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2023

http://hdl.handle.net/10138/574316

Jauho, M 2023, Risk Factor Epidemiology Viewed from Below : Lay Reception of the North Karelia Project (Finland) in the 1970s and Early 1980s. in H Hakosalo, K Parhi & A Sailo (eds), Historical Explorations of Modern Epidemiology : Patterns, Populations and Pathologies. Medicine and Biomedical Sciences in Modern History, Palgrave Macmillan, pp. 135-156. https://doi.org/10.1007/978-3-031-20671-9_7

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Risk factor epidemiology viewed from below: Lay reception of the North Karelia Project (Finland) in the 1970s and early 1980s

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Introduction

On 12 January 1971, the Governor of North Karelia, together with local members of the parliament and representatives of administration and voluntary organizations, issued a petition for national aid to reduce cardiovascular disease (CVD) mortality in North Karelia, a county in the northeast of Finland, plagued by an extremely severe CVD situation. The petition was addressed to the Finnish Government, National Board of Health, the Medical Research Council of the Finnish Academy, and Finnish Heart Association (FHA). It proposed that the authorities "should urgently undertake efficient action to plan and implement a program which would organize and finance general health information to the public, necessary basic research, and individual health education to reduce this greatest public health problem of the county."[1]

The petition was the symbolic starting shot of the North Karelia project (NKP), an important intervention trial aimed at reducing cardiovascular risk factors, morbidity, and mortality in the community.[2] Finland had gained notoriety in international comparisons from the late

[1] Cited in *Community Control of Cardiovascular Diseases: Evaluation of a Comprehensive Community Programme for Control of Cardiovascular Diseases in North Karelia, Finland 1972-1977* (Copenhagen: WHO Europe, 1981), 4.
[2] The petition was symbolically important, as it gave legitimacy to the project and grouped the local community behind it. However, preparations for a preventive CVD effort were started already in the previous year. See National Archives of Finland (NAF), Suomen Sydänliiton arkisto, Liittohallituksen pöytäkirjat, Ca:2 Pöytäkirjat (1970–75), Liittohallituksen kokouspöytäkirja 21.9.1970 5§. A more thorough discussion on the launching of

1940s onwards as one of the darkest areas in terms of coronary heart disease (CHD) mortality.[3] North Karelians were among the hardest hit populations in the country.[4] A relatively underdeveloped area, with agriculture and forestry as the main sources of livelihood, North Karelia was greatly affected by the modernization processes of industrialization, urbanization, and migration that took place in Finland in the 1960s. Especially small-scale farmers faced problems, which led to farm closures and migration either to cities or abroad.[5] North Karelia was also lacking in health services compared to other, more affluent parts of Finland. For example, the number of physicians per inhabitant was relatively low in the region.[6]

The 1960s and 1970s were decades of intensified welfare service development, which emphasized equality in their availability and use. The reforms were driven by the two leading political parties, the Agrarian Centre Party and the Social Democrats. The former emphasized regional policy, while the latter promoted the development of welfare services.[7] This combination generated policy efforts to ameliorate the situation of people living in underdeveloped areas and to provide services to all parts of the country, a wave that the petition and the subsequent project rode.[8]

NKP is Mikko Jauho, "Becoming the North Karelia Project: The Shaping of an Iconic Community Health Intervention in Finland (1970–1977)," *Social History of Medicine* (2020), doi.org/10.1093/shm/hkaa057.

[3] Väinö Kannisto, "Miksi Suomen miehet kuolevat ennenaikaisesti?," *Duodecim* 67 (1951), 1108–12. WHO data was the key source, see for example Alex. M. Burgess, Zdenek Fejfar and Aubrey Kagan, *Arterial hypertension and ischaemic heart disease: comparison in epidemiological studies* (Geneva: World Health Organization, 1963), 7.

[4] Finland and North Karelia were part of the Seven Countries Study, a large comparative cohort study on CVD risk factors. It generated regular data on the CVD situation in North Karelia. Daan Kromhout, Alessandro Menotti and Henry Blackburn, eds, *The Seven Countries Study: A Scientific Adventure in Cardiovascular Disease Epidemiology* (Bilthoven: The Seven Countries Study, 1994). Preliminary information on its ten-year results were published in late 1969 and once again highlighted the poor situation in the area, prompting the local residents to act, according to Henry Blackburn, "Research and Demonstration Projects in Community Cardiovascular Disease Prevention", *Journal of Public Health Policy* 4 (1983), 398–421, 402–03.

[5] Leo Granberg, "Tuotannon kasvun vuosikymmenet" [Years of production growth], in Viljo Rasila and Pirjo Markkola, eds., *Suomen maatalouden historia 3: Suurten muutosten aika* [History of Agriculture in Finland 3: The Time of Great Changes] (Helsinki: SKS, 2004), 141-86, 170-9.

[6] Minna Harjula, *Hoitoonpääsyn hierarkiat. Terveyskansalaisuus ja terveyspalvelut Suomessa 1900-luvulla* [Hierarchies of Access to Care: Health Citizenship and Health Services in Finland in the 20th Century] (Tampere: Tampere University Press, 2015), 69.

[7] Minna Harjula, "Health Citizenship and Access to Health Services: Finland 1900-2000," *Social History of Medicine* 29 (2016), 573-89.

[8] For a more thorough discussion of the influences behind the project, see Mikko Jauho, "The North Karelia Project (1972–1997) and the Origins of the Community Approach to Cardiovascular Disease Prevention", *American Journal of Public Health* 111 (2021), 890-5.

