Social History of Medicine Vol. 39, No. 3 pp. 591–616

Patient Mobilisation in the Epidemiological Transition: How Tuberculosis Patients made the 'Heart Sick'

Ylva Söderfeldt* and Jonatan Samuelsson*,†

Summary. In the first decades of the 20th century, patients at lung sanatoria all over Sweden formed clubs that organised mutual support and arranged social events. By the late 1930s, they banded together in a national organisation, which quickly became a respected and influential actor in the health and social policy landscape. However, the decline of tuberculosis became a major threat to the continued relevance of this otherwise flourishing organisation. In this paper, we show how tuberculosis became a basis for political mobilisation, and how the organisation managed to survive through a targeted effort to assemble people with cardiovascular disease as a new group to organise. This sheds light on the transformation of disease concepts in the epidemiological transition, and demonstrates how patient mobilisation played a key role in reshaping them.

Keywords: Patient organisations; tuberculosis; heart disease; epidemiological transition; disease concepts; patient activism

Introduction

Besides fostering community and offering support, patient organisations for various diseases often articulate goals of helping to find a cure or effective prevention for the disease in question. Yet, for their survival, they rely on the disease being prevalent and recognized as a public health concern. In the past, there are examples of organisations that have experienced a drastically reduced incidence of the disease they mobilised around. One is the Swedish National Federation of the Lung-Sick (DLR),[1] which formed

*Department of History of Science and Ideas, Uppsala University, Thunbergsvägen 3 P, Box 629 751 26, Uppsala, Sweden. E-mail: ylva.soderfeldt@idehist.uu.se
†Department of Historical, Philosophical and Religious Studies, Umeå University, Umeå universitet SE901 87, Umeå, Sweden

Ylva Söderfeldt is Associate Professor in History of Science and Ideas and Director of the Centre for Medical Humanities at Uppsala University. A historian of medicine, she has worked extensively on disability history, medical humanities, and the history of emotions. Her current research focus is on the structure and impact of patient organizations in the 20th century.

Jonatan Samuelsson is a researcher in History of Science and Ideas at Uppsala University and Umeå University. Since defending his thesis on the Swedish dental amalgam controversy of the late 20th century in 2022, he has been teaching and researching the history of media and medicine. His main research focus is on medical news journalism and patient organisation publications.

[1]For simplicity and consistency, we have chosen to refer to this organisation by the Swedish abbreviation they used from 1939 to 1961, short for *De Lungsjukas Riksförbund*. In 1962, they changed the name to *Riksförbundet för Hjärt-och Lungsjuka*, abbreviated RHL, but we maintain DLR as the abbreviation even in our discussion the time after 1961 to avoid confusion. For other organisations, we also maintain their Swedish abbreviations of the original name. In some cases, when the organisations did not use any abbreviation, we have assigned one based on our English translation of the name.

© The Author(s) 2025. Published by Oxford University Press on behalf of the Society for the Social History of Medicine. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs licence (https://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial reproduction and distribution of the work, in any medium, provided the original work is not altered or transformed in any way, and that the work is properly cited. For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact journals.permissions@oup.com.
https://doi.org/10.1093/shm/hkaf051

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

in 1939 and two decades later decided to shift its focus towards cardiac disease. In the following, we study this organisation as an example of how a patient organisation faced the challenge of losing its base, and how their change of direction contributed to establishing 'the heart sick' as a patient group.

Background

In 1911, tuberculosis was the second leading cause of death in Sweden, only slightly behind 'diseases of old age'.[2] Fifty years later, cardiovascular disease was by far the leading cause of death, accounting for nearly half of the total mortality, while tuberculosis was only responsible for less than 1 per cent of the deaths.[3] While these figures should be taken with a grain of salt, not least due to the stark difference in reporting mechanisms and classifications between the 1910s and 1960s, they show a tendency in Sweden which is also well-known all over the Western world, namely the decline of infectious disease in general and tuberculosis in particular, and the rise of cardiovascular disease. Why and how this shift occurred has been subject to ceaseless debates. The 'magic bullet' narrative, which credits modern medicine with conquering infectious disease, has been thoroughly criticised from a multitude of angles, beginning with René and Jean Dubos' 1952 classic *The White Plague*, which argued that improved standard of living, not medical intervention, should be credited with the decline of tuberculosis.[4] Expanding on that perspective, Thomas McKeown concluded from demographic data from England and Wales that better nutrition was the key factor in reduced mortality overall and TB mortality in particular.[5] Others have, however, argued for other explanations, like decreased virulence, effective public health measures including educational efforts, and finally medical interventions—vaccination and therapeutics.[6] Furthermore, the very notion of tuberculosis having been conquered—whether by medicine or other measures—has also been challenged as being Eurocentric and ignoring disadvantaged populations. It is more accurate to say that TB never went 'away', it only went elsewhere—to affect mainly people in the global South and marginalised communities in the North.[7]

