair propulsion. The 16 others reported the following activities: swimming, wheelchair handball, wheelchair basketball, weightlifting, fitness and physical therapy. Five (20%) reported an average of 30 min. of PA a day (range 30-100 min.), four (16%) between 10 and 30 min. and the other seven (28%) reported less than 10 min. a day of PA. Several of the older participants reported that they had trained a lot when younger, taking part in competitive swimming, but that when they grew older they got fed up with the practicing and swimming and quit all exercising.

All the wheelchair users were asked when they came for measurements if they had a standing frame or a standing wheelchair. None of them had one.

4.2.4 Waist Circumference and Waist-Hip Ratio

Of the nine men taking part in the study, six were able to stand during the measurement and ten of the 16 woman were able to stand. Table 12 shows their results in a standing position.

Table 12. Waist Circumference and Waist-Hip Ratio while standing

	Waist circumference (cm)	n (%)	Waist-hip ratio	n (%)
Men	<94	5 (83)	<0.90	3 (50)
	>94	0	≥0.90	3 (50)
	>102	1 (17)		
Total men		6 (100)		6 (100)
Women	<80	2 (20)	<0.85	5 (50)
	>80	1 (10)	≥0.85	5 (50)
	>88	7 (70)		
Total women		10 (100)		10 (100)

Of the 16 people able to stand 15 were also measured in a supine lying position. There was a difference between the measurements while standing and lying, from -6 to 2.9 cm for the waist circumference and from -0.07 to 0.06 for the waist-hip ratio. The biggest differences (3-6 cm) were found with the participants having a waist circumference >100 cm. The measurements of those unable to stand are shown in table 13.

Table 13. Waist Circumference and Waist-Hip Ratio while lying supine

	Waist circumference (cm)	n (%)	Waist-hip ratio	n (%)
Men	<94	3 (100)	<0.90	
	>94	0 (0)	≥0.90	3 (100)
Total men		3 (100)		3 (100)
Women	>80	1 (17)	<0.85	
	>88	5 (83)	≥0.85	6 (100)
Total women		6 (100)		6 (100)
Total all		9		9

4.3 Health and well-being - comparison of aspects of health and well-being between Icelanders with Spina Bifida and Icelanders without Spina Bifida

Table 7 demonstrates the results from the Icelandic comparison group to the same questions (the column marked control). The results from the chi square test are shown in the same table.

In most questions there was no statistically significant difference between the two groups. However, in some aspects there was a significant difference. A greater proportion of the SB population had never used alcohol and drank less frequently. They tended to eat less fruit, vegetables and milk or milk products and drank more often sweetened soda. They sat more hours, but when those in wheelchair were excluded there was no significant difference between the two groups. People with SB judged themselves more often as having less physical endurance and less physical strength than their peers, felt themselves more often not useful, less sexually attractive and less often physically unattractive.

In a few questions related to stress and participation the answer “does not apply” was used significantly more often in relation to work, spouse or children which can lead to the conclusion that the participants with SB less often had a job, spouse or children than the comparison group.

5 Discussion

The results of the study show that the incidence of SB declined in Iceland between 1972 and 2011. At five years of age most of the children with SB were able to walk, had low borderline or normal intelligence and the comorbidities were mostly orthopedic impairments, impairments affecting the central nervous system and urinary and bowel function, as was expected. The adult population is at risk of developing lifestyle-related conditions as they tend to have an unhealthy diet and do not meet the criteria of 30 min. of moderate-intensity PA.

5.1 Epidemiology

5.1.1 Incidence and prevalence

The incidence of SB in Iceland has continually and significantly declined during the last forty years. The main reason for this decrease has been induced abortion. Another possible reason might be the availability of cereal fortified by folic acid. Although food is not fortified by folic acid in Iceland, fortified foods like breakfast cereals are imported from other countries. The incidence of SB in Iceland in the period 2002-2011 was 0.7 per 10,000 live births which is lower than in other countries where the rate is 1.9 – 8.0 per 10,000 live births (14, 16, 17). There are several possible reasons for this. It might be lower in Iceland because the results from this study are more recent. The induced abortion rate is lower in Iceland than in the rest of the world. In 2008 the abortion rate for the world was 28 abortions for every 1000 women aged 15-44, in Iceland 14 (75, 76) although there are perhaps more pregnancies with diagnosed SB terminated in Iceland than elsewhere. Research should be carried out to confirm or reject this hypothesis.

The male to female ratio of SB in 2014 was 0.92. The male to female ratio was found to be 0.76 in a study done by Hall *et al.* (18). The difference can be explained by the small size of the Icelandic cohort. Little changes can have a great impact. The male to female ratio in the original Icelandic cohort was 0.77, similar to what Hall *et al.* found. Since then, two of the women had died and one of the men, two women moved abroad and two men moved to Iceland and the male to female ratio had changed in 0.92.

Hreinsdóttir *et al.* found in their study 14 persons born with SB in the period 1972-1976 (19). This study found 5 persons for that same period. There are several possible reasons for this discrepancy. Hreinsdóttir *et al.* reported in that same period 14 children with CNS defects who were stillborn and 5 who died in the first week. There might have been children with SB among them. Another reason might be the inaccuracy noticed in the medical files. It is possible that persons were excluded in this study who had been included in the first study.

Three of the Icelandic cohort (5.8%) died before the age of 50, which is a considerably lower rate than Oakeshott *et al.* found in their study (26% died between the ages of five and 40) (20). The reason for this discrepancy might be that the Icelandic cohort was younger (91% of the Icelandic cohort was born 1967 or later) than Oakeshott's cohort (born in 1963-1971).

5.1.2 Mobility

Of the 31 individuals who were evaluated at the SDCC at the age of five years, 87% could walk and 13% could not. Of the 25 participants taking part in the second part of the study (of adults with SB) 60% could walk and 40% did not. Sixteen of the participants were also in the cohort of five year olds, six of whom could walk then but do not walk today. When children with SB grow up and become teenagers, their bodies change and the center of gravity changes as well as the relative muscle strength. The center of gravity moves up as they grow, making balance in an upright position more difficult. It becomes harder to ambulate and costs more energy. More individuals choose wheelchairs as a way of mobility when they grow up. It is faster, more efficient and they look a lot cooler doing a wheelie (riding only on the two back wheels) than going slowly, with a lot of effort, on crutches.

In the study by Hunt *et al.* (21) (n=117) 35% could walk 50 meters or more around the age of 35, in the study by Verhoef *et al.* (2) (n=142, aged 16-25 years) 51% could walk and 49% didn't walk, and in the study by Soe *et al.* (39) (n=130, aged, 16-31 years) 49% could walk and 48% didn't walk (2, 20, 39). Soe *et al.* did not distinguish between meningocele and meningomyelocele. In both Hunt's and Verhoef's study individuals with meningocele are included (n=4 in Hunt's study, and not given up in Verhoef's study). In this current study worse gait outcomes were expected because individuals with meningocele were excluded but the results did not demonstrate this. The Icelandic group did much better than the group in Hunt's study. The explanation can be that the Icelandic cohort was younger (91% of the Icelandic cohort born in 1967 or later) than in Hunt's study (born in 1963-1971).

5.1.3 Cognitive function at five years

A little more than half of the children (55%) had normal intelligence, 30% had sub-average intelligence and 15% were diagnosed with mild intellectual impairment. The average FSIQ for all children with hydrocephalus (n=18) was 81.9 (SD 20.4). In a study done by Danzer *et al.* (77) 14 children with SB and hydrocephalus (mean age 61 months) were tested with the WPPSI-III. The mean Full Intelligent Quotient in their study was 88.6 (SD 20.4) or slightly higher than in the current study.