NKP was internationally one of the first community interventions that made a concerted effort to test methods to reduce CVD mortality in a specific area. Instead of only high-risk people, it targeted the whole North Karelian population, which numbered around 180 000 at the start of the project. The principal aim of NKP was to influence three risk factors considered to be key to CHD prevention, namely smoking, elevated cholesterol, and high blood pressure, but objectives also included early detection, treatment, and rehabilitation of CVD patients in the community. Targeting the local culture and working through various stakeholder and civil society groups, such as teachers, healthcare personnel, NGOs, and media representatives, it comprised a massive information and education campaign on the causes and prevention of CHD, supported by changes in the social environment. Designed as an intervention trial, with the neighboring county of Kuopio serving as control, NKP started in 1972 and was initially planned to last five years. However, it was later continued and augmented with new elements, until finally terminated in 1997.[9]

NKP is significant in several respects. It is situated at a specific juncture in the development of cardiovascular epidemiology, signifying the move from risk factor studies to preventive intervention studies. NKP is held in extremely high esteem in Finland. It is often given the role of turning the tide on Finnish heart health, and it is regularly evoked as a model for tackling other pressing public health problems.[10] It undoubtedly had an important role in popularizing the key cardiovascular risk factors and in introducing the corresponding lifestyle-focused

[9] Studies on NKP can be divided into two groups. Initially, they were produced by authors personally involved in the project, see Pekka Puska, *Sydänprojekti* [The Heart Project] (Helsinki: Otava, 1985); Harri Mustaniemi, *Saappaat savessa: Pohjois-Karjala projektin tuloksia tekemässä* [Boots in the Mud: Making the Results of the North Karelia Project] (Joensuu: Pohjois-Karjala projektin tutkimussäätiö, 2005). Useful are also the extensive reports published by the project group, see *Community Control of Cardiovascular Diseases* (1981); Pekka Puska et al., eds, *The North Karelia Project: From North Karelia to National Action* (Helsinki: National Institute for Health and Welfare, 2009). Recently, there has emerged a new set of studies, which take a more evaluative look at NKP or use it as an entry point for theoretically motivated explorations, see Marja-Liisa Honkasalo, *Reikä sydämessä: sairaus pohjoiskarjalaisessa maisemassa* (Tampere: Vastapaino, 2008); Mikko Jauho, "'Give People Work, and the Blood Pressure Will Sink': Lay Engagement with Cardiovascular Risk Factors in North Karelia in the 1970s," *Health, Risk & Society* 18 (2016), 21–37; idem., "Contesting Lifestyle Risk and Gendering Coronary Candidacy: Lay Epidemiology of Heart Disease in Finland in the 1970s," *Sociology of Health & Illness* 39 (2017), 1005–18; idem. (2020); idem. (2021); Johannes Kananen, "Science, Politics and Public Health: The North Karelia Project," in J. Kananen, S. Bergenheim and M. Wessel, eds, *Conceptualising Public Health: Historical and Contemporary Struggles over Key Concepts* (Abingdon: Routledge, 2018), 174–89; Tiina Ritvala and Nina Granqvist, "Institutional Entrepreneurs and Local Embedding of Global Scientific Ideas – The Case of Preventing Heart Disease in Finland," *Scandinavian Journal of Management* 25 (2009), 133–45; Tiina Ritvala and Asta Salmi, "Mobilisation of Issue Networks: The Case of Fighting Heart Disease in Finland," *International Journal of Business Environment* 2 (2009), 400–17.

[10] Erkki Vartiainen et al., "Thirty-five year trends in cardiovascular risk factors in Finland," *International Journal of Epidemiology* 39, (2010), 504-18.

approach to public health in Finland. Internationally, NKP acted as model for other community interventions in Europe,[11] and insights from it have been integrated into WHO policies and imported to developing countries.[12]

Part scientific study, part health promotion effort, NKP offers an excellent vantage point for studying how epidemiological reasoning and knowledge moves from scientific spaces into society. The chapter looks at how the local population negotiated its relationship to NKP and the novel etiological and practical knowledge on heart disease that it offered. Special focus is on how local people who were involved in the project as research subjects interpreted and responded to project methods and goals. The chapter offers insights on the way epidemiological knowledge becomes effective in practical social contexts and provides a rare historical view on participant viewpoints concerning epidemiological research and its practical application.

This focus is enabled by the unique archival material: the correspondence between project officials and various local residents. This correspondence was both private and public, that is, it includes both letters and notes sent to the project office and questions and inquiries published in local newspapers and answered by experts working in the project. The main material consists of communications with the project office and includes notes on why the participant has missed a project assignment, pleas for help directed to the project officials, and ideas and theories concerning the origin of heart conditions and ways to prevent them. The main stimulus for these messages was the project surveys. Many respondents supplemented their answers with extra material, such as explanations concerning singular questions, result sheets from previous laboratory tests, or even complete life stories. This corpus consists of around 200 texts of varying length, ranging from two-line notes to long letters. They mostly include a signature, and almost all writers that can be identified have presented only a single text. Most texts are from the first phase of the project, 1972-77, after which their number tapers off.

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[11] Pekka Puska, ed., *Comprehensive Cardiovascular Community Control Programmes in Europe* (Copenhagen: WHO, 1988).

[12] From a critical or cautious perspective, see Shah Ebrahim and George Davey Smith, "Exporting failure? Coronary Heart Disease and Stroke in Developing Countries," *International Journal of Epidemiology* 30 (2001), 201–05; Lindsay McLaren et al., "Out of Context? Translating Evidence from the North Karelia Project Over Place and Time," *Health Education Research* 22 (2007), 414–24.