The rise of cardiovascular disease is at the centre of another, equally classic proposition: Abdel Omran's epidemiologic transition thesis. Omran describes a shift from

[2]Kungliga Statistiska Centralbyrån, '*Dödsorsaker år 1911*', series: *Sveriges officiella statistik. Folkmängden och dess förändringar*, 1915, 11–12.

[3]Kock, *Medicinalväsendet*, 673; Statistiska Centralbyrån, 'Dödsorsaker år 1961', *Sveriges officiella statistik. Folkmängden och dess förändringar*, 1963.

[4]René Dubos and Jean Dubos, *The White Plague: Tuberculosis, Man and Society* (Boston: Little, Brown and Company, 1952).

[5]Thomas McKeown, *The Modern Rise of Population* (London: Arnold, 1976).

[6]Johan P. Mackenbach, *A History of Population Health: Rise and Fall of Disease in Europe* (Brill, 2020), 155–62.

[7]Janina Kehr and Flurin Condrau, 'Recurring Revolutions? Tuberculosis Treatments in the Era of Antibiotics', in Jeremy A. Greene, Flurin Condrau, and Elizabeth Siegel Watkins, eds, *Therapeutic Revolutions. Pharmaceuticals and Social Change in the Twentieth Century* (Chicago: University of Chicago Press, 2016), 126–49; Paul E. Farmer, 'The Consumption of the Poor: Tuberculosis in the 21st Century', *Ethnography* 2000, 1, 183–216; Katherine Ott, *Fevered Lives: Tuberculosis in American Culture Since 1870* (Cambridge: Harvard University Press, 1996), 156–68.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

pandemics to 'degenerative and man-made diseases', including heart disease and cancer, which occurred in the West around the mid-20th century. Since infectious disease affected mainly the young, and the 'degenerative' diseases the old, life expectancy rose and the demographic makeup of the population changed as a result.[8] While the timelines and exact dynamics of these changes have been debated, there is no doubt that cardiovascular disease increased in the developed world in the mid-20th century not only as a function of increased life expectancy and decline in mortality overall, but also in absolute terms.[9]

Between 1900 and 1945, tuberculosis care and prevention in Sweden expanded on all fronts, from virtually non-existent to 'perhaps the most well-organised in the world'.[10] Through a public donation campaign to celebrate the 25-year reign of King Oscar II, four 'jubilee sanatoria' opened their doors between 1900 and 1912. This was a start, but their altogether 500 beds were far insufficient compared to the magnitude of the problem. In response to this, the Swedish Medical Association initiated the National Association Against Tuberculosis (NAAT) in 1904 as an interprofessional charity and lobbying organisation.[11] The NAAT had tremendous influence on state policy regarding tuberculosis in the following decades. Its first success came in 1908, when the government approved public funding for building and maintaining further sanatoria, so that in 1910 there were over 3,500 beds in specialised institutions and clinics. Over the following decades this figure increased steadily, reaching its peak in the 1940s with nearly 9,000 beds.[12] The Swedish sanatoria were modelled after continental institutions and employed the typical resting and diet cures, combined with fresh air and educational measures to reduce behaviours that contributed to the spread of the disease. Surgical treatments became common in the 1920s, and some institutions engaged in experimentation with drugs, including tuberculin. In 1943, the Danish-Swedish chemist Jörgen Lehmann developed PAS (para-aminosalicylic acid), which in combination with streptomycin became the standard treatment for tuberculosis.[13]