Almost all the children in this study (90%) had hydrocephalus. Children with hydrocephalus show significantly lower scores on performance-based measures than on verbal measures (78) but the results in this study did not confirm this. It might be that the difference between the verbal and performance IQ is hidden. In both the WPPSI and WPPSI-R the US norms were used. In the study by Guðmundsson *et al.* (63) on Icelandic children, the mean VIQ was 107.0, the mean PIQ 114.7 and the mean FSIQ 111.9 on the WPPSI. In the study by Georgsdóttir *et al.* (64) on Icelandic children, the mean VIQ was 102.9, the mean PIQ 115.6 and the mean FSIQ 110.0 on the WPPSI-R. This could mean that the WPPSI and WPPSI-R overestimate Icelandic children and the cognitive function of the children with SB may not be as good as the results from the tests demonstrated. In those two studies the PIQ was better than the VIQ suggesting that the VIQ in children with SB could be better than the PIQ. But it must be taken in consideration that these samples are very small and that the 20 children with SB were tested over a period of 30 years by 8 different psychologists.

Since only two of the 20 children did not have hydrocephalus it is not possible to calculate the effect of having hydrocephalus on cognitive function.

While going through the database of SDCC there were scores found of intelligent tests from the same children but at a later age (16-19 years). Some children performed significantly worse and others did much better. It could be interesting to study this and to see if an explanation can be found, to see if problems with shunt functioning or the concurrence of seizures could explain these differences.

5.1.4 Comorbidities at five years

The comorbidities found in the SB population were mostly orthopedic impairments, impairments affecting the central nervous system and impairments in urinary and bowel function, as was expected and has been demonstrated in other studies (5, 6). Breech presentation (34.8%) was more frequent in the current study than elsewhere. Other studies report an incidence of 25% (79, 80). In the normal population the incidence of breech presentation is below 5% (81-83). It is not known why, but this is a very small population and little changes can have a large impact. A reason for the higher incidence of breech presentation by children with SB might be the low muscle tone and reduced strength of the muscles around the hip joints.

5.2 Health and well-being – risk factors for developing lifestyle-related conditions

5.2.1 Survey

The results from the survey show that most participants with SB ($\geq 72\%$) considered their physical and mental health as being good or very good and similar or better than last year. Ninety-two percent of them didn't smoke and 32% didn't drink alcohol. But concerning nutrition they are at risk for developing lifestyle related conditions. The Directorate of Health recommends that fruit and vegetables are consumed daily, at least 500 grams a day of fruit, vegetables or juice, and at least 200 grams of vegetables and at least 200 grams of fruit. Fish should be consumed twice a week or more, which 44% of the participants did. Milk and milk products should be consumed at least twice a day and whole grain products should be chosen rather than refined products. It is also recommended that everybody should take cod liver oil or vitamin D daily (49). From the results shown in table 7 it can be concluded that the majority of the participants did not follow these recommendations while at the same time 80% said they were trying to eat healthy food. Sixty-eight percent reported a BMI ≥ 25 , 40% were not satisfied with their weight and 60% were trying to lose weight during the preceding 12 months.

Soe *et al.* (39) also found that individuals with SB tended to eat less healthy diets and were less likely to use alcohol. In their study, however, the individuals with SB also tended to smoke less and nearly one half reported mild to major depressive symptoms, which was not the case in this study. Murray *et al.* (40) found in their study of young adults with SB that they reported similar frequencies of cigarette use compared to their peers but less frequent alcohol use, or similar to the results in this study. According to the DASS 16% of the participants in the current study scored moderate to severe for depression. Sixteen percent scored moderate for anxiety and four percent scored severe on stress. In Hayter *et al.*'s study 22% could be classified with severe-to-extremely severe levels of depression, anxiety (23%) and/or stress (16%) according to the DASS (43). The Icelandic SB population did slightly better in this respect, but again, it must be taken into account that the sample was very small.

5.2.2 Physical activity

This winter has not been good for people with limitations in mobility or wheelchair users as many days have had limited wheelchair accessibility. But living in Iceland, this is the everyday reality for a large part of the year, and when weather and accessibility of the sidewalks do not permit outdoor PA indoor solutions should be found.

5.2.2.1 *ActivPAL accelerometer*

The results from the ActivPAL accelerometer show that all the fourteen participants using the ActivPAL were sitting 9-15 hours a day and took 1,173-11,654 steps a day. Tudor-Locke *et al.* found in their review that special populations take 1,200-8,800 steps a day (52). All but one of the participants in this study fell within this range. Sixty-five percent of the SB participants took less than 5,000 steps a day, which is far from the recommended 10,000 steps a day. Of course, it must be taken into account that the limitations in mobility make it difficult to follow the recommendation of 10,000 steps a day.

There is limited evidence of the effects of PA on individuals with SB. Oliveira *et al.* found that it appeared that exercise training is valuable for increasing cardiorespiratory endurance and muscle strength in individuals with SB (17). A systematic review done by Paterson *et al.* confirmed that greater aerobic physical activity was associated with reduced risk of functional limitations and disability with age in the older population (84). The same results might be expected in the SB population. But further research should confirm this. It might be necessary to examine each individual with SB to determine individualized daily target steps that suit their limitations. Long term follow up might be needed to adjust this target when changes in mobility or limitations occur. It is now recognized that some activity is better than none and that even small increases in PA can have relatively important health benefits (52, 85).

More and more research shows that prolonged sitting is an independent risk factor for all-cause mortality and metabolic syndrome. The risk is higher for those who are physically inactive (86-89). The results from ActivPAL use show that the participants spend a long time (9-15 hours a day) sitting each day which puts them at a higher risk for all-cause mortality and for developing metabolic syndrome. The sitting time can be reduced if they use a height adjustable desk at work or while studying so they can alternate sitting and standing. They might not be able to stand for as long as people without disabilities because of reduced endurance and muscle strength but they might be able to stand regularly for shorter periods and thus break up the sitting time.

5.2.2.2 *Actigraph accelerometer*

The number of total counts a day in this study varied from 644,000- 2,363,000. In a study done by Gorter *et al.* adolescents with Cerebral Palsy (both the adolescents who were ambulant and those who were wheelchair users) wore the ActiGraphGT1M for seven days (90). Since they wore the Actigraph over the right hip and not on the wrist as in this study, the results cannot be compared. In another study done by Warms *et al.* 22 wheelchair users wore the Actiwatch for four days on their wrist (91). The number of total counts a day varied from 112,670 to 360,925. However, the Actiwatch is a uniaxial activity monitor and the Actigraph a triaxial activity monitor. Measurements with triaxial accelerometers have been reported to be more valid compared to uniaxial accelerometers (92). In a

study where six monitors were validated the Actigraph was found more valid than the Actiwatch (93). Therefore it is not possible to compare the results from this study with the study by Warms *et al.* Other studies where wheelchair users used the Actigraph for several days were not found.

None of the wheelchair users in this study owned a standing frame or standing wheelchair. As they are spending almost all day sitting they are at increased risk for all-cause mortality and metabolic syndrome. A standing frame or standing wheelchair can be useful to break up the sitting time, to positively affect bone mineral density, hip stability and spasticity and has a positive impact on well-being and quality of life (94, 95). A standing frame also has a beneficial effect on the range of motion of the hip, knee and ankle and bowel function. Therapists and individuals who use standing frames report benefits on weight bearing and pressure relief. Likewise standing is said to have a positive effect on cardiopulmonary and bladder function, muscle strength and alertness. But evidence is inconclusive (95). Standing is important both in free time as well as during work and study.

5.2.2.3 Self-reported physical activity

Only five (20%) of the 25 participants reported 30 minutes of PA a day, nine (36%) did not report any PA. This is in agreement with the results of Crytzer *et al.* (29) and Soe *et al.* (39) who found individuals with SB had an inactive lifestyle.

