Scandinavian Journal of Public Health, 2022; 50: 980–987

SCAND J PUBLIC HEALTH 50TH ANNIVERSARY ISSUE

FarGen – participants in the genetic research infrastructure of the Faroe Islands

KATRIN D. APOL[1], LEIVUR N. LYDERSEN[1], ÓLAVUR MORTENSEN[1], PÁL WEIHE[2], BJARNI Á. STEIG[3], GUÐRIÐ ANDORSDÓTTIR[1] & NOOMI O. GREGERSEN[1]

[1]FarGen, The Genetic Biobank of the Faroe Islands, Tórshavn, Faroe Islands, [2]Department of Occupational Medicine and Public Health, Tórshavn, Faroe Islands, and [3]General Medical Department, National Hospital of the Faroe Islands, Tórshavn, Faroe Islands

Abstract

Background: The demographic history of the Faroe Islands makes this isolated population – founded in the 9th century – interesting for genetic research. The goal of the FarGen project was to recruit individuals to the FarGen infrastructure to promote research into the genetic features of the Faroese people, and to develop a reference panel of population-specific variants. We aimed to recruit 1500 individuals. Participation was voluntary; participants had to donate a blood sample for whole-genome sequencing, and had to answer a questionnaire regarding sociodemographics, health, motivation and attitude towards participation in genetic research. *Methods:* A total of 1541 participants voluntarily joined the project, donated a blood sample and returned the questionnaire. *Results:* Answers from the questionnaire show that participants are, in general, European, have children, have a relatively high level of education, rate their health to be good, are willing to participate in future health-related research, and were motivated to sign up primarily to participate in research to help others and local research competency building. ***Conclusions:*** **Overall, the initial cohort of the FarGen infrastructure comprises 3% of the Faroese population, and represents the general population well based on the collected sociodemographic data. However, there is an excess of women, and some geographic sub-regions and age groups are slightly underrepresented. We find the recruitment method with voluntary sign-up appropriate, and knowledge acquired through the first phase will aid the next phase of the project, with the aim of expanding the FarGen cohort with additional individuals, bio-specimens and body measurements in order to perform multifactorial analyses.**

Keywords: *Biobanking, research-infrastructure, sociodemographic characteristics, Faroe Islands, isolated population, FarGen*

Background

Population biobanks are increasingly becoming the bases for integrated research that explores the impact of genetic, environmental and life-style factors in shaping population health. In recent decades, we have seen research infrastructures emerging worldwide, collecting bio-specimens to conduct research in both urban and rural populations to enhance the understanding and prevention of human genetic diseases [1,2].

The FarGen-infrastructure was established by the Genetic Biobank of the Faroe Islands in 2016 with the overall goal of promoting research into the health of the Faroese population – an isolated population founded in the 9th century by a few hundred founders descending primarily from Scandinavia and the British Isles [3,4]. The archipelago of 18 islands has been relatively isolated for centuries, and historical records show little fluctuation in population size from settlement until the 19th century, when the population grew from about 4000 individuals to the

Correspondence: Katrin Didriksen Apol, FarGen, Genetic Biobank of the Faroe Islands, J.C. Svabosgøta 43, 100 Tórshavn, Faroe Islands.
E-mail: katrin@fargen.fo