In addition, I have used, first, newspaper pieces from special health advice columns in two local newspapers maintained by the project in 1972 and 1973, which answer CVD-related questions from the public. This material contains 48 original letters sent to these columns with the published answers. The second bulk of additional material consists in educational writing assignments organized by the project for various groups: members of the Martha organization (a citizens' organization providing advice on home economics), school children, and members of the general public. The writing assignments had various themes (e.g., tobacco, healthcare), and produced ca. 100 texts that have been preserved in the archive. The majority of these contributions are written by women, perhaps reflecting their position as caretakers of the family, in charge of the home and cooking, or their role as survivors after their husbands had succumbed to a heart condition. Some have been signed by name, other are anonymous. No socio-demographic details of the writers are available. Judged by handwriting and grammar, as well as by details provided in the texts, most writers represented the lesser educated and older generations, and were engaged in agriculture or manual labor. It is difficult to say how well the texts represented the outlook of the local population at large, as it is likely that those critical of the project goals and approaches were more keen to express their sentiments than those who agreed with them. Nonetheless, the material paints a vivid picture of local viewpoints concerning the heart health situation and the project that aimed to tackle it.

The chapter is structured as follows: The first section gives a short account on the rise of risk factor epidemiology and situates Finland and NKP in its development. The following section describes local reactions to the research activities in NKP, foregrounding three issues in which the project approach and local expectations differed: the definition of the proper target group of the surveys and health examinations; the tension between the population approach of the project and the individualized responses of the participants; and questions regarding the aims of the project. According to the analysis, not all participants accepted the goals of the project. Instead of a long-term epidemiological study with a population approach and focus on prevention, they expected the project to provide better access to medical services, thus catering to more immediate and individualized health needs. This view reflected both the social situation of the respondents and the inherent tensions in the design of NKP, as I will discuss in the concluding section.

Risk factor epidemiology and Finland

Chronic noncontagious conditions took the place of infectious diseases as the main cause of mortality and morbidity in the industrialized West after the Second World War. This transition affected the targets and objectives of epidemiology. The sudden statistical rise of such formerly relatively rare diseases as CHD and lung cancer raised questions about the causes of the shift. Chronic diseases were no longer perceived as a residual category, as inevitable companions of old age, as it was established that also younger people were affected. Gradually, a societal consensus formed that an alarming epidemic of CHD was on-going.[13] This triggered a vibrant research interest and a significant investment in heart disease studies. Various lines of inquiry were opened, epidemiological studies being one of them.[14] The most significant of the early epidemiological studies was the Framingham Study, in which a cohort of people was followed over time in order to identify predisposing traits – later dubbed risk factors – to CHD.[15] Starting in the early 1950s, the Framingham Study was crucial not only in establishing the key risk factors for CHD – smoking, hypertension, and elevated cholesterol – but also in justifying that causality could be established by epidemiological methods.[16]

Towards the end of the 1960s, the majority of CVD epidemiologists considered the key risk factors for CHD as established, and research interests shifted towards the impact of risk factor

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[13] William G. Rothstein, *Public Health and the Risk Factor. A History of an Uneven Medical Revolution* (Rochester and Woodbridge: University of Rochester Press, 2003).

[14] Gerald M. Oppenheimer, "Profiling Risk: the Emergence of Coronary Heart Disease Epidemiology in the United States (1947–70)," *International Journal of Epidemiology* 35 (2006), 720–30.

[15] Thomas R. Dawber, *The Framingham Study: the Epidemiology of Atherosclerotic Disease* (Cambridge, MA: Harvard UP, 1980); Gerald M. Oppenheimer, "Becoming the Framingham Study 1947–50," *American Journal of Public Health* 95 (2005), 602–10; Robert A. Aronowitz, "The Framingham Heart Study and the Emergence of the Risk Factor Approach to Coronary Heart Disease, 1947-1970," *Revue d'histoire des sciences* 64 (2011), 263-95. Risk factors were mentioned in William B. Kannel, Thomas Dawber, Abraham Kagan, Nicholas Revotskie and Joseph Stokes, "Factors of risk in the development of coronary heart disease, six-year follow-up experience, the Framingham study," *Annals of Internal Medicine* 55 (1961), 33–48. See however, David S. Jones and Gerald M. Oppenheimer. "If the Framingham Heart Study Did Not Invent the Risk Factor, Who Did?," *Perspectives in Biology and Medicine* 60 (2017), 131-50.

[16] In addition to CHD research, establishing a connection between smoking and lung cancer cemented the status of risk factors as "causes." On the causality debate, see Luc Berlivet, "'Association or Causation?' The Debate on the Scientific Status of Risk Factor Epidemiology, 1947–c.1965," in Victoria Berridge, ed., *Making Health Policy: Networks of Research and Policy after 1945* (Amsterdam & New York: Rodopi, 2005), 39–74; Élodie Giroux, "Risk Factor and Causality in Epidemiology," in Philippe Huneman, Gérard Lambert and Marc Silberstein, eds., *Classification, Disease and Evidence: New Essays in the Philosophy of Medicine* (Dordrecht: Springer, 2015), 179-92; Todd. M. Olszewski, "The Causal Conundrum: The Diet-Heart Debates and the Management of Uncertainty in American Medicine," *Journal of the History of Medicine and Allied Sciences* 70 (2015), 218–49; Mark Parascandola, "Skepticism, Statistics, and the Cigarette: A Historical Analysis of a Methodological Debate," *Perspectives in Biology and Medicine* 47 (2004), 244–61; Colin Talley, Howard I. Kushner and Claire E. Sterk, "Lung Cancer, Chronic Disease Epidemiology, and Medicine, 1948–1964," *Journal of the History of Medicine and Allied Sciences* 59 (2004), 329-74.