5.2.3 Waist Circumference and Waist-Hip Ratio

Of the six men measured standing three of them (50%) were at substantially increased risk of metabolic complications, whereas of the ten women measured standing eight of them (80%) were at substantially increased risk of metabolic complications. No other studies were found where the waist circumference and waist-hip ratio was measured in individuals with SB.

In this study there was a difference between the measurements taken lying and standing. The measurements of the three men in a lying position were not possible to interpret and it is impossible to say whether they were at increased risk for metabolic complications. The measurements of the six women indicated that they were all at increased risk or substantially increased risk of metabolic complications.

Because of the discrepancy between the measurements between lying and standing positions a better way of measuring body composition for those unable to stand should be found. Maybe the waist circumference of this group could be measured while sitting. Research should be done to decide special cut-off points for this group of people in a sitting position. Instead of the waist-hip ratio BMI could be used together with the waist circumference. When calculating the BMI arm span could be used instead of height. But it is important that a consensus should be found so results of different studies can be compared.

5.3 Health and well-being - comparison of aspects of health and well-being between Icelanders with Spina Bifida and Icelanders without Spina Bifida

In most aspects there was no statistically significant difference between the SB participants and the Icelandic population with a few exceptions. There was a difference in the use of alcohol: a greater

proportion of the SB population had never used alcohol and drank less frequently. They tended to eat less fruit, vegetables and milk or milk products and drank more often sweetened soda. These results were similar to those of studies done by Soe *et al.* and Murray *et al.* (39, 40).

People with SB judged themselves more often as having less physical endurance and less physical strength than their peers, felt themselves more often not useful, less sexually attractive and less often physically unattractive.

5.4 Strengths and limitations of the study

The main strength of this study was that it most likely comprises a complete cohort of people with SB. The incidence and prevalence of SB in Iceland have not been studied recently and this is the first time the mobility, cognitive function and comorbidities at five years at age have been described for this group. The health and well-being of the adult SB population of Iceland was also studied for the first time. As 69.4% of the adult population with SB took part it is possible to generalize the results to the whole group except for persons with severe cognitive limitations who were excluded from the second and third parts of the study. The conclusions do not necessarily apply to them. This study was the first to measure PA for seven days with ActivPAL and/or Actigraph of a large part of a SB cohort which gives valuable objective information about the PA of this group.

The small size of the sample is a limitation. Each of the measurements has its limitations but by combining them it is possible to draw stronger conclusions. The use of the questionnaire and PA diary was limited by recall bias, over- and under-estimation or misinterpretation. It is a subjective measurement which depends on the memory of the participant. It was noticed that some of the participants made mistakes when answering the questions in the questionnaire. In such a small sample this can influence the results. The comparison group in part three of the study answered the survey in 2012, and this could also influence the results. The ActivPAL accelerometer and the Actigraph accelerometer are objective methods which can estimate overall PA but are unable to measure correctly activities like cycling, swimming or weight lifting. The Actigraph is not waterproofed and is therefore taken off when taking a bath or shower or when going swimming. This can increase the risk that participants forget to put the Actigraph back on. The measuring of the waist and hip circumference had limited results for the participants not able to stand.

5.5 The clinical importance of the study

The results from this study give a wealth of information and can be used to improve the health and quality of life of individuals with SB.

This study shows that the adult SB population drinks less alcohol than the comparison group but tends to eat unhealthily and the majority do not carry out moderate-intensity PA for 30 min. a day. Most of them had an increased waist-circumference. They are therefore at increased risk of developing lifestyle-related conditions and several of them already have some of these conditions as they were clearly obese.

It is therefore important to inform and educate people with SB about the risks of an unhealthy lifestyle and how they can improve their lifestyle. They should be informed about the importance of

nutrition. Because they are less active it is very important that they not eat more than they need. Eating a well-balanced diet can help with optimizing bowel health and is important to prevent obesity, hypertension or diabetes. It can also help with preventing fractures (96, 97).

They should be offered opportunities to be educated about the importance of PA. It might be necessary to make individualized programs with targets which take into consideration the individual limitations in mobility. Those who are not able to walk should be informed about the importance of standing and weight bearing. Weight bearing has a positive effect on bone density (95). The use of standing wheelchairs and standing frames can be useful as well as assisted walking, where individuals are suspended in a harness over a treadmill (95, 98). That makes walking easier and weight bearing possible without putting too much strain on the joints. It is important to know that small improvements can have significant effects on health. They should also be informed of the risks of prolonged sitting and how they can reduce sitting time.

It is important that people with SB should be supported in finding an activity they enjoy doing. It is not good when after years of training for competitive sports people get fed up and quit. It might be easier and more fun if they go with friends to motivate each other. There are several sports for wheelchair users, like wheelchair handball and wheelchair basketball. If more wheelchair users realize the importance of PA and join sport clubs the diversity can increase. It is also important that sports can be practiced at all levels. When outdoor PA is not possible due to weather or road and pavement conditions indoor solutions should be found. Waiting for the summer is not a healthy option in Iceland. It is important that competitive athletes realize the importance of PA, that after they quit competing they need to find some activity they enjoy doing.

Most of the participants attend physical therapy regularly. The physical therapists have thus a great opportunity to inform and educate people with SB about the importance of a healthy lifestyle. The physical therapist should put emphasis on the importance of a well-balanced, healthy diet and PA which takes into account both the individual possibilities and limitations and is something the individual with SB enjoys doing. He/she should also point out the risks of prolonged sitting and the importance of standing and should help with finding ways to reduce sitting time. Old habits die hard so it might be necessary for the physical therapists to use motivational interviewing (99). The physical therapist should increase the awareness of individuals with SB of the potential risk of their behavior, help to envision a better future and thus increase motivation to change their behavior. When individuals with SB have no interest they are more likely to find excuses against change and nothing will happen. It is thus very important to get them interested because then they might be more ready to change and be committed to following a plan. The physical therapist can help with finding solutions which suit the abilities and the interest of the individuals with SB.

Most of the adults with SB are followed up at Grensásdeild, the rehabilitation department of the National University Hospital of Iceland. The time between two visits varies between one and five years. It might be necessary to shorten the time between two visits. A recent Dutch study (n= 184, age >25 years) showed that a majority of adults with SB report newly arising physical and psychological problems during the previous five years (100). The multi-disciplinary team has great opportunity to offer education about nutrition, PA and other aspects important in leading a healthy life, including

informing the individuals with SB about the importance of standing and weight bearing and helping with applying for the necessary equipment. It might also be necessary for individuals with SB to get help to implement the advice they get at Gensásdeild in their daily life.

At the SDCC where the children with SB come once or twice a year, the results from this study should be implemented in the recommendations when they come for follow up. It is essential to stress the importance of good nutrition and PA, to point out the risk of prolonged sitting and to promote a healthy lifestyle to prevent the development of debilitating lifestyle conditions later on. Focus should be put on participation: the children and their families should be made aware of the importance of education and participation in all aspects of life. It might be important to repeat the evaluation of the cognitive skills for all children with SB before they go for secondary education.

When going through the medical records discrepancies in diagnoses were noticed. It is clear that registration can be and should be improved. It is important that diagnoses are registered correctly, both for the individuals to improve therapy and for researchers.

5.5.1 Suggestions for the future

A follow-up study can be done where the participants are offered an intervention program. Part of the same measurements could be used again to complement other measurements like blood pressure, triglycerides, cholesterol and blood sugar levels. With the use of motivational interviewing ways to improve the lifestyle are found and implemented. It is important that the participants who are offered this follow-up are interested. Otherwise they might not be ready to change their behavior and the effect will be little or nothing. After a certain time the measurements need to be repeated to see if the intervention has had any effect.

Another study can be done with the families with children with SB where all family members take part in the measurements, the potential risk behaviors are analyzed and the family is educated about the need for change. The families could support each other in helping obtain healthy lifestyles.