Date received 19 April 2021; reviewed 17 August 2021; accepted 29 August 2021

DOI: 10.1177/14034948211046817
journals.sagepub.com/home/sjp
SAGE

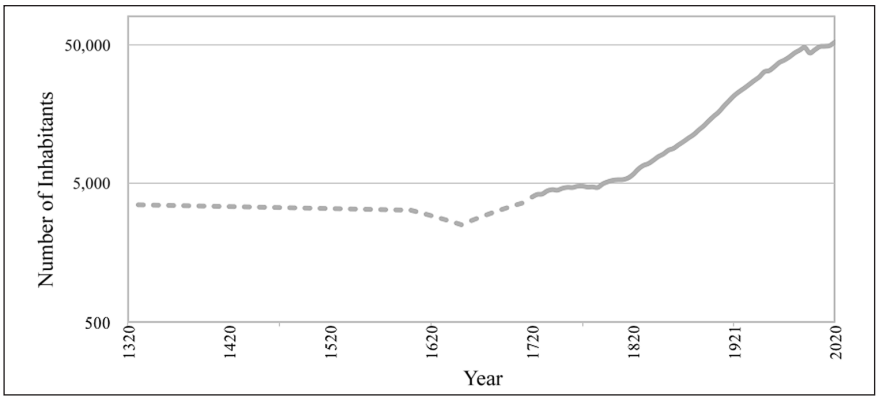


Figure 1. Number of inhabitants of the Faroe Islands, year 1330–2020 [5–7], reprinted from Statistics Faroe Islands.

current 53,000 individuals (Figure 1) [5–7]. The effect of founder event, genetic drift, recent population expansion and isolation may explain the increased prevalence of diseases seen in the Faroese population as well as enrichment of otherwise rare genetic risk variants [8–15].

With the FarGen infrastructure, we are collecting biological material for whole-genome sequencing to build a reference panel of genetic variants within this population [16]. Coupled with registry data such as extended genealogical records, which go back to 1650 for 85% of the population, with some lineages going back to the 1100s (http://biobank.fo/en), this population may be ideal for population-based genetic research to reveal unprecedented details about human genetic disease and as a stepping stone towards precision medicine [17–20].

Here, we present the first participants of the FarGen infrastructure, the recruitment procedures, the sociodemographic characteristics of the participants, their motivation to participate and attitude towards being included in genetic research, and elaborate on how well they represent the general Faroese population.

Subjects and methods

The FarGen project was approved by Vísindasiðsemisnevndin, Heilsumálaráðið (the Faroese Research Ethical Committee, Ministry of Health), 1 August 2016, in accordance with the Declaration of Helsinki.

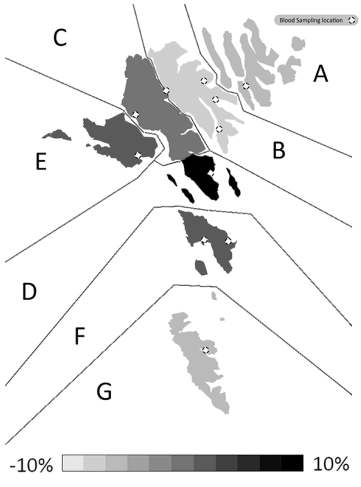
Inclusion criteria and recruitment

Essential for recruitment to the FarGen infrastructure was that participants had to be 18 years of age or older, had to live in the Faroe Islands or be of Faroese descent and had to join the project voluntarily. No prior knowledge about health status or ethnicity was required.

Awareness of the FarGen project was made through an active PR-effort and publicity campaign comprising TV commercials, flyers, social media and the FarGen homepage (www.fargen.fo). Participants signed up actively for the infrastructure on the FarGen homepage or by contacting the FarGen coordinator; no individual invitations were sent out. After signing up, participants were given the Participant Information Sheet, a self-administered questionnaire and the consent form either by direct contact at local information meetings or by e-mail. To give the participants direct opportunity to ask questions about the project, and explain the advantages and disadvantages of the project, such as the potential risk of incidental findings, eight local information meetings were held in a period of three months. In addition, 40 sampling events were held around the islands to collect blood samples, questionnaires and consent forms. See locations of blood sampling events in Figure 2. Recruitment took place from September 2016 to February 2018.