Besides the inpatient treatment at sanatoria and lung clinics, the NAAT began in 1904 to promote and fund dispensaries, that is outpatient clinics tasked with identifying and diagnosing suspected cases, surveilling the infected and their families, and educating the public. A decade later, the government took over the funding, which lead to rapid expansion of the dispensary system. In many ways, dispensaries were precursors of later, general policlinics. Similarly, many other measures introduced in the TB field-like screening and morbidity statistics—were later deployed for other diseases as well. The dispensaries' scope went beyond the purely medical, and also encompassed social services including placing children in foster care and distributing funds for treatment or other

[8]Abdel R. Omran, 'The Epidemiologic Transition: A Theory of the Epidemiology of Population Change', *The Milbank Quarterly* 2005, 83, 731–57.
[9]Mackenbach, *A History of Population Health*, 217–31.
[10]Britt-Inger Puranen, *Tuberkulos: En sjukdoms förekomst och dess orsaker, Sverige 1750–1980* (PhD dissertation, Umeå University, 1986), 321.
[11]The Swedish name for this organisation was Nationalföreningen mot Tuberkulos. They did not use an abbreviation.
[12]Wolfram Kock, *Medicinalväsendet i Sverige 1813–1962* (Stockholm: Nordiska bokh., 1963), 384.
[13]H. Dubovsky, 'Correspondence with a Pioneer, Jürgen Lehmann (1898–1989), Producer of the First Effective Antituberculosis Specific', *South African Medical Journal* 1991, 79, 48–50; Kock, *Medicinalväsendet*, 395–97.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

needs. When the BCG vaccine became available in the 1920s, the NAAT funded and organised vaccine production and distribution through the dispensaries.[14]

Heart disease, and particularly its socio-cultural dimensions, has garnered significantly less attention among historians of medicine than tuberculosis has. Instead, studies are more focused on the development of cardiology and specific procedures within that field. The boundaries and placement of heart disease have fluctuated immensely throughout history, ranging from the idea of the heart as exempt from disease to a narrow focus on morbid anatomy, to inclusion of the functionality of the entire circulatory system. Demarcations between psychological and physical aetiologies of various conditions of the heart have also fluctuated. In the early 20th century, cardiology experienced a fundamental shift: towards specialisation, emphasis on scientific measurement through a range of new diagnostic technologies, and a physiological, rather than anatomical, disease concept.[15] By the 1910s, surgeons were breaking the taboo of touching the heart and began developing invasive techniques for treating disorders of the heart valves. Experiences from treating war injuries and the development of antibiotics that enabled a more widespread use of surgery led to the further development and more widespread use of heart surgery from the 1940s.[16] At the same time, the idea of heart disease as a public health threat emerged. Not only did the incidence appear to be rising, but data from the years of wartime food shortages also indicated that there was a connection to lifestyle and diet.[17] As cardiovascular illnesses became more common, their social connotations transformed, from being associated with the wealthy to increasingly being seen as a problem of the disadvantaged segments of society.[18]

Like other Western countries, Sweden experienced important societal changes between the late 19th and mid-20th century that contributed to the shifting disease panorama. In the 1890s, Sweden's 'second industrial revolution' had immensely increased productivity. Simultaneously the tuberculosis mortality, which had risen since the late 18th century, began to drop.[19] Although the country was plagued by recurring economic crises, the overall development during the first half of the 20th century was towards

[14]Bertil Buhre and Gustaf Neander, *Svenska Nationalföreningen Mot Tuberkulos 1904–1929. En Återblick*. (Stockholm, 1929), 38–42; Puranen, *Tuberkulos*, 325–29; Kock, *Medicinalväsendete*, 385–87, 389–91.

[15]Fay Bound Alberti, *Matters of the Heart: History, Medicine, and Emotion* (Oxford: Oxford University Press, 2010), 61–89; Joel D. Howell, '"Soldier's Heart": The Redefinition of Heart Disease and Specialty Formation in Early Twentieth-Century Great Britain', *Medical History* 1985, 29, 34–52; Christopher Lawrence, 'Moderns and Ancients: The "New Cardiology" in Britain 1880–1930', *Medical History* 1985, 29, 1–33; Peter Robert Fleming, *A Short History of Cardiology*, Clio Medica, 40 (Amsterdam: Rodopi, 1997), 143–66.