More research should be done where the PA is measured by people with SB (and other disabilities), both to find cut-off points for the different levels of PA but even more important to measure the effect of PA on health and well-being of people with SB (and other disabilities).

Information about the risks of an unhealthy lifestyle, about the risks of prolonged sitting, the importance of PA should be easily accessible for individuals with SB. Brochures could be made, one for the wheelchair users and a different one for those who can walk, with this information as well as suggestions and examples of how to make improvements. This information should also be available online. Interviews (on video) could be made with people who have limitations in mobility but who are active in sports and have a healthy lifestyle and let them explain how they live their healthy lives. These videos can be available online and be an inspiration for other people. Peer education might be more effective than professional education.

More physical therapy practices should offer assisted walking, where individuals are suspended in a harness over a treadmill and have movement trainers who offer passive, motor-assisted or active resistive training for people in a wheelchair. Physical therapists should help with applying for the necessary equipment like a standing wheelchair. All fitness centers should have good accessibility for

wheelchair users and have the knowledge to instruct wheelchair users in what kind of exercises they can and should do and have movement trainers who offer passive, motor-assisted or active resistive training for people in a wheelchair.

The media could play a role as well. A lot of attention is paid to regular sport activities, both in the press and on television, but sport for the disabled gets very little attention.

6 Conclusion

The results of the study show that the incidence of SB has declined in Iceland between 1972 and 2011. At five years of age most of the children with SB were able to walk, had low borderline or normal intelligence and the comorbidities were mostly orthopedic impairments, impairments affecting the central nervous system and urinary and bowel function.

The adult population is at risk of developing lifestyle-related conditions as they tend to have an unhealthy diet and do not meet the criteria of 30 min of moderate-intensity PA. Most of them have an increased waist-circumference and several are indeed already obese.

Compared to the Icelandic population the participants with SB tend to drink less alcohol, eat less healthy food and drink more sweetened drinks. They consider themselves more often with less physical endurance and less physical strength than their peers, and find themselves less sexually attractive and less often physically unattractive. They found themselves more often not useful. It appeared that fewer of them have a job, spouse or children than the Icelandic population in the same age group.

Physical therapists should be aware of these results and help the individuals with SB to become aware of the risks of their lifestyle and how they can take responsibility for their own health and try to change and lead a healthy lifestyle. This is important for other health care workers as well. Healthcare authorities should offer opportunities for people with SB to be educated about the importance of PA, a healthy diet and reduced sitting time and about the risk of an unhealthy lifestyle. It is better to prevent lifestyle conditions than trying to cure them.

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Appendix 1

Letter of introduction

Kynningarbréf til þátttakenda



Hrygggrauf á Íslandi: heilsan og líðan meðal fullorðinna og faraldsfræði

Ágæti viðtakandi

Undirritaður vinnur nú að meistaraverkefni í Hreyfivísindum við Námsbraut í sjúkráþjálfun við Háskóla Íslands þar sem tilgangur er að rannsaka heilsu og líðan meðal fullorðinna með hrygggrauf (Spina Bifida eða klofinn hryggur). Rannsakandi er Marrit Meintema sjúkráþjálfari við Greiningar- og ráðgjafarstöð ríkisins. Leiðbeinandi og ábyrgðarmaður rannsóknarinnar er Þjóðbjörg Guðjónsdóttir sjúkráþjálfari og lektor við Námsbraut í sjúkráþjálfun við Háskóla Íslands. Hægt er að ná í hana í síma 525-4092 eða með tölvupósti á netfangið thbjorg@hi.is.

Tilgangur rannsóknar

Markmið þessarar rannsóknar er í fyrsta lagi að kanna hvort einstaklingar með hrygggrauf séu í hættu á að þróa með sér lífsstílstengda sjúkdóma með því að lýsa þáttum tengdum heilsu og líðan, mæla hreyfingu, mittismál og lærisummál. Í öðru lagi er markmið rannsóknarinnar að framkvæma lýsandi faraldsfræðilega athugun á hrygggrauf meðal barna á Íslandi með því að lýsa algengi og viðbótarfötlunum.

Þátttakendur

Úrtakið í fyrri hluta rannsóknarinnar samanstendur af öllum Íslendingum með hrygggrauf 18 ára og eldri sem hafa getu til að svara spurningalista um líðan og heilsu. Úrtakið í seinni hluta rannsóknarinnar eru allir Íslendingar með hrygggrauf sem fæddir voru á árunum 1980 til 2008 og komu til skoðunar á GRR. Óskað er eftir þátttöku þinni í fyrri hluta rannsóknarinnar.

Framkvæmd

Hver þátttakandi úr fyrri hluta rannsóknarinnar mætir á Greiningarstöð í eitt skipti og tekur heimsóknin um 1-2 klukkustundir. Við komu fylla þátttakendur út spurningalista um líðan og heilsu. Síðan verða framkvæmdar eftirfarandi mælingar: mittismál og lærisummál. Í lok heimsóknar verður hreyfímælir festur á læri eða úlnlið og notkun útskýrt. Óskað verður eftir að þátttakendur beri hreyfímælinn í sjö daga og haldi hreyfidagbók á meðan.

Þær mælingar sem framkvæmdar eru í þessari rannsókn hafa ekki í för með sér neina áhættu eða óþægindi fyrir þátttakenda. Rannsakandi og ábyrgðarmaður munu einir hafa aðgang að gögnum rannsóknarinnar og verður ekki hægt að rekja þau til einstaklinga. Þátttakendum er frjálst að hafna þátttöku eða hætta í rannsókninni á hvaða stigi sem er, án útskýringa og án nokkurra eftirmála.

Þessi rannsókn hefur verið samþykkt af Vísindasiðanefnd og hún tilkynnt til Persónuverndar. Niðurstöður rannsóknarinnar verða kynntar á meistarávörn Marrítar við Háskóla Íslands og birtar í MSc. lokaritgerð. Einnig verður stefnt að fá birta grein með niðurstöðum í ritrýndu vísinditímariti.

Rannsakandi mun hafa samband við þig og kanna áhuga fyrir þátttöku. Ef áhugi er fyrir hendi biðjum við þig um að skrifa undir upplýst samþykki. Rannsakandi munu svo skipuleggja heimsókn þína inn á Greiningarstöð til að framkvæma mælingar þar.

Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Tryggvagötu 17, 101 Reykjavík. Sími: 551-7100, tölvupóstfang: vsn@vsn.is.

Með fyrirfram þökk og von um þátttöku,

Þjóðbjörg Guðjónsdóttir
thbjorg@hi.is

Marrit Meintema
marrit@greining.is

Appendix 2

Written consent

Upplýst samþykki



Hrygggrauf á Íslandi: heilsan og líðan meðal fullorðinna og faraldsfræði

Upplýst samþykki

Undirritaður þátttakandi samþykkir að taka þátt í rannsókn um hrygggrauf á Íslandi: heilsa og líðan meðal fullorðinna og faraldsfræði. Undirritaður hefur fengið allar upplýsingar um tilgang, framkvæmd og mögulegar áhættur rannsóknarinnar.

Niðurstöður rannsóknarinnar verða hluti af meistaraverkefni Marrit Meintema í hreyfivísindum við Námsbraut í sjúkraþjálfun við Háskóla Íslands. Gætt verður fyllsta trúnaðar við meðhöndlun allra upplýsinga sem fram koma í rannsókninni.

Með undirritun þessa skjals er ekki verið að afsala sér neinum réttindum eða skuldbinda sig á nokkurn hátt. Þátttakendum er heimilt að hætta þátttöku í rannsókninni á meðan á henni stendur, án skýringa og án nokkurra eftirmála.