modification on illness and death.[17] Health and nutritional authorities issued recommendations towards behavior change, at first tentatively but then gradually with increasing firmness.[18] The cardiovascular research community was divided; the majority wanted to wait for conclusive proof of the benefits of risk factor modification in controlled trials before moving forward with recommendations, but an active minority was ready to test methods of behavioral change.[19] Subsequent developments followed along these two lines. In the U.S., an attempt was made to start a large, multi-year National Diet-Heart Study, with the aim of assessing conclusively the effects of dietary modification on heart health. After a successful pilot, it was nonetheless abandoned and two other large trials were fielded. The Multiple Risk Factor Intervention Trial (MRFIT) and the Lipid Research Centers Coronary Primary Prevention Trial (LRC-CPPT) focused on high-risk individuals, covered multiple risk factors, and involved the use of cholesterol lowering drugs (LRC-CPPT).[20] The other line, represented by the active minority, moved into exploring methods of behavioral change through community intervention studies. Here, the key early projects were the Stanford Three Community Study in the U.S., led by John Farquhar, and the North Karelia Project in Finland.[21]

Why Finland, a small country at the fringes of Europe? Finland became woven into international epidemiological research on the causes of cardiovascular problems at an early stage. Ancel Keys, who was the father of the diet-heart hypothesis and always on the lookout

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[17] A number of scattered smaller trials had studied the effects of risk factor modification through diet or drugs, with varying results. A. Stewart Truswell, *Cholesterol and Beyond: The Research on Diet and Coronary Heart Disease 1900-2000* (Dordrecht: Springer, 2010), 57-60.

[18] See, for example, the development of nutritional recommendations on dietary fat in the U.S. Karin Garrety, "Social Worlds, Actor-Networks and Controversy: The Case of Cholesterol, Dietary Fat and Heart Disease," *Social Studies of Science* 27 (1997), 727–73; idem., "Dietary Policy, Controversy and Proof: Doing Something versus Waiting for the Definitive Evidence," in J. Ward and C. Warren, eds., *Silent Victories: The History and Practice of Public Health in Twentieth Century America* (Oxford: Oxford University Press, 2006), 401-19; Ann F. La Berge, "How the Ideology of Low Fat Conquered America," *Journal of the History of Medicine and Allied Sciences* 63 (1998), 139–77.

[19] Henry Blackburn, "The National Cooperative Trial on Multifactorial Prevention of First Heart Attacks and Coronary Mortality in Free-living, High-risk Middle-aged American Men (a.k.a. 'JUMBO')! A Short Story," *American Journal of Epidemiology*, 189 (2019), 491–98, Gerald M. Oppenheimer, Henry Blackburn and Pekka Puska, "From Framingham to North Karelia to U.S. Community-Based Prevention Programs: Negotiating Research Agenda for Coronary Heart Disease in the Second Half of the 20th Century," *Public Health Reviews* 33 (2011), 450–83. In 1970, WHO was still discouraging from large-scale screening and intervention projects and endorsing randomised controlled multiple risk factor studies on the effect of risk factor modification in high risk groups. *Methodology of Multifactorial Preventive Trials in Ischaemic Heart Disease. Report on a Working Group Rome 17-20 November 1970* (Copenhagen: WHO, Regional Office for Europe, 1971).

[20] Blackburn (2019); Garrety (1990); idem. (2006); Harry M. Marks, *The Progress of Experiment: Science and Therapeutic Reform in the United States, 1900-1990*. Cambridge, U.K.: Cambridge University Press, 1997), 164-93.

[21] Oppenheimer, Blackburn and Puska (2011). On the Stanford study see "John W. Farquhar," Stanford Oral Histories Series, https://exhibits.stanford.edu/oralhistory/catalog/zb736mw3032 (last accessed February 4, 2020). Other community studies soon followed, coordinated by WHO. See Puska, ed. (1988).

for new countries to compare in his attempt to verify it, became interested in Finland when he learned about the exceptionally fat-rich diet and high cholesterol levels among the farmers and loggers in the predominantly rural eastern part of the country. Finland participated in the Seven Countries Study coordinated by Keys, as the country with both the highest cholesterol levels and the highest CHD mortality.[22] Involvement in this study put Finland on the international CHD map, both in statistical terms and in terms of research collaboration, epidemiological training, and so on. The key Finnish expert at this stage was Martti Karvonen, the Head of the Physiology Department of the newly created Finnish Institute of Occupational Health, an early hub of public health-oriented research in Finland.[23] A physiologist like Keys and trained in Cambridge, U.K., Karvonen led the national arm of the Seven Countries Study and was the mastermind behind NKP. Through the Seven Countries Study and Karvonen, Finland was connected to the international research community and informed of topical developments in cardiovascular epidemiology and public health.

NKP thus took place at an interesting juncture in the development of cardiovascular epidemiology. Instead of stopping at the study of the effects of risk reduction, it went further to develop and test methods to facilitate such a reduction. Thereby it opened a new chapter in the fight against coronary heart disease, introducing and formulating a community approach to cardiovascular prevention and treatment, an approach that has since become an established part of public health work.[24]

Encountering epidemiological research

The texts written by the local people paint a vivid picture of the burden of heart disease in North Karelia. They tell about persistent heart problems in the family over generations and loss of husbands at a relatively young age. For example, A.E. told in her letter how her husband died at the age of 44 from complications of a heart attack. His brothers, too, had succumbed in their 40s, and also her family was plagued by coronary thromboses. Although she suffered from high blood pressure herself, her main interest was the health of her

[22] Kromhout, Menotti and Blackburn, eds. (1994).
[23] Martti J. Karvonen, *Työterveyslaitoksen fysiologinen osasto 1950–65* [The Physiology Unit at the Finnish Institute of Occupational Health 1950-65] (Helsinki: Työterveyslaitos, 1991); Alpo Väänänen, *Työn jäljet: Työterveyslaitos 1945–95* [The Traces of Work: Finnish Institute of Occupational Health 1945-95] (Helsinki: Työterveyslaitos, 1995), 64–5.
[24] Oppenheimer, Blackburn and Puska (2011).

children: How could she prevent them from becoming ill? ”I have three under-aged children. What else can I do to help them but teach nutrition and order [them] to run all over the woods?” she asks.[25]

Against this background, it is not surprising that many local people welcomed efforts to tackle the severe problem of heart disease, and the texts convey a feeling of satisfaction that it was finally being addressed. According to the testimonies of project officials, the locals were generally enthusiastic about the project.[26] One indication of their positive attitude was the high participation rate in project surveys and health examinations.[27] However, some responses suggest there were those who disagreed with the project focus and expected more immediate measures and benefits.