[16]Ayesha Nathoo, *Hearts Exposed: Transplants and the Media in 1960s Britain* (London: Palgrave Macmillan, 2009), 8–10; Fleming, *A Short History of Cardiology*, 216–29.

[17]P. M. Clark, '"Lifestyle", Heart Disease, and the British Public: c.1950 to c.2000' (Phd dissertation, LSHTM, 2019); 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* 2015, 70, 218–49; S Rydenfeldt, 'Bilaga 34. Sjukvårdsbehovet och befolkningsutvecklingen', in *Bilagor till Medicinalstyrelsens utredning om den öppna läkarvården i riket*, SOU 1948:24 (Stockholm, 1948), 354–78; Haqvin Malmros, 'The Relation of Nutrition to Health', *Acta Medica Scandinavica* 1950, 138, 137–53.

[18]Richard G. Wilkinson, 'The Epidemiological Transition: From Material Scarcity to Social Disadvantage?', *Daedalus* 1994, 123, 61–77.

[19]Puranen, *Tuberkulos*, 122–27; Lars Magnusson, *Sveriges ekonomiska historia* (Stockholm: Prisma, 2002), 359–63.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

increased standard of living, greater social equality, and expanded public support systems. State subsidies and municipal as well as cooperative and charitable initiatives led to better housing for the working classes, while increased incomes and better distribution infrastructure enabled many to improve their diet, and public health policies focusing on the socio-economic drivers of disease promoted access to health care and prevention.[20] Hence, all factors that have been suggested as key to decreasing tuberculosis mortality and morbidity were given, whether the decline is ascribed to public health measures, economic growth, or improved living conditions. The decrease in mortality was steady until the 1940s, when it experienced a sharp drop. Morbidity also sank consistently, but much faster from the early 1970s. By 1975, tuberculosis was no longer considered a public health threat, and TB vaccinations ceased to be routinely offered to all children.[21]

Sources and Methods

Our study uses a combination of archival and printed sources from the DLR, government offices, news media, as well as professional literature in medicine and social policy. The main sources are the DLR archive and its magazine *Status.* Furthermore, archival records from local organisations provide insight into the DLR's grassroots level, where much of the organising and campaigning took place.

In investigating how the lung sick became a patient group with a national voice and a resourceful organisation, and how they then coped with the disintegration of the particular medical, political, and epistemic conditions that enabled them to establish themselves as such, we rely on Ian Hacking's framework for analysis of 'making up people'. The question here is not so much about people having diseases of the lung or the cardiovascular system, but of the making, centred on those conditions, of a kind of person. This making up does not imply that the conditions in question are not real—as we have already touched upon, they were in fact among the deadliest diseases of the time. Rather, it means that we are investigating why and how being 'lung sick' or 'heart sick' became 'a way to be a person, to experience oneself, to live in society'.[22] According to Hacking, this dynamic and ever-evolving process involves

> the *experts* or professionals who generate or legitimate the knowledge …, judge its validity, and use it in their practice. They work within … institutions that guarantee their legitimacy, authenticity, and status as experts. They study, try to help, or advise on the control, of the people … who are classified as of a given kind.[23]

[20]Urban Lundberg and Klas Åmark, 'Social Rights and Social Security: The Swedish Welfare State, 1900–2000', *Scandinavian Journal of History* 2001, 26, 157–76; Karin Johannisson, 'The People's Health: Public Health Policies in Sweden', in Dorothy Porter ed, *The History of Public Health and the Modern State* (Amsterdam: Editions Rodopi, 1994), 165–82; Yvonne Hirdman, *Magfrågan: mat som mål och medel: Stockholm 1870–1920* (Stockholm: Rabén & Sjögren, 1983); Christina Fjellström, 'Drömmen om det goda livet: livskvalitet och matvanor i ett uppväxande industrisamhälle: Stocka sågverk 1870–1980' (PhD dissertation, Umeå University, 1990); Lars-Arne Norborg, *Sveriges historia under 1800-och 1900-talen: svensk samhällsutveckling 1809–1996* (Stockholm: Almqvist & Wiksell, 1995), 58–63, 74–75; Klas Ramberg, *Allmännyttan: Välfärdsbygge 1850–2000* (Stockholm: Byggförlaget, 2000), 44–128.