Ef einhverjar spurningar vakna á meðan á rannsókn stendur eða ef draga á þátttöku til baka er hægt að leita til Marrit í síma 857 8964.

Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Tryggvagötu 17, 101 Reykjavík. Sími: 551-7100, tölvupóstfang: vsni@vsni.is.

Staður og dagsetning

Undirskrift þátttakanda og kennitala

Undirskrift þess er leggur yfirlýsinguna fyrir

Appendix 3

Selected questions from the survey “Research on the health and well-being of Icelanders in 2012” from the Icelandic Directorate of Health.



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Almennt heilsufar

1. Hvernig metur þú almennt líkamlega heilsu þína?

Finnst þér hún vera mjög góð, góð, sæmileg eða léleg?

Merktu í einn reit.

- ☐ Mjög góð
- ☐ Góð
- ☐ Sæmileg
- ☐ Léleg

2. Er líkamleg heilsa þín betri eða verri en fyrir ári?

Merktu í einn reit.

- ☐ Mun betri en fyrir ári
- ☐ Nokkru betri en fyrir ári
- ☐ Svipuð og fyrir ári
- ☐ Nokkru verri en fyrir ári
- ☐ Mun verri en fyrir ári

3. Hvernig metur þú almennt andlega heilsu þína?

Finnst þér hún vera mjög góð, góð, sæmileg eða léleg?

Merktu í einn reit.

- ☐ Mjög góð
- ☐ Góð
- ☐ Sæmileg
- ☐ Léleg

4. Er andleg heilsa þín betri eða verri en fyrir ári?

Merktu í einn reit.

- ☐ Mun betri en fyrir ári
- ☐ Nokkru betri en fyrir ári
- ☐ Svipuð og fyrir ári
- ☐ Nokkru verri en fyrir ári
- ☐ Mun verri en fyrir ári

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Reykingar

15. Reykir þú?

Merkstu í einn reit.

- ☐ Já, daglega. Svaraðu næst spurningu 18
- ☐ Já, að minnsta kosti vikulega. Svaraðu næst spurningu 18
- ☐ Já, en sjaldnar en vikulega. Svaraðu næst spurningu 18
- ☐ Nei, ég er hætt/ur að reykja. Svaraðu næst spurningu 16
- ☐ Nei, ég hef aldrei reyktt. Svaraðu næst spurningu 21

16. Ef þú ert hætt/ur að reykja, hvað er langt síðan þú hættir?

Merkstu í einn reit.

- ☐ Minna en 3 mánuðir
- ☐ Um 3–6 mánuðir
- ☐ Um 7–12 mánuðir
- ☐ Um 1–2 ár
- ☐ Um 3–4 ár
- ☐ Um 5–10 ár
- ☐ Um 11–20 ár
- ☐ Meira en 20 ár. Hversu mörg ár? _____ ár
- ☐ Á ekki við

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Heilsa og líðan Íslendinga 2012

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17. Ef þú ert hætt/ur að reykja, hvað reyktir þú venjulega mikið?*Merktu í einn reit.*

- ☐ Ég reykti minna en eina sígarettu á dag
- ☐ 1–4 sígarettur á dag
- ☐ 5–14 sígarettur á dag
- ☐ 15–24 sígarettur á dag
- ☐ 25–34 sígarettur á dag
- ☐ 35 eða fleiri sígarettur á dag
- ☐ Ég reykti vindla. Hversu marga vindla á dag? _____ vindla á dag
- ☐ Ég reykti píputóbak. Hversu margar pípur á dag? _____ pípur á dag
- ☐ Á ekki við

18. Hvað varst þú gamall / gömul þegar þú byrjaðir að reykja?*Merktu í einn reit.*

- ☐ Yngri en 15 ára
- ☐ 15–19 ára
- ☐ 20–24 ára
- ☐ 25–29 ára
- ☐ 30–34 ára
- ☐ 35 ára eða eldri
- ☐ Á ekki við

19. Hvað reykir þú venjulega mikið?*Merktu í einn reit.*

- ☐ Ég reyki minna en eina sígarettu á dag
- ☐ 1–4 sígarettur á dag
- ☐ 5–14 sígarettur á dag
- ☐ 15–24 sígarettur á dag
- ☐ 25–34 sígarettur á dag
- ☐ 35 eða fleiri sígarettur á dag
- ☐ Ég reyki vindla. Hversu marga vindla á dag? _____ vindla á dag
- ☐ Ég reyki píputóbak. Hversu margar pípur á dag? _____ pípur á dag
- ☐ Á ekki við

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20. Hver af eftirfarandi staðhæfingum á best við um þig?*Merktu í einn reit.*

- ☐ Ég ætla að hætta að reykja á næstu 30 dögum
- ☐ Ég ætla að hætta að reykja á næstu 6 mánuðum
- ☐ Ég ætla að hætta að reykja en ekki á næstu 6 mánuðum
- ☐ Ég hef ekki hugsað mér að hætta að reykja
- ☐ Ég er hætt/ur að reykja

21. Hversu oft ert þú að jafnaði innandyra þar sem reykt er?*Merktu í einn reit.*

- ☐ Daglega
- ☐ Nokkrum sinnum í viku
- ☐ Nokkrum sinnum í mánuði
- ☐ Um það bil einu sinni í mánuði
- ☐ Sjaldnar en einu sinni í mánuði
- ☐ Aldrei

22. Notar þú eða hefur þú notað tóbak í vörina?*Merktu í einn reit.*

- ☐ Já, ég nota tóbak daglega í vörina
- ☐ Já, ég nota tóbak í vörina sjaldnar en daglega
- ☐ Já, en er hættur að nota tóbak í vörina í Svaraðu næst spurningu 24
- ☐ Nei, ég hef aldrei notað tóbak í vörina í Svaraðu næst spurningu 24

23. Hver af eftirfarandi staðhæfingum á best við um þig?*Merktu í einn reit.*

- ☐ Ég ætla að hætta að nota tóbak í vörina á næstu 30 dögum
- ☐ Ég ætla að hætta að nota tóbak í vörina á næstu 6 mánuðum
- ☐ Ég ætla að hætta að nota tóbak í vörina en ekki á næstu 6 mánuðum
- ☐ Ég hef ekki hugsað mér að hætta að nota tóbak í vörina
- ☐ Ég er hætt/ur að nota tóbak í vörina

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Áfengi og áfengisnotkun

24. Hefur þú einhvern tíma drukkið áfengi?

Merktu í einn reit.

- ☐ Já
☐ Nei → Svaraðu næst spurningu 30

25. Hversu oft á síðustu 12 mánuðum hefur þú drukkið minnst eitt glas af einhverjum drykk sem inniheldur áfengi? (Hér er átt við áfengan bjór, vín, áfengt gos og sterkt áfengi en ekki maltöl eða pilsner)

Merktu í einn reit.

- ☐ Daglega eða næstum daglega
☐ Þrisvar til fjórum sinnum í viku
☐ Einu sinni til tvisvar í viku
☐ Einu sinni til þrisvar í mánuði
☐ Sjö til ellefu sinnum á síðustu 12 mánuðum
☐ Þrisvar til sex sinnum á síðustu 12 mánuðum
☐ Einu sinni til tvisvar á síðustu 12 mánuðum
☐ Aldrei á síðustu 12 mánuðum

26. Þegar þú hefur neytt einhverra áfengra drykkja, hversu mörg glös, dósir eða drykki hefur þú að jafnaði drukkið í hvert skipti? (Einn drykkur samsvarar litlum bjór, léttvinsglasi eða einum einföldum af sterku áfengi. Tveir stórir bjórar eru álíka mikið og þrír litlir.) *Skrifaðu fjölda drykkja eftir því sem við á.*

_____ drykk/i

27. Hversu oft, ef nokkurn tíma, á síðustu 12 mánuðum hefur þú drukkið á einum degi að minnsta kosti 5 áfenga drykki?

Merktu í einn reit.