Although primarily a public health intervention, NKP included a thorough evaluation, which included surveys and examinations of population samples before, during, and after the intervention. The project started with a baseline survey that randomly sampled 6.6% of the people living in the intervention and reference areas for a health examination. The sample included men and women born between 1913 and 1947.[28] The short invitation letter explained that the respondent had been randomly selected to participate and was expected to complete a questionnaire on ”factors associated with heart diseases” and to attend ”a health examination focused on risk factors for heart diseases.”[29] The 129 questions of the 12-page self-administered questionnaire covered socio-demographic variables, medical contacts, health status and perceived health, risk factor levels, family history of CVD, exercise, eating and smoking habits, social relationships, psycho-social issues, and knowledge and beliefs concerning heart diseases.[30] In the subsequent health examination, a public health nurse measured the height and weight of the subject, took the blood pressure and a blood sample for cholesterol levels measurement, and inquired about aspects of fat use in the diet.[31] The

[25] NAF, The Archive of the North Karelia Project (NKP Archive), Folder XVI:4 Tilannekartoitus 2 - kevät 1973 (1973-1973). All citations from the letters are translated by the author.
[26] Puska (1984), 44, 99.
[27] Puska (1984), 51–53. For example, the participation rate for the first follow-up survey late 1972 was 92%. P. Puska, *North Karelia Project, a programme for community control of cardiovascular diseases*. Publications of the University of Kuopio, Community Health – Series A:1 (Kuopio: U. of Kuopio, 1974), 78.
[28] *Community Control of Cardiovascular Diseases* (1981), 69-70.
[29] NAF, NKP Archive, Folder I:1C Peruskartoitus, Pohjois-Karjala projektin peruskartoitus 1972-73.
[30] NAF, NKP Archive, Folder I:1C Peruskartoitus, Pohjois-Karjala projektin peruskartoitus 1972-73.
[31] *Community Control of Cardiovascular Diseases* (1981), 73-4; NAF, NKP Archive, Folder I:1C Peruskartoitus, Pohjois-Karjala projektin peruskartoitus 1972-73.

questionnaire was to be returned at the examination, where it was checked and augmented, if necessary. While waiting for their examination, participants filled in a separate short health knowledge questionnaire.

This design was repeated in the terminal survey.[32] Results from blood pressure measurements were reported to the participants at the examination place, and those with high values were advised to contact a physician. In addition, the participants received a feedback letter that detailed their risk factor values (blood pressure, cholesterol, triglycerides, number of cigarettes smoked, amount of physical exercise, plus ratio of weight and height), pointed out values that were elevated, and contained a health information leaflet to facilitate behavior change. After the initial baseline survey, project officials conducted bi-annual follow-up surveys for smaller samples in the intervention area. These surveys queried participants' knowledge about and exposure to project activities, aspects of health behavior (smoking, exercising, eating), blood pressure and cholesterol levels, medication, and contact to healthcare services.[33] These measures put a significant number of the local population into contact with the study. Those outside the samples encountered the project in other ways, for example through persistent health propaganda in local media or at the doctor's office, where they might get their blood pressure measured.

Inclusion criteria: random residents vs. individuals with medical needs

The project surveys – especially the baseline survey with the health examination – created great interest among the local people. This interest, however, did not always follow the protocols of the project officials. Many locals ignored the computer-based random sampling, cited in the invitation letter as the motivation for inclusion, and determined their willingness to participate based on their perceived needs. The leader of the project, Pekka Puska, later reminisced how uninvited people occasionally came to the baseline health examination localities in the hope of meeting a physician, or invited people brought along their family members.[34] In the notes and letters, some individuals inquired about the possibility to attend even though they or their family members were not selected in the sample. For example, A P.

[32] *Community Control of Cardiovascular Diseases* (1981), 71.
[33] NAF, NKP Archive, Folder VI Eri tutkimuksissa käytetyt kyselylomakkeet.
[34] Puska (1984), 46

explained that her husband was presently unable to attend, as he was being treated for a stroke, and continued:

> Therefore I ask with utmost courtesy, could I come to his place? I think that I would need this examination as well. When you have been the multi-function processor (*yleiskone*) in the family, with no electricity and no drainage [in the house], I have numerous times been forced to exert all my strength to the limits of my endurance.[35]

Similarly, I. H. asked that her husband be included in the project, as ”he weighs 111 kg” and ”seems to have weak blood, since he feels often dizzy and has been anemic since childhood.”[36]

In the reverse case, invited participants declined, explaining that they were in good health, were already being treated for their heart problems or received disability pension, implicating that the project was therefore redundant for them. Thus, H.U. explained that she did not want to participate in the terminal survey as she was currently on holiday, was examined regularly by a doctor, and had already participated at an earlier stage.[37] T.K., suggested that a friend with documented health problems could replace him: ”I have had my heart checked several times and it is healthy, and I do not have [high] cholesterol, so I suggest S. V. takes my place because he has experienced heart problems.”[38]