Participant information sheet

The Participant Information Sheet comprises the information required before informed consent can be given. In short, the document explains in layman's terms that a blood donation is required for whole-genome sequencing, that the genomic data will be included in the Faroese reference panel of genetic variants, that summary statistics will be published and that the reference panel of genetic variants will be made available for research in collaboration with the Genetic Biobank of the Faroe Islands. Further, it explains that no feedback regarding individual genomic data will be given unless it is an incidental finding, i.e. the responsible clinician has the obligation to inform and report about incidental finding of genetic variants that are



	Blood sampling (n=40)	FarGen (n=1504)	FO (n=37,703)
Norðoyggjar (A)	4 (10%)	128 (8.5%)	4576 (12.1%)
Eysturoy (B)	8 (20%)	258 (17.2%)	8353 (22.2%)
Norðstreymoy (C)	6 (15%)	128 (8.5%)	2881 (7.6%)
Suðurstreymoy (D)	13 (32.5%)	737 (49%)	14,986 (39.7%)
Vágar (E)	3 (7.5%)	114 (7.6%)	2344 (6.2%)
Sandoy (F)	3 (7.5%)	56 (3.7%)	984 (2.6%)
Suðuroy (G)	3 (7.5%)	83 (5.5%)	3579 (9.5%)

FarGen: FarGen participants with residence in the Faroe Islands

FO: General Faroese population in 2018

Figure 2. Local residence of the FarGen participants at enrolment. The table shows the number of participants, the number of total inhabitants and the number of blood sampling events in each sub-region. The colour scheme represents each sub-region compared with the percentage of total inhabitants of the different regions in 2018. Gapped circles show the locations of the 40 blood sampling events.

likely to cause a genetically inheritable disease, provided disease prevention or treatment exists using the Danish National Committee on Health research Ethics guidelines, 4 February 2016. It is clearly stated that the participants are free to withdraw from the study at any time. Further, it explains how and where the samples and data will be stored: pseudonymous at the Genetic Biobank of the Faroe Islands and protected by the Parliamentary Act No. 62 on Human Genetics Research. Finally, participants were informed about the need to re-consent to future research projects that may give feedback regarding their genomic data.

Questionnaire

A questionnaire was constructed according to MIABIS [21], and questions from the Coriell Personalized Medicine Collaborative (CPMC) study were also partially adapted to gain insight into the participants' motivation for engaging in the project [22]. The self-administered questionnaire had a total of 25 questions, including basic sociodemographic data: name, surname, gender, age, current residence, ethnicity and education level. Health-related questions comprised self-rated health and health/disease status (only self-rated health will be presented here). To quickly evaluate the degree of relatedness, we asked if the participants had related parents, i.e. second cousins or closer related. Finally, participants were asked to rank their decision to participate according to 12 different motivations factors, and their attitude towards participating in health-related research. Most questions were administered using tick boxes.

Census data

The sociodemographic characteristics of the FarGen participants were compared with publicly available census data (2011 and 2018) from Statistics Faroe Islands (www.hagstova.fo/en), which is responsible for collecting and analysing official statistics in the Faroe Islands. Official statistics available for comparison comprised 2018 census data ($n = 37{,}703$, $\geqslant 18$ years) for gender, age, residence and ethnicity (place of birth), and 2011 census data ($n = 37{,}964$, $\geqslant 15$ years) for women with children, education level and self-rated health. The education level in the FarGen data was stratified into groups corresponding to the 2011 census data. As census data provide information on place of birth – not ethnicity – the comparison should be viewed with certain reservations.

Statistical analysis

We used χ^2 goodness-of-fit test to compare the FarGen cohort data (i.e. observed) with the general Faroese population census data (i.e. expected). Distributions available to compare were gender, age, ethnicity, education level, self-rated health and residence in the Faroe Islands. Analyses were performed in RStudio version 1.2 using a significance level of 0.05 [23].

Results

Characteristics of FarGen participants

At present, 1541 individuals are participating in the FarGen project, i.e. have donated a blood sample for