- ☐ Daglega eða næstum daglega
☐ Þrisvar til fjórum sinnum í viku
☐ Einu sinni til tvisvar í viku
☐ Einu sinni til þrisvar í mánuði
☐ Sjö til ellefu sinnum á síðustu 12 mánuðum
☐ Þrisvar til sex sinnum á síðustu 12 mánuðum
☐ Einu sinni til tvisvar á síðustu 12 mánuðum
☐ Aldrei á síðustu 12 mánuðum

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28. Hversu oft á síðustu 12 mánuðum hefur þú drukkið áfengi með mat?

Merktu í einn reit.

- ☐ Daglega
- ☐ Þrisvar til fjórum sinnum í viku
- ☐ Einu sinni til tvisvar í viku
- ☐ Einu sinni til þrisvar í mánuði
- ☐ Sjö til ellefu sinnum á síðustu 12 mánuðum
- ☐ Þrisvar til sex sinnum á síðustu 12 mánuðum
- ☐ Einu sinni til tvisvar á síðustu 12 mánuðum
- ☐ Aldrei á síðustu 12 mánuðum

29. Hversu oft á síðustu 12 mánuðum hefur...

Merktu í einn reit í hverjum lið.

	Aldrei	Mánaðar- lega eða sjaldnar	Einu sinni til þrisvar í mánuði	Vikulega	Daglega eða nánast daglega
a) þú fengið þér áfengi til að komast yfir eftirköst drykkju?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) þú komist að því að þú gast ekki hætt að drekka þegar þú varst á annað borð byrjuð/byrjaður?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) þú fundið til eftirsjár eða sektarkenndar eftir drykkju?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) þú ekki getað munað það sem gerðist kvöldið áður vegna þess að þú hafðir drukkið áfengi?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) þú ekki getað gert það sem venjulega er ætlast til af þér vegna drykkju?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) áfengisneysla þín haft skaðleg áhrif á vinnu þína, nám eða atvinnutækifæri?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Mataræði

34. Hversu oft borðar/drekkur þú eftirfarandi fæðutegundir?

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldnar en einu sinni í viku	Einu sinni í viku	2–3 sinnum í viku	4–6 sinnum í viku	Einu sinni á dag	2 sinnum á dag eða oftar
a) Rúgbrauð, heilhveiti- brauð eða annað gróft brauð	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Morgunkorn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Mjólk eða sýrðar mjólkurvörur (að undan- skilinni mjólk/rjóma í kaffi eða te)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Ávexti eða ber	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Grænmeti (ferskt, fryst, soðið eða matreitt)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Fisk, fiskrétti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Kjöt, kjötrétti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Sykrað gos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Sælgæti, súkkulaði	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Kex, kökur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Hrisgrjón, pasta eða kartöflur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Skyndibita (á skyndibita- stað eða tekið með heim)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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35. Hversu oft tekur þú eitthvað af eftirfarandi vörum?

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldnar en einu sinni í viku	Einu sinni í viku	2–3 sinnum í viku	4–6 sinnum í viku	Einu sinni á dag	2 sinnum á dag eða oftar
a) Lýsi, lýsisbelgi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Vítamín eða steinefni	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Önnur fæðubótarefni eða náttúruvörur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. Hversu oft að jafnaði borðar þú eftirfarandi máltíðir eða millibita?

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldnar en einu sinni í viku	Um það bil einu sinni í viku	Nokkrum sinnum í viku	Daglega/ næstum daglega
a) Morgunmat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Millibita að morgni	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hádegismat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Millibita á milli hádegismatar og kvöldmatar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Kvöldmat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Biti/snarli eftir kvöldmat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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37. Næst koma fullyrðingar um viðhorf til mataræðis. Vinsamlegast merktu við hversu vel eða illa hver fullyrðing á við um þig.

Merktu í einn reit í hverjum líð.

	Á mjög vel við um mig	Á frekar vel við um mig	Hvorki né	Á frekar illa við um mig	Á mjög illa við um mig
a) Ég fæ samviskubit ef ég borða sætindi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ég er sátt/ur við eigin matarvenjur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ég er hrædd/ur um að geta ekki hætt að borða þegar ég byrja á annað borð	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Mér líður vel eftir að hafa borðað góðan mat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Mér finnst ég þurfa að hafa stjórn á því hvað ég borða	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Ég borða meira þegar mér líður illa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ég borða meira þegar ég finn fyrir streitu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Ég reyni að borða hollan mat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hæð og þyngd

38. Hver er hæð þín í sentímetrum?

Hæð í sentímetrum: _____ cm

39. Hver er þyngd þín í kílógrömmum? (Konur; ef þú ert barnshafandi vinsamlegast svara þú til um þyngd þína mánuðinn áður en þú varst þunguð)

Þyngd í kílógrömmum: _____ kg

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40. Hversu sátt/ur eða ósátt/ur ert þú við eigin líkamsþyngd?*Merktu í einn reit.*

- ☐ Mjög sátt/ur
- ☐ Frekar sátt/ur
- ☐ Hvorki sátt/ur né ósátt/ur
- ☐ Frekar ósátt/ur
- ☐ Mjög ósátt/ur

41. Hefur þú reynt að léttu þig eða þyngja (t.d. með breyttu mataræði eða aukinni hreyfingu) á síðastliðnum 12 mánuðum?*Merktu í einn reit.*

- ☐ Ég er að reyna að léttu mig núna
- ☐ Ég hef reynt að léttu mig sl. 12 mánuði en ég er ekki að reyna það núna
- ☐ Ég hef hvorki reynt að léttu mig né þyngja á síðastliðnum 12 mánuðum
- ☐ Ég hef reynt að þyngja mig sl. 12 mánuði en ég er ekki að reyna það núna
- ☐ Ég er að reyna að þyngja mig núna

Algengar athafnir**42. Háir heilsufar þitt eða skert athafnageta þér við eftirtaldar athafnir?***Merktu í einn reit í hverjum lið.*

	Já, háir mér mjög	Já, háir mér nokkuð	Nei, háir mér alls ekki
a) Mikla áreynslu, t.d. að hlaupa, lyfta þungum hlutum eða taka þátt í erfiðum íþróttum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Miðlungsáreynslu, t.d. að færa til borð, ryksuga eða hjóla	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Lyfta eða bera innkaupapoka	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Ganga upp nokkrar hæðir í húsi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Ganga upp eina hæð í húsi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Beygja þig, krjúpa, halla þér fram	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ganga meira en einn kílómetra	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Ganga nokkur hundruð metra	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Ganga um 100 metra	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Klæða þig eða fara í bað	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Heilsa og líðan Íslendinga 2012

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Hreyfing og kyrrseta

52. Hversu miklum tíma samtals síðustu 7 daga, eyddir þú í líkamlega hreyfingu í frítíma og við virkan ferðamáta (t.d. göngu eða hjólríðar til eða frá vinnu)? Teldu með alla miðlungserfiða og erfiða hreyfingu sem stóð yfir í að minnsta kosti 10 mínútur í hvert skipti. Þess háttar hreyfing eykur hjartslátt og öndun. Dæmi eru erfið garðvinna, rösk ganga, stafganga, hjólríðar, golf og skokk.

Áætlaðu svarið að næstu 30 mínútum

_____ klukkustundir og _____ mínútur

53. Hversu mikið af þeirri hreyfingu sem þú gafst upp í síðustu spurningu (spurningu 52) var erfið hreyfing? Þess háttar hreyfing orsakar töluverða aukningu á hjartslætti og svita, og hraðari öndun sem gerir fólki erfitt að tala. Dæmi eru röskleg fjallganga, hlaup, hraðar hjólríðar og að spila fótbolta.