These writers thus expected the sampling to target individuals with a present or potential illness, not any random resident. They also interpreted the role of the computer in this light. For example, V.T. commented after receiving a questionnaire that he was delighted that the computer had wisely deduced that he needed medical attention: ”The computer has found me. I’m happy about it. I’m ill and think that the computer has shown wisdom in its selection.”[39] In contrast, S.S. declined the invitation and stated somewhat aggressively that the computer must have made a mistake, as he was healthy: ”You can have any kind of computer, I do know

[35] NAF, NKP Archive, Folder XVI:12 Peruskartoituksen mukana tulleet kirjeet (1972-1972).
[36] NAF, NKP Archive, Folder XVI:5 Tilannekartoitus 3 - syksy 1973 (1973-1973). The project office seems to have reacted to these pleas by explicating the principles of random sampling, see Pekka Puska’a answer to I. P., who had inquired about the possibility to be included among the examined when the examinations reach his home village. NAF, NKP Archive, Folder XVI:12 Peruskartoituksen mukana tulleet kirjeet (1972-1972).
[37] NAF, NKP Archive, Folder XVI:2_1 Loppukartoituksen mukana tullut aineisto (1977-1977).
[38] NAF, NKP Archive, Folder XVI:12 Peruskartoituksen mukana tulleet kirjeet (1972-1972).
[39] NAF, NKP Archive, Folder XVI:3 Tilannekartoitus 1 - syksy 1972 (1972-1972).

myself, there is nothing wrong with me. I have been healthy. I have no heart defect. Believe what I say. As far as I'm concerned, you can scrap your computer."[40] These writers expected the computer – the scientific "knowledge-machine"[41] – to be able to identify the health status of the respondent, which was taken to be the criterion on which inclusion rested.

The follow-up surveys created similar issues. Thus, a man included in a follow-up wondered why he was again receiving the same questionnaire he had already completed once before: "Please do not send your inquiries. My situation has not changed."[42] Another man, who was interested in participating but was not invited, complained about the scope of the study: "Shouldn't the field of research be expanded, and not always the same [persons be selected]?"[43] Both interpreted the inclusion criteria based on their personal situation and needs, not from the perspective of charting the characteristics of randomly selected members of the population.

Standardised members of a population vs. individual cases

Another issue was the form and content of the surveys and examinations, which some respondents had difficulties fitting together with their personal attributes. Some seemed to regard the questionnaires as too formulaic. They provided detailed descriptions of their individual situation by attaching extra information to their completed forms, such as information on previously established risk factor values or medical diagnoses, notes explaining their alcohol use and smoking habits, or life stories that related their personal histories leading to heart problems. This mismatch between the general formula and personal detail is made explicit in E.R.'s motivation for her additions to the follow-up questionnaire: "I answered in such a length, because I wanted to be precise in my answers and I am also enthusiastic about this North Karelia Project."[44]

[40] NAF, NKP Archive, Folder XVI:3 Tilannekartoitus 1 - syksy 1972 (1972-1972).
[41] Computer (*tietokone*) means literally knowledge (*tieto*) machine (*kone*) in Finnish. They were still a novelty in the early 1970s, see Mika Pantzar, *Tulevaisuuden koti: arjen tarpeita keksimässä* [Home of the Future: Inventing Everyday Needs] (Helsinki: Otava, 2000), 93-96.
[42] NAF, NKP Archive, Folder XVI:8 Tilannekartoitus 7 - syksy 1975 (1975-1975).
[43] NAF, NKP Archive, Folder XVI:2_1 Loppukartoituksen mukana tullut aineisto (1977-1977).
[44] NAF, NKP Archive, Folder XVI:5 Tilannekatsaus 3 - syksy 1973 (1973-1973).

Another reason for providing separate information could be difficulties in filling in the complex questionnaires. In such cases, the personal details were intended to replace the questionnaire, to provide the key facts of the person in a shortened manner. This stance is evident in O.P.'s note, which he started by explaining that he was not capable of answering "your dear questions" and that he did not suffer from heart defects or blood pressure, and then went on to provide some key pointers of his life and health.[45] While the project regarded the respondents as members of a population sample who were all decomposed into a similar set of variables, these writers sought to present themselves as individual, idiosyncratic cases.

This accentuation of the personal could also be connected to a more reserved and mistrustful stance. Some sample members felt that the questions addressing socio-demographic situation pried into matters too private and sensitive, such as income, or compromised anonymity. Thus, an anonymous woman who was highly critical of the whole endeavor, commented sceptically: "Are you going to start seizing private property, or is it for taxation or other reasons that you are trying to find out about people's personal matters and possessions?"[46] Another respondent declined to complete the questionnaire, because he felt that he could be identified based on the information. He, too, suspected dubious motives behind the questions: "for scientific purposes no such information is necessary that discloses the identity of the person. You could have performed the study differently, if you were interested only in science."[47]

Questions on personal habits also touched matters that could be sensitive. Alcohol and smoking were typically mentioned even in the shortest of notes sent to the project office. The frequency with which they were noted indicates that they were morally charged. Many respondents felt the need to underline that they used alcohol only in moderation, if at all, and did not smoke or had quit smoking. A good example of this trope is an anonymous letter-writer who stressed that her family was poor but respectable:

[45] NAF, NKP Archive, Folder XVI:8 Tilannekartoitus 7 - syksy 1975 (1975-1975). Note that many of the letters or shorter notes were responses to reminders to return the questionnaire sent by the project office to the sampled respondents. Thus they explain why it was not returned.
[46] NAF, NKP Archive, Folder XVI:2_1 Loppukartoituksen mukana tullut aineisto (1977-1977).
[47] NAF, NKP Archive, Folder XVI:12 Peruskartoituksen mukana tulleet kirjeet (1972-1972).