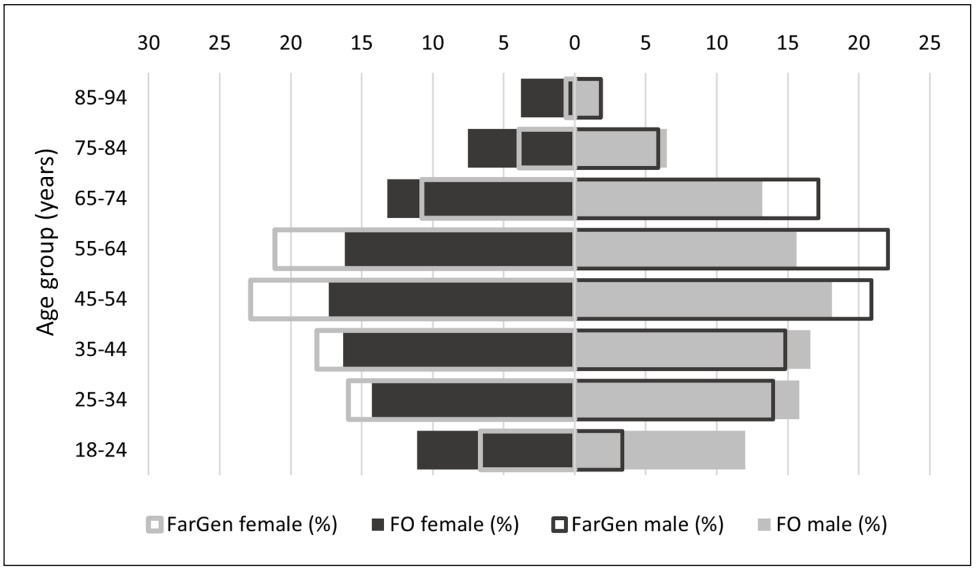


Figure 3. Age groups of women and men (%) in the FarGen cohort compared with the general Faroese population (FO).

whole-genome sequencing and returned the questionnaire. Self-reported sociodemographic characteristics and corresponding census data from the general Faroese population (2011 and 2018) are presented in Table I. The FarGen data show that women feel more inclined to participate (61.5% are women). The data show a significant difference in gender distribution ($p < 0.01$) in the FarGen data versus census data, 83.3% of the women have children, in contrast with 76.8% in the general Faroese population. Participants in the FarGen cohort tend to have a higher level of education compared with the general Faroese population ($p < 0.0001$). A large majority of both women and men rate their health to be good or very good, which is consistence with the census data ($p > 0.05$).

Mean age at enrolment is 47.9 ± 14.9 years versus 49 ± 14.9 for the general Faroese population. The age distribution within the FarGen cohort is grouped into female and male in Figure 3 and shows a tendency towards higher enrolment of women in the younger age groups, while opposite is seen for men. In comparison with the general Faroese population (FO in Figure 2), we see some of the age groups are underrepresented in the FarGen cohort, e.g. the 18–24 age group, while others are overrepresented, e.g. the 45–64 age groups. However, the age distributions in the FarGen cohort are not significant different from the age distributions in the general Faroese population ($p > 0.05$).

Background and residence of the FarGen cohort

In total, 89.5% of participants reported European ethnicity, 1.2% (19 individuals) reported ethnicity other than European (2 Africans, 4 Asians, 8 Americans, and 5 other), while 9.3% (143 individuals) did not respond on the ethnicity question. Looking into the genealogical data of the non-responders, we see all but one have multiple relatives registered in the Multi Generation Registry. Therefore, it is likely that the percentage of participants with European ethnicity is higher than reported, and approximates the numbers for the general Faroese population, which is 98.0% European.

The participants gave information about their current residence according to seven geographic sub-regions: Norðoyggjar (A), Eysturoy (B), Norðurstreymoy (C), Suðurstreymoy (D), Vágar (E), Sandoy (F) and Suðuroy (G); represented as a table and a heat plot in Figure 2. The heat plot data is based on the individuals' current residence compared with the percentage of total inhabitants of the different regions in 2018. The results show some underrepresentation of sub-regions A, B and G versus census data, while the capital area located in sub-region D is overrepresented. However, the FarGen residence distributions are not significantly different from the residence distributions of the general Faroese population ($p > 0.05$). Figure 2 also includes the number of blood sampling events in the respective sub-regions and shows that the number of blood collecting events reflects the representativeness of the respected sub-region in the FarGen cohort; however, some of the events may have been more effective than others, e.g. sub-regions D versus sub-region C (see Figure 2).