Áætlaðu svarið að næstu 30 mínútum.

_____ klukkustundir og _____ mínútur

54. Hver af eftirfarandi lýsingum passar best athöfnum þínum í frítíma, síðustu 7 daga?

Merktu í einn reit.

- ☐ Lestur, sjónvarpsáhorf eða önnur kyrrseta
- ☐ Ganga, hjólríðar eða önnur tegund af léttri áreynslu í að minnsta kosti fjórar klukkustundir síðustu sjö daga. Teldu með göngu eða hjólríðar til vinnu, sunnudagsgöngu og þess háttar
- ☐ Þátttaka í íþróttum í tómstundum, erfið garðyrkja og þess háttar, þar sem tímalengd hreyfingar er að minnsta kosti fjórar klukkustundir síðustu sjö daga
- ☐ Þátttaka í erfiðri þjálfun eða íþróttakeppni, reglulega nokkrum sinnum síðustu sjö daga

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55. Hve löngum tíma á dag varðir þú að jafnaði sitjandi í síðustu viku. Aðeins skal miða við virka daga. Teldu með tímann sem þú situr í vinnunni, heima og í frítíma. (Hér getur talist með tími sem setið er við skrifborð, matarborð, í heimsókn, við lestur eða fyrir framan sjónvarp eða tölvu.)

Merktu í einn reit.

- | | |
|---|--|
| <input type="checkbox"/> Minna en klukkustund á dag | <input type="checkbox"/> Um 8–10 klukkustundum á dag |
| <input type="checkbox"/> Um 1 klukkustund á dag | <input type="checkbox"/> Um 11–13 klukkustundum á dag |
| <input type="checkbox"/> Um 2–3 klukkustundum á dag | <input type="checkbox"/> Um 14–16 klukkustundum á dag |
| <input type="checkbox"/> Um 4–5 klukkustundum á dag | <input type="checkbox"/> Meira en 16 klukkustundum á dag |
| <input type="checkbox"/> Um 6–7 klukkustundum á dag | |

56. Hversu langt frá heimili þínu er eftirfarandi (km = kílómetri)?

Merktu í einn reit í hverjum lið.

	Minna en ½ km (innan við 10 mínútna göngu- fjarlægð)	Um ½–1 km (10–20 mínútna göngufjarlægð)	Um 2–5 km	Um 6–10 km	Um 11–20 km	Meira en 20 km
a) Útivistarsvæði (svo sem hjóla- eða göngustígar við strönd eða í gróður- lendi)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Opið náttúrulegt landsvæði sem nýtist til útivistar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Vinnustaður þinn (eða skóli)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

57. Hversu oft, ef einhvern tíma, nýtir þú þér eftirfarandi útivistarsvæði að jafnaði?

Merktu í einn reit í hverjum lið.

	Daglega	Þrisvar til sex sinnum í viku	Einu sinni til tvisvar í viku	Einu sinni til þrisvar í mánuði	Sjaldnar en einu sinni í mánuði	Aldrei
a) Útivistarsvæði (svo sem hjóla- eða göngustígar við strönd eða í gróðurlendi)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Opið náttúrulegt landsvæði	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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58. Hvað af eftirfarandi lýsir best líkamlegri áreynslu í starfi þínu eða námi?

Merktu í einn reit.

- ☐ Kyrrsetuvinna/nám að mestu leyti sem ekki krefst líkamlegrar áreynslu
- ☐ Vinnan/námið krefst göngu eða uppréttrar stöðu en ekki líkamlegrar áreynslu
- ☐ Vinnan/námið krefst göngu eða uppréttrar stöðu og að lyfta eða bera hluti
- ☐ Erfiðisvinna/nám krefst mikillar líkamlegrar áreynslu
- ☐ Á ekki við, er ekki í starfi eða námi

59. Hvernig finnst þér líkamlegt þol (úthald) þitt vera að jafnaði í samanburði við jafnaldra þína af sama kyni?

Merktu í einn reit.

- ☐ Mun meira en hjá jafnöldrum mínum
- ☐ Nokkru meira en hjá jafnöldrum mínum
- ☐ Svipað og hjá jafnöldrum mínum
- ☐ Nokkru minna en hjá jafnöldrum mínum
- ☐ Mun minna en hjá jafnöldrum mínum

60. Hvernig finnst þér líkamlegur styrkur þinn vera að jafnaði í samanburði við jafnaldra þína af sama kyni?

Merktu í einn reit.

- ☐ Mun meiri en hjá jafnöldrum mínum
- ☐ Nokkru meiri en hjá jafnöldrum mínum
- ☐ Svipaður og hjá jafnöldrum mínum
- ☐ Nokkru minni en hjá jafnöldrum mínum
- ☐ Mun minni en hjá jafnöldrum mínum

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Líðan og lífsgæði

61. Næst eru staðhæfingar um hugsanir og tilfinningar. Vinsamlegast merktu í þann reit sem lýsir best reynslu þinni síðastliðnar 2 vikur.

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldan	Stundum	Oft	Alltaf
a) Ég hef litið bjartsýnum augum til framtíðarinnar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Mér hefur þótt ég gera gagn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ég hef verið afslöppuð/afslappaður	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Mér hefur gengið vel að takast á við vandamál	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Ég hef hugsað skýrt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Mér hefur fundist ég náin/n öðrum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ég hef átt auðvelt með að gera upp hug minn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

62. Næst eru spurningar um tilfinningar þínar, hugsanir og líðan undanfarinn mánuð.

Merktu í einn reit í hverjum lið.

	Aldrei	Næstum aldrei	Stundum	Nokkuð oft	Mjög oft
a) Hversu oft undanfarinn mánuð fannst þér að þú værir að missa stjórn á mikilvægum þáttum í lífi þínu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Hversu oft undanfarinn mánuð varst þú örugg/ur með þær ákvarðanir sem þú þurftir að taka til að leysa úr persónulegum vandamálum?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hversu oft undanfarinn mánuð fannst þér að hlutirnir gengju þér í hag?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Hversu oft undanfarinn mánuð hefur þú upplifað að vandamálín hrönnuðust upp án þess að þú réðir við þau?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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63. Þegar á heildina er litið, hversu hamingjusama/n telur þú þig vera?

Merkðu í einn reit.

Mjög óhamingju- söm/ -samur	1	2	3	4	5	6	7	8	9	10	Mjög hamingju- söm/ -samur
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

64. Hversu litlu eða miklu álagi telur þú þig hafa orðið fyrir að undanfögnu vegna atburða eða aðstæðna sem þú hefur búið við?

Merkðu í einn reit í hverjum lið.

	Á ekki við	Mjög miklu álagi	Frekar miklu álagi	Hvorki miklu né litlu álagi	Frekar litlu álagi	Mjög litlu álagi
a) Í vinnu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Í námi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Við uppeldi barna	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Í samskiptum við maka	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Í öðrum þáttum einkalífs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Í að samræma vinnu/ nám og einkalíf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

65. Eftirfarandi staðhæfingar snúast um andlega líðan þína síðustu 2 vikur.

Vinsamlegast merktu við hverja staðhæfingu hversu oft þér hefur liðið þannig á síðustu tveimur vikum.

Merkðu í einn reit í hverjum lið.

Undanfarnar 2 vikur...	Alltaf	Oftast	Rúmlega helming tímans	Tæplega helming tímans	Öðru hvoru	Aldrei
a) var ég glöð / glaður og í góðu skapi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) var ég róleg/ur og afslöppuð/afslappaður	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) var ég full/ur af orku og krafti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) leið mér vel og var úthvöld/ur þegar ég vaknaði	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) var margt áhugavert að gerast á hverjum degi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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66. Hversu oft varðst þú var/vör við eftirfarandi vanlíðan eða óþægindi síðastliðna viku?