> this old woman has not been a victim of the Finnish welfare state, not even electricity nor machines have we had, [I] take care of a family of three and the same amount of cows and small cattle […] in our house no cigarettes are burning and no beer and wine is flowing, we sleep from 21-5.30, and it is enough when you a have clear conscience as a pillow and give the worries to the horse, which has a larger head [than a human].[48]

Such messages, too, accentuate the personal - not as idiosyncratic traits or as sensitive or private matters in danger of being exposed, but from the point of view of the moral integrity of the individual. The personal, that is, the characteristics that singularize an individual and determine the image he or she presents to others, was thus opposed to the population approach of the NKP, which treated participants as interchangeable units representing a larger ensemble, the North Karelians.

Scientific study on prevention vs. help for present health problems

A further issue was the general focus of the questions and examinations – and hence of the whole NKP. Some respondents wondered why healthy people were examined when there were so many who were ill and in need of medical treatment. Why did future scientific goals bypass existing real medical needs, which might have fatal consequences? A good example of this sentiment is a local woman, M.K., who thought it was irresponsible to chart risk factor levels and leave present health problems unattended. ”[T]here is no preventive effect at all in the examination, it is only a compilation of statistics for the project. How many people have died in the meanwhile?”[49] In a similar vein, S.S. criticized physicians for not listening to patients and saw the project as one further instance of this neglect:

> Best PUBLIC HEALTH WORK would be to take issue with false diagnoses, because they lead to wrong medication. <u>THE PATIENT gets sicker and sicker</u> and <u>THE STATE gets poorer and poorer</u>, I am not the only one. If the time now used for getting forms printed and filled in by frail people in order to register in computer blocks each and everyone”s snacks and fartings, if this time would be directed to

[48] NAF, NKP Archive, Folder XVI:6 Tilannekartoitus 4 - kevät 1974 (1974-1974).
[49] NAF, NKP Archive, Folder XVI:2_1 Loppukartoituksen mukana tullut aineisto (1977-1977).

> relevant treatment procedures, there would be plenty of TIME TO LISTEN TO THE PATIENT, and study resources could be saved. It surely must feel fantastic to make money on the state of distress of fellow human beings.[50]

Thus, local people did not always recognize or accept the public health focus of the project on risk factors and prevention. Instead, they expected the project to provide much needed medical assistance to existing health problems. A clear indication of this is a reader's letter to the project's regular column in the newspaper *Karjalan Maa*. After recapitulating her failed attempts to gain access into the central hospital, the pseudonym "Steel missus" asked: "do you have a reception in Joensuu for the examination and treatment orders of CVD?"[51] Hence, she approached the project as a further outlet for healthcare services, not as a scientific study on lifestyle and prevention.

This focus on present and pressing medical needs is overwhelming in the preserved letters and notes written by the locals to the project officials. People asked for help on various health related issues, which were often outside the scope of the project. First, they described their symptoms and previous test results and asked for expert advice. For example, a 53-year-old man provided a detailed account of his previous medical diagnoses ("dilatatio cordis", "dissociatio atrioventricularis cordis"), medication ("3 Sembrina, 4 Esbatal and 2 Uretren Comp tablets per day"), relevant lifestyle factors ("alcohol I use one large bottle of Frapin cognac per year"), and recent symptoms, asking for a diagnosis, suggestions for behavior changes for prevention, and a general verdict: "do I need to start believing that I am a lost cause with respect to the labor market?"[52] Second, locals looked for help in gaining entry into medical treatment, a hospital or the disability pension system due to their heart or other health problems. For example, L.N., a 35-year-old woman, wanted to reverse her sterilization operation, forced on her by her mother-in-law, as she felt broody and was subjected to ridicule in her social surroundings.[53] Third, writers asked the project officials to influence decision-makers to ensure that the sick and the poor were given free access to expensive

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[50] NAF, NKP Archive, Folder XVIII:2 Väestön kirjeet (1980-1987), 1983. Typographical additions as in the original.
[51] NAF, NKP Archive, Folder XVI:13 Karjalan maa –asiakirjat (1972-1972).
[52] Tilanne 5. [AUTHOR'S NOTE: This item is missing from the archive records. It should be there as I have organized and sent the material to the archive on behalf of Pekka Puska. There is an inquiry ongoing on the matter.]
[53] NAF, NKP Archive, Folder XVI:8 Tilannekartoitus 7 - syksy 1975 (1975-1975).

heart disease medications. For example, an anonymous saleswoman with a 8.4 mmol/l cholesterol reading lamented the high price of cholesterol medications and asked if ”the project could help to make them free for cholesterol patients?”[54] Last, the writers vented their anger about poor or unavailable treatment and benefits. For example, one anonymous woman detailed her symptoms and asked rhetorically, ”why cannot a housewife get sick leave if she does not have strength to do anything?”[55] Regular gripes were difficulties to gain access to doctors and disability benefits or pensions, long waiting times for treatment, and the high costs associated with prescribed medicines and travel to consultations and examinations.

A more explicit and sophisticated version of the way that some local people questioned the project targets can be found in a letter from M.N., who criticizes NKP on ethical grounds. According to him, people living in the control area of the study should be entitled to the same preventive measures as the North Karelians living in the intervention area. Declining members of the control group these services makes them ”guinea pigs” for ”research purposes.” ”Those 7000 plus residents in the county of Kuopio, who unexpectedly gained access to a heart check in Spring 1972 did not know that in the examination their illnesses were only registered, nothing else. The identified heart diseases were by no means meant to be cured, at least not by the researchers.”[56] Here, too, the future goals concerning epidemiological knowledge-generation on risk factors and their modification are juxtaposed with the more immediate health needs of the subjects of the study.