A large majority of participants (90.1%) stated that they did not have related parents, while 5.5% affirmed related parents as close as second cousins or

Table I. Characteristics of the FarGen participants ($n = 1541$) in comparison with the general Faroese population.[a,b]

	FarGen participants		Census[a,b]	*p* value[c]
	n	%	%	
Gender, age, children				
Female	947	(61.5)	48.2	<0.01
Male	594	(38.5)	51.8	
Mean age (SD)	47.9	(14.9)	49.0 (18.8)	
Have children (women only)	789	(83.3)	76.8	
Education level				
Primary school only	210	(13.6)	35.8	<0.0001
Upper secondary[d]	582	(37.8)	37.2	
Diploma or Bachelor's degree	501	(32.5)	22.5	
Master or PhD degree	239	(15.5)	4.5	
N/A	9	(0.6)		
Self-rated health				
Very good	432	(28.0)	32.2	>0.01
Good	828	(53.7)	46.5	
Satisfying	248	(16.1)	17.6	
Bad	23	(1.5)	2.9	
Very bad	4	(0.3)	0.8	
N/A	6	(0.4)		
Ethnicity				
European	1379	(89.5)	98.0	<0.0001
Non-European	19	(1.2)	1.9	
N/A	143	(9.3)	0.1	
Parents related[e]				
Yes	85	(5.5)		
No	1388	(90.1)		
Don't know	52	(3.4)		
N/A	16	(1.0)		
Can we contact your family about FarGen?				
Yes	1474	(95.7)		
No	55	(3.6)		
N/A	12	(0.8)		
Attitude towards participating in health-related research				
Include me in all health-related research	1248	(81.0)		
Include me in research of specific diseases	247	(16.0)		
Little desired to be included in research	19	(1.2)		
N/A	27	(1.8)		

[a]2018 census data ($n = 37{,}703$) from Statistics Faroe Islands comprises gender, mean age and ethnicity.
[b]2011 census data (n = 37,965) from Statistics Faroe Islands comprises children, education level and self-rated health.
[c]χ^2 Goodness-of-fit test results for FarGen cohort data against census data from the general Faroese population.
[d]Upper secondary includes college, vocational educations and 2–3 year long educations.
[e]Parents second cousins or closer related, self-reported.
SD, Standard deviation; FO, Faroe Islands; N/A, No answer.

closer (Table I). To get information about family connections within the cohort, we used the Multi-Generation Registry at the Genetic Biobank to reconstruct the genealogies of the participants. According to these genealogies, a large majority (70.5%) of the participants have at least one close relative (child, parent, sibling, grandparent, first cousin or aunt/uncle) also participating in the FarGen project. Moreover, most participants (95.7%) agreed to the possibility of FarGen contacting non-participating family members about possible enrolment in the project in order to conduct future family studies.

Motivation to participate in FarGen

A large majority (97%) of both women and men stated a positive attitude towards participating in future health-related research. Further, the response rate to the 12 motivations factors that might have influenced the decision to enrol in the FarGen-infrastructure was high for both genders, and we see little discrepancy on how they rank the importance of each motivation factor (Table II). Most important motivation factors were local research competency building, to participate in research to help others and that FarGen is a Faroese project. Curiosity about risk

Table II. Response on motivation factors for participating in the FarGen project.