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldan	Stundum	Oft
a) Það var auðvelt að pirra mig eða ergja	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ég fékk reiðiköst sem ég gat ekki stjórnað	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Mig langaði að brjóta eða mólva hluti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Ég öskraði eða henti hlutum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Ég lenti í rifrildi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Mig langaði til að slá, slasa, eða skaða einhvern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

67. Hversu mikið eða lítið traust berð þú til eftirfarandi stofnana?

Merktu í einn reit í hverjum lið.

	Mjög mikið	Frekar mikið	Hvorki mikið né lítið	Frekar lítið	Mjög lítið
a) Alþingis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Þjóðkirkjunnar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Háskóla Íslands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Fjölmíðla	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Lögreglunnar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

68. Lestu hverja fullyrðingu hér að neðan og svaraðu hversu vel þær áttu við í þínu tilviki síðustu 7 daga. Það eru engin rétt eða röng svör. Eyddu ekki of miklum tíma í að velta fyrir þér hverri fullyrðingu.

Merktu í einn reit í hverjum lið.

	Átti alls ekki við mig	Átti við mig að einhverju leyti eða stundum	Átti töluvert vel við mig eða drjúgan hluta vikunnar	Átti mjög vel við mig eða mest allan tímann
a) Mér fannst erfitt að ná mér niður	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ég fann fyrir munnþurrki	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ég virtist alls ekki geta fundið fyrir neinum góðum tilfinningum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Mér fannst erfitt að hleypha í mig krafti til að gera hluti	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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69. Lestu hverja fullyrðingu hér að neðan og svaraðu hversu vel þær áttu við í þínu tilviki siðustu 7 daga. Það eru engin rétt eða röng svör. Eyddu ekki of miklum tíma í að velta fyrir þér hverri fullyrðingu.

Merktu í einn reit í hverjum lið.

	Átti alls ekki við mig	Átti við mig að einhverju leyti eða stundum	Átti töluvert vel við mig eða drjúgan hluta vikunnar	Átti mjög vel við mig eða mest allan tímann
a) Ég átti í erfiðleikum með að anda (t.d. allt of hröð öndun, mæði án líkamlegrar áreynslu)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ég hafði tilhneigingu til að bregðast of harkalega við aðstæðum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ég fann fyrir skjálfta (t.d. í höndum)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Mér fannst ég eyða mikilli andlegri orku	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Ég hafði áhyggjur af aðstæðum þar sem ég fengi hræðslukast (paník) og gerði mig að fífla	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Mér fannst ég ekki geta hlakkað til neins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ég var ergileg/ur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Mér fannst erfitt að slappa af	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Ég var dapur/döpur og niðurdregin/n	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Ég þoldi ekki þegar eitthvað kom í veg fyrir að ég héldi áfram við það sem ég var að gera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Mér fannst ég nánast gripin/n skelfingu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Ég gat ekki fengið brennandi áhuga á neinu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Mér fannst ég ekki vera mikils virði sem manneskja	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Mér fannst ég frekar hörundsár	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) Ég varð var/vör við hjartsláttinn í mér þó ég hefði ekki reynt á mig (t.d. hraðari hjartsláttur, hjartað sleppti úr slagi)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Ég fann fyrir ótta án nokkurrar skynsamlegrar ástæðu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Mér fannst lífið vera tilgangslaust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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70. Hversu sammála eða ósammála ert þú eftirfarandi fullyrðingum?

Merktu í einn reit í hverjum lið.

	Mjög sammála	Frekar sammála	Hvorki sammála né ósammála	Frekar ósammála	Mjög ósammála
a) Ég er ánægð/ur með útlit mitt eins og það er	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Flest fólk myndi segja að ég væri aðlaðandi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ég er óánægð/ur með líkamsbyggingu mína	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Ég er ánægð/ur með hvernig ég lít út nakin/n	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Líkami minn er kynferðislega aðlaðandi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Mér líkar hvernig fötin passa á líkama minn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ég er líkamlega óaðlaðandi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Félagsleg þátttaka

71. Hversu auðvelt eða erfitt átt þú með að treysta eftirtöldum fyrir persónulegum málefnum?

Merktu í einn reit í hverjum lið.

	Á ekki við	Mjög erfitt	Frekar erfitt	Hvorki né	Frekar auðvelt	Mjög auðvelt
a) Maka /unnusta /unnustu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Öðrum fjölskyldumeðlimum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Vinum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Vinnu- /skólafélögum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

72. Hversu auðvelt eða erfitt átt þú með að fá aðstoð frá eftirtöldum við að leysa úr vandamálum?

Merktu í einn reit í hverjum lið.

	Á ekki við	Mjög erfitt	Frekar erfitt	Hvorki né	Frekar auðvelt	Mjög auðvelt
a) Maka /unnusta /unnustu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Öðrum fjölskyldumeðlimum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Vinum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Vinnu- /skólafélögum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

73. Hversu ánægð/ur eða óánægð/ur ert þú með samband þitt við eftirtalda?

Merktu í einn reit í hverjum lið.

	Á ekki við	Mjög óánægð/ur	Frekar óánægð/ur	Hvorki né	Frekar ánægð/ur	Mjög ánægð/ur
a) Maka /unnusta /unnustu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Aðra fjölskyldumeðlimi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Vini	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Vinnu- /skólafélaga	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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74. Hversu oft á síðustu 12 mánuðum hefur þú unnið sjálfboðastörf eða tekið þátt í starfsemi góðgerðasamtaka?

Merktu í einn reit

- ☐ Að minnsta kosti einu sinni í viku
- ☐ Að minnsta kosti einu sinni í mánuði
- ☐ Að minnsta kosti einu sinni á þriggja mánaða fresti
- ☐ Að minnsta kosti einu sinni á sex mánaða fresti
- ☐ Sjaldnar
- ☐ Aldrei

Svefn

75. Hversu margar klukkustundir sefur þú að jafnaði á nóttu?

Merktu í einn reit.

- ☐ Minna en 5 klukkustundir
- ☐ Um 5 klukkustundir
- ☐ Um 6 klukkustundir
- ☐ Um 7 klukkustundir
- ☐ Um 8 klukkustundir
- ☐ Um 9 klukkustundir
- ☐ Um 10 klukkustundir
- ☐ Meira en 10 klukkustundir

76. Hversu oft hefur þú upplifað eftirfarandi á síðustu 3 mánuðum?

Merktu í einn reit í hverjum lið.

	Aldrei	Sjaldan	Stundum	Oft	Alltaf / á hverri nóttu
a) Átt erfitt með að sofna	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Vaknað eftir að hafa fest svefn og átt erfitt með að sofna aftur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Verið útsofin/n eftir nætursvefn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Vaknað nokkrum sinnum á nóttu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Appendix 4

Extra questions focusing on aspects of SB

Viðbótarspurningar varðandi hrygggrauf

1. Hvernig er göngugeta þín?

- ☐ Ég fer að mestu leyti um gangandi (ef til vill með spelkum, stöfum).
- ☐ Ég geng einungis innandyr, nota aðallega hjólastól utandyr.
- ☐ Ég geng einungis í þjálfunarskyni.
- ☐ Ég geng ekki.

2. Ertu með ventil í höfði?

- ☐ Já
- ☐ Nei

3. Hvar á hryggnum er taugaskaðinn?

- ☐ Á brjósthrygg
- ☐ Á mjóhrygg
- ☐ Á spjaldhrygg
- ☐ Veit ekki

Ef þú veist staðsetningu nákvæmlega: _____

4. Þarftu aðstoð við athafnir dagslegs líf?

- ☐ Nei, ég er sjálfstæð(-ur)
- ☐ Já, ég fæ aðstoð frá fjölskyldu minni
- ☐ Já, ég fæ aðstoð frá þjónustuaðila