[21]Björn Petrini, 'BCG-vaccination – kontrovers och kompromiss', *Läkartidningen* 2000, 97, 5618–20; Puranen, *Tuberkulos*, 122–27.

[22]Ian Hacking, 'Kinds of People: Moving Targets', *Proceedings of the British Academy* 2007, 151, 299.

[23]Hacking, 'Kinds of People', 297.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Our study is focused on one venue of this complex process, self-organisation by patients, which has frequently been overlooked when it comes to research on how disease categories are made. This focus means something different than 'people' in Hacking's framework. While the lung sick, and the heart sick, are people being classified and interacting with these classifications, organisations by and for heart and lung sick people act in this process in ways similar to what Hacking describes for experts. Like experts, they generate knowledge and gain legitimacy from institutions—and the organisations are arguably themselves also one of the institutions involved in awarding legitimacy and disseminating knowledge. Hence, this is not a study of what it was like to have lung disease or heart disease in 20th century Sweden, but of how an organisation helped define, assemble, and carve out a space for those who did.

Building Up: The Tuberculosis Patients' Movement 1901–1956

Tuberculosis patient organisations, ranging from local patient clubs to national associations, are documented in several countries but have been subject to relatively little historical research. In Sweden and Denmark, there were nationwide movements that began with local clubs for sanatorium patients, whereas Norway and Finland had national organisations formed as top-down initiatives either by patients or professionals. Outside of the Nordics, there are also examples of local patient clubs, but to our knowledge no larger organisations.[24]The DLR and its Nordic counterparts still operate today.

In 1901, the first Swedish tuberculosis patient club formed at the jubilee sanatorium in Österåsen. More followed, and by the mid-1930s, Sweden had at least 40 clubs for inpatients at tuberculosis facilities. Several sanatoria have been the subject of institutional memoirs that frequently offer some glimpses from the patient club. Most of the clubs had as their main purpose to distribute monetary support to patients, either during the stay or at their discharge. The funds came from a combination of sources. It was common to take collections among people and businesses in the community, patients themselves, or their families, as donations, at charity sales and feasts, or through selling magazines that the patients and staff produced. In many instances, the patient clubs also ran a commissary, where the inmates could get sweets, hygiene articles, writing utensils, and other goods.[25] In at least one case, a patient club received support from public funds.[26] Besides the support function, however, the clubs engaged in a wide range of

[24]On Danish, Norwegian and Finnish tuberculosis patient organisations, see *Lungeforeningen Boserup Minde: patientforening* (Glamsbjerg: Lungeforeningen Boserup Minde, 2009); Dag Skogheim, *Gå foran, vis vei! Landsforeningen for hjerte-og lungesyke gjennom 50 år* (Oslo: Scanbok, 1993); and Hannu Mähonen, 'Vammaisjärjestötoiminta Suomessa 1880-Luvulta 1990-Luvulle', in Toivo Nygård and Kari Tuunainen eds, *Avun Kohteesta Itsensä Auttajaksi. Katsaus Suomen Vammaishistoriaan* (Jyväskylä: Atena Kustannus Oy, 1996), 185–252; Flurin Condrau has studied a German sanatorium club in '"Who Is the Captain of All These Men of Death": The Social Structure of a Tuberculosis Sanatorium in Postwar Germany', *The Journal of Interdisciplinary History* 2001, 32, 243–62. The periodical *Die TBC-Hilfe. Organ Des Deutschen Tuberkulosen-Vereins* was issued in 1929 by what appears to have been a short-lived attempt at a national German patient organisation. Furthermore Fred H. Broecker, 'The Come-Back Clubs of Wisconsin', *Journal of Rehabilitation* 1951, 17, 18 mentions patient clubs in the United States.

[25]Jan Wernström, *Söderby under 100 år: från sanatorium till bostadsområde* (Rönninge: Salems hembygdsförening, 2010), 37–40; *Målilla sanatoriums historia: slottet i skogen: 1904–1973* (Målilla: M. Wikstål, 2000).