	Female ($n=947$) (%)				Male ($n=594$) (%)			
	Very important	Somewhat important	Not important	NA[a]	Very important	Somewhat important	Not important	NA[a]
Local research competency building	82.4	14.3	1.3	2.1	78.5	16.7	2.0	2.9
Participate in research to help others	80.4	17.5	0.7	1.4	76.8	19.2	1.3	2.7
FarGen is a Faroese project	68.1	24.7	3.4	3.8	60.4	27.6	8.4	3.5
Curious about risk of health conditions of family members	55.3	32.9	7.9	3.8	54.2	31.0	9.3	5.6
Find out about diseases for which I am at risk	54.2	33.2	9.0	3.7	50.3	33.5	10.4	5.7
Curiosity about my genes	46.4	39.9	9.4	4.3	41.8	40.6	12.2	5.6
Find out what I can do to improve my health	41.4	38.0	16.5	4.1	36.9	37.5	20.7	4.9
Interested in my ancestry	40.1	38.6	17.0	4.2	35.2	37.2	22.9	4.7
Interested in specific medical conditions	32.7	41.4	21.5	4.3	21.5	41.9	31.3	5.2
No cost to me to participate	24.0	24.5	46.4	5.2	20.4	23.2	50.7	5.7
Influence from family and friends	15.0	28.4	51.0	5.6	14.1	29.1	51.3	5.4
Influence from the media	10.3	38.1	46.0	5.5	7.6	32.5	54.4	5.6

[a]No response to the question.

of health conditions of family members and finding out about risk of diseases were also considered as very important motivation factors for more than half of the total cohort.

Discussion

Here, we have presented characteristics of the 1541 participants of the FarGen infrastructure, which is based on a self-administered questionnaire. The response rate was high for most of the questions, especially when disregarding some of the health-related questions (data not shown). In summary, nearly all the participants are of European origin, have children (data shown only for women), have a relatively high level of education, rate their health to be good and state a positive attitude towards participation in health-related research. Women are better represented in the FarGen cohort (61.5% female vs 38.5% male). However, the skewed gender distribution is strengthened when accounting for the excess of men in the general Faroese population – 48.2% female and 51.8% male (Table I), which could pose a limitation to the data, such as matching cases and controls by gender in future studies. The emerging trends in characteristics of the FarGen participants are in accordance with the general tendencies in other epidemiological studies, particularly regarding the excess of women and participants with relatively high education level [24–26]. We see no difference in the age distribution in the FarGen cohort compared with the general Faroese population, though some of the age groups e.g., the 45–64 age groups are better represented. A national awareness survey about FarGen in 2017 (data not shown) showed that 62 % of the 18–24 years old had not heard about the FarGen project despite a significant national public relations campaign and advertising effort. In comparison, this number is between 6% and 19% for the other age groups. Thus, our recruitment efforts seem better suited to the older age groups, which calls for a revised marketing effort to reach younger age groups, e.g. choice of media platforms.

Participants with residence in the capital area are slightly overrepresented, despite the relative low blood sampling events in this sub-region. The geography and the infrastructure of the respective sub-regions varies and may explain the efficiency of the blood sampling events. Hence, the capital area has the vast majority of residents distributed over a limited geographical area with a relatively good infrastructure to move around. The underrepresented sub-regions, on the other hand, all cover larger areas with many small, scattered settlements, and therefore it may be more inconvenient to get to the blood sampling events, which were held predominately in the larger villages in the respective sub-region. The importance of the representativeness of the Faroese population reflects the aim of the FarGen project, i.e. to build a reference panel of genetic variants within this population. There have been indications of a genetic population structure in the Faroese population due to geographic barriers [27]; however, the question is to what extent each sub-region represents different gene pools. The improved infrastructure between the main islands, as well as the growing

centralisation around the capital area has removed many of the previous geographic barriers between regions, and has most likely increased the gene flow between sub-regions. Future work on genetic data will reveal the extent of cryptic relatedness and population structures within the Faroese population, which will demonstrate the degree of sub-regions and the need for an even representation of all sub-regions. The fact that 70% of the participants have at least one close relative enrolled in the project may give a skewed representation of the Faroese population as well as it may present a limitation for selection of cases and controls for future association studies. Therefore, the Multi-Generation Registry will be an important tool to account for confounding due to relatedness in future research studies.