Understanding the response of the local residents

Although the local people in principle welcomed efforts to ameliorate the poor heart health of North Karelians, some of them disagreed with the methods and goals adopted by NKP. Many of those contacting project officials seemed to be puzzled by or simply ignored the fact that NKP was interested in assessing and changing their lifestyle rather than identifying and treating their illnesses. Focusing on their personal situation and health problems, they did not acknowledge the epidemiological logic that underpinned the project, that of risk-factor modification on population level. Although probably a minority position, this attitude attests

[54] NAF, NKP Archive, Folder XVI:6 Tilannekartoitus 4 - kevät 1974 (1974-1974).
[55] NAF, NKP Archive, Folder XVI:6 Tilannekartoitus 4 - kevät 1974 (1974-1974).
[56] NAF, NKP Archive, Folder XVII:1 Kirjeet (1973-1973).

to the novelty of the epidemiological study design and to the slow acceptance of risk factor-focused preventive efforts in 1970s Finland.

Three interlinked issues structured the response. First, many local residents sought entry to the project based on their present health problems and medical needs. This clashed with the random sampling as selection criteria. Thus, some participants perceived the examination conducted as part of the project as a screening effort rather than as risk factor measurement. Second, the project approached individuals as members in a population, characterized by a pre-set battery of variables. Many participants, however, felt that this approach neglected important individual attributes or relevant details of their personal situation. This stance implies a criticism of the explanatory model of heart problems espoused by NKP: while the project foregrounded singular risk factors embedded into a ”lifestyle”, these writers sought to explain heart disease from their personal life history, influenced by a broader social context.[57] Third, the project emphasized CVD prevention with a focus on risk factors, aspects of lifestyle, and behavior modification, while the critical participants were interested in getting medical attention and assistance. In fact, NKP included a significant treatment aspect, especially in relation to hypertension, but in its official image these biomedical aspects were subordinated to risk factor modification and CVD prevention.[58]

This tension between project goals and local expectations was primarily not between the population and individual approaches. The lay comments did not really address what has been called “the prevention paradox”, that is, the discrepancy between the significant population effect and negligible individual benefit.[59] Rather, the friction was located between the epidemiological approach, on the one hand, and the clinical and socio-medical approaches on the other hand. In this distinction, “epidemiological” refers to a population-focused approach to health problems, while “clinical” refers to an individual, case-based, and treatment-focused approach, and “socio-medical” to an approach that stresses the role of social factors in disease causation and prevention.

[57] See Jauho (2016).
[58] See Jauho (2020).
[59] Geoffrey Rose, ”Sick individuals and sick populations,” *International Journal of Epidemiology* 14 (1985), 32–8.

The described criticisms, questions, and confusions around the goals and methods of NKP should not be taken as signs of popular misapprehension or ignorance. Rather, the criticisms and questions signified specific problems and health needs of the critical local residents, which were linked to their social situation. The on-going structural changes in the area strongly affected small farmers, who faced an existential question: should they cling to their traditional livelihood, which promised diminishing returns, or abandon it and perhaps move to a city or abroad to become industrial workers. Small farming involved hard work, which tore on the body, and economic worries caused ”livelihood stress,” which the locals connected with heart problems.[60] At the same time, the availability of health services was relatively poor and was only slowly alleviated by the recent welfare reforms. It was this problem-complex that the local residents writing to the project office wanted NKP to address.

Moreover, the position described in this chapter reflects a fundamental tension in the fabric of NKP. The project was presented as a response to a local petition, which the project officials used to legitimate it and to mobilize the community. The petition spoke about illness and death, actual health problems in the present. The adequate response to such problems were medical care and practical public health work. At the same time, the project had the scientific goal of demonstrating the feasibility of risk factor modification and its effects on CVD health. The latter task pointed to the future, to the effects of behavior change on future morbidity and mortality. This tension between the practical and scientific goals structured the response to the project. It was a headache for the scientific reviewers of the funding proposals of the project[61], but it also vexed the lay people discussed here. While the former wanted to put the emphasis on the scientific aspects of the project, critical local residents prioritized the practical side of the project.

Previous studies on public health (research) endeavors in the Global South and among disadvantaged, ethnic, or lay groups have highlighted the discrepancies and tensions between scientific aspirations and practical public health work, between outside experts with their theories and local residents with intimate knowledge of their situation. As regards heart disease, previous research has illuminated the dominant position of epidemiology in defining the causal pathways behind CVD, the characteristics of the groups that are primarily affected

[60] Jauho (2016).
[61] Jauho (2020).

by it, and the principal ways of countering heart disease. While epidemiology is itself a heterogeneous ensemble, with multiple outlooks and approaches, this dominance has tended to silence the voices of more marginalized people, such as members of ethnic groups, the socially disadvantaged, and women, and their lived experiences of heart trouble.[62] While most research has focused on lay explanations of heart disease, detailing the multifaceted and nuanced nature of this "lay epidemiology", this chapter has taken a different route. Instead of the lived experience of heart disease, the focus has been on the experience of being a participant in an intervention/research project on CVD prevention. The findings show the long historical trajectory of the silencing of marginalized voices and reiterate the need to craft study designs that give proper room to participant voices and viewpoints.

[62] Charlie Davison, George Davey Smith and Stephen Frankel, "Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education," *Sociology of Health & Illness* 13 (1991), 1–19; Carol Emslie, Kate Hunt and Graham Watt, "Invisible women? The importance of gender in lay beliefs about heart problems," *Sociology of Health & Illness* 23 (2001), 203–33; Jauho (2017); Janet K. Shim, *Heart-Sick: The Politics of Risk, Inequality, and Heart Disease* (New York and London: New York University Press, 2014).