The response regarding motivation factors show that participants engage primarily in the FarGen project for altruistic reasons; local research competency building and participating in research to help others ranked as highest motivators. Motivation factors with a more intrinsic character, such as curiosity about their genes or finding out how to improve personal health had only an intermediate effect on enrolment in FarGen. These results contrast with the CPMC study, where engagement was highly motivated by intrinsic factors [22]. This may be explained by the different assumptions underlying participation in the two studies, especially regarding feedback of personal genomics: FarGen participants were told clearly that they would not receive feedback on personal genomics at this stage of the project, while such feedback is one of the goals of the CPMC study. Thus, to compare hypothetical options with real response options may yield misleading results and will be revised in the next phase of the FarGen project. However, derivative research projects using FarGen data may provide feedback in the future; therefore, responses regarding motivation factors may give indications for user participation and the likelihood of re-consenting to future research projects.

It is with certain reservations that we point out altruism as ranking highest as a motivating factor, but nevertheless it is consistent with previous sociological research on altruism, which shows that reasons for engagement in research studies with no financial compensation or individual health benefits generally tend to have altruistic character [28,29]. Common for the FarGen and the CPMC studies is the low ranking of external motivators, such as influence from media, family, friends or due to everyone else was enrolling. However, some influence from family members on the engagement in the FarGen project may be indicated, given the high number of related individuals in the FarGen cohort.

Conclusion and future perspective

Overall, the initial cohort in the FarGen infrastructure represents the general Faroese population well based on the collected sociodemographic data. However, some of the geographic sub-regions and age groups may have been better represented. We find the recruitment method with voluntary sign-up appropriate for the FarGen infrastructure, though we should strive to be more present in some of the sub-regions, get a more even gender distribution and target underrepresented age groups more directly in our future marketing. The experience gained from the recruitment process is beneficial for the next phase of the FarGen project, e.g. questions should be asked more precisely, and we should use primarily closed questions with tick boxes.

The collected samples are now in the process of being sequenced, self-reported diagnoses are being confirmed according to electronic medical records and the reference-panel of population specific variants is being constructed, which will become the basis for identifying and filtering out disease variants in future medical studies. Future perspectives will be to expand the FarGen cohort with additional individuals, bio-specimens and body measurements in order to perform multifactorial analyses.

Acknowledgements

The authors thank all the participants for their contribution to the FarGen project. Further, we thank Hans Atli Dahl, Gunnrið Jóanesarson and Nina Djurhuus for great collaboration on this work.

Data availability

Data collected for the FarGen-infrastructure is available for research up on participants' re-consent. Researchers will be granted access to de-identified genetic-data and meta-data provided that the project protocol has been approved by the Faroese Scientific Ethical Committee and a template material/data transfer agreement has been signed with the Genetic Biobank of the Faroe Islands in compliance with GDPR [16].

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the

Faroese Parliament; the Danish Parliament; the Faroese Research Council and the Betri Foundation.

ORCID iD

Katrin D. Apol https://orcid.org/0000-0001-5488-2334

References

[1] Kinkorová J. Biobanks in the era of personalized medicine: objectives, challenges, and innovation. *EPMA J* 2016;7:4.

[2] Sudlow C, Gallacher J, Allen N, et al. UK Biobank: an open access resource for identifying the causes of a wide range of complex diseases of middle and old age. *PLoS Med* 2015 12:e1001779.

[3] Jorgensen TH, Buttenschøn HN, Wang AG, et al. The origin of the isolated population of the Faroe Islands investigated using Y chromosomal markers. *Hum Genet* 2004;115:19–28.

[4] Als TD, Jorgensen TH, Børglum AD, et al. Highly discrepant proportions of female and male Scandinavian and British Isles ancestry within the isolated population of the Faroe Islands. *Eur J Hum Gen* 2006;14:497–504.

[5] Degn A. Hvat kann Rómaskatturin í Føroyum siga okkum, *Varðin 12. b.*, 1932.

[6] Garði í B. En historisk demografisk undersøgelse af udviklingen på Færøerne 1720–1831, Københavns Universitet, 1984 (Unpublished).

[7] Guttesen R. Veðurlag, framleiðsla og fólkatal í 1800-talinum og fyrr, í Brot úr Føroya søgu, *Fróðskapur* 2010

[8] Schwartz M, Sørensen N, Brandt NJ, et al. High incidence of cystic fibrosis on the Faroe Islands: a molecular and genealogical study. *Hum Genet* 1995;95:703–706.

[9] Rasmussen J, Nielsen OW, Janzen N, et al. Carnitine levels in 26,462 individuals from the nationwide screening program for primary carnitine deficiency in the Faroe Islands. *J Inherit Metab Dis* 2014;37:215–222.

[10] Hammer T, Nielsen KR, Munkholm P, et al. The Faroese IBD study: incidence of inflammatory bowel diseases across 54 years of population-based data. *J Crohns Colitis* 2016;10:934–942.

[11] Joensen P. Multiple sclerosis: variation of incidence of onset over time in the Faroe Islands. *Mult Scler* 2011;17:241–244.

[12] Wermuth L, Bech S, Petersen MS, et al. Prevalence and incidence of Parkinson's disease in The Faroe Islands. *Acta Neurol Scand* 2008;118:126–131.

[13] Veyhe AS, Andreassen J, Halling J, et al. Prevalence of type 2 diabetes and prediabetes in the Faroe Islands. *Diabetes Res Clin Pract* 2018;140:162–173.

[14] Gregersen NO, Lescai F, Liang J, et al. Whole-exome sequencing implicates DGKH as a risk gene for panic disorder in the Faroese population. *AM J Med Genet B Neuropsychiatr Genet* 2016;171:1013–1022.

[15] Leblond CS, Cliquet F, Carton C, et al. Both rare and common genetic variants contribute to autism in the Faroe Islands. *NPJ Genom Med* 2019; 21:4:1.

[16] Gregersen NO, Apol KD, Weihe P, et al. FarGen: bioresource from the Faroes genome project. *O J Bioresourc* 2021;8:1–6.

[17] Wright AF, Carothers AD and Pirastu M. Population choice in mapping genes for complex diseases. *Nat Genet* 1999;23:397–404.

[18] Peltonen L, Palotie A and Lange K. Use of population isolates for mapping complex traits. *Nat Rev Genet* 2000;1:182–190.

[19] Arcos-Burgos M and Muenke M. Genetics of population isolates. *Clin Genet* 2002;61:233–247.

[20] Hatzikotoulas K, Gilly A and Zeggini E. Using population isolates in genetic association studies. *Brief Funct Genomics* 2014;13:371–377.

[21] Norlin L, Fransson MN, Eriksson M, et al. A minimum data set for sharing biobank samples, information, and data: MIABIS. *Biopreserv Biobank* 2012;10:343–348.

[22] Gollust SE, Gordon ES, Zayac C, et al. Motivation and perceptions of early adopters of personalized genomics: perspectives from research participants. *Public Health Genomics* 2012;15:22–30.

[23] R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL https://www.R-project.org/ (2020, accessed 10 June 2021).

[24] Kesse-Guyot E, Andreeva V, Castetbon K, et al. Participant profiles according to recruitment source in a large web-based prospective study: experience from the Nutrinet-Santé study. *J Med Internet Res* 2013;15:e205.

[25] Galea S and Tracy M. Participation rates in epidemiologic studies. *Ann Epidemiol* 2007;17:643–653.

[26] Fry A, Littlejohns TJ, Sudlow C, et al. Comparison of sociodemographic and health-related characteristics of UK Biobank participants with those of the general population. *Am J Epidemiol* 2017;186:1026–1034

[27] Als TD, Lescai F, Grove J, et al. Population structure and cryptic relatedness of the isolated population of the Faroe Islands. In: XXII World Congress of Psychiatric Genetics, Copenhagen, Denmark, 12–16 October 2014.

[28] Carrera JS, Brown P, Brody JG, et al. Research altruism as motivation for participation in community-centered environmental health research. *Soc Sci Med* 2018;196:175–181.

[29] Hunter J, Corcoran K, Leeder S, et al. Appealing to altruism is not enough: motivators for participating in health services research. *J Empir Res Hum Res Ethics* 2012;7:84–90.