[26]Kalle Danielsson, *Vänner för livet: Söderby sanatorium* (Stockholm: Bilda, 2004), 81–82.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

activities to entertain the patients and make their lives more comfortable. One example is Kroppefjälls county sanatorium, where the patients ran their own radio station and cinema, distributed the mail, tended to the aquarium and the swans, put together cabaret performances, and organised study groups.[27]

Tuberculosis has multifaceted socio-cultural connotations, both associated with the poor and destitute—even the degenerate—and with artists and intellectuals. It was surrounded by fear and stigma as well as romanticism.[28] Similarly, the sanatorium was an institution filled with contradictions and has been subject to diverse interpretations in historical research. On one hand, they were highly ineffective in terms of providing a cure and instead to a great extent served the purpose of separating the sick from the rest of society. Life within the sanatoria was ordered according to strict rules, enforced in a hierarchical structure, and often uncomfortable.[29] On the other hand, sanatoria were also sites where patients took solace in being among others in the same situation, and the relationships between staff and inmates were frequently characterised by negotiation, subtle challenging of hierarchies, and even affection.[30] Swedish sanatoria contained all of these ambiguities. Patient recollections are riddled with intense emotions, including grief and fear as well as deep fondness towards staff members and fellow patients. Although some sanatoria were more exclusive, most had patients from a wide range of social backgrounds. This mix, and the fact that the stay at the sanatorium for many working-class patients constituted the first time they had access to and time for reading, studying, and creative expression, made them into a sort of cultural institution which bracketed social divides.[31] Humour was a recurring theme in patient recollections, as well as in publications from the patient clubs, and expressed in many in-jokes, special idioms, and pranks.[32] Romantic liaisons between patients, in the Swedish institution lingo to 'clover', were both a common occurrence and a core part of the cultural fabric.[33]

[27]Per-Olof Lampers, *När livet tog en omväg: en bok om Kroppefjälls sanatorium* (Dals Rostock: Calluna, 2011), 92–110.

[28]Ott, *Fevered Lives*, 11–134; Frank M. Snowden, *Epidemics and Society: From the Black Death to the Present* (New Haven: Yale University Press, 2020), 269–331.

[29]Ott, *Fevered Lives*, 135–68; Linda Bryder, *Below the Magic Mountain: A Social History of Tuberculosis in Twentieth-Century Britain* (Oxford: Clarendon Press, 1988), 199–214.

[30]Sheila M. Rothman, *Living in the Shadow of Death: Tuberculosis and the Social Experience of Illness in American History* (New York: BasicBooks, 1994), 211–25; Condrau, '"Who Is the Captain"'; Flurin Condrau, 'Urban Tuberculosis Patients and Sanatorium Treatment in the Early Twentieth Century', in Peter Shapely and Anne Borsay eds, *Medicine, Charity and Mutual Aid: The Consumption of Health and Welfare in Britain, C. 1550–1950* (Oxford: Taylor & Francis Group, 2007), 183–205; Stephanie Kirby, 'Sputum and the Scent of Wallflowers: Nursing in Tuberculosis Sanatoria 1920–1970', *Social History of Medicine* 2010, 23, 602–20; Heini Hakosalo, 'The Walled-in Illness: The Twentieth Century Finnish Tuberculosis Sanatorium as a Lived Space', in Johanna Annola, Hanna Lindberg, and Pirjo Markkola eds, *Lived Institutions as History of Experience* (Cham: Palgrave Macmillan, 2024), 213–38.

[31]Puranen, *Tuberkulos*, 91–92; Birgitta Meurling, 'Från klövrande till rysk diplomati: Om relationer på sanatorier', *Kulturella Perspektiv – Svensk etnologisk tidskrift* 2022, 31, 1–11.

[32]Lampers, *När livet tog en omväg*, 111–33; Annie Svärd, *Romanäs sanatorium 1903–1940: en berättelse och en dokumentsamling* (Jönköping: Jönköpings läns museum, 2004), 159–61; *Målilla sanatoriums historia*; Bi Puranen, *Förälskad i livet: en bok om tuberkulosens historia* (Höganäs: Wiken, 1987), 132.

[33]In Swedish 'klövra', see Lampers, *När livet tog en omväg*, 106; Birgitta Andersson, *Brobysjukhusets historia 1912–1995: livet på ett sanatorium* (Broby: B. Andersson, 2000), 46–48; *Målilla sanatoriums historia*.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Sanatorium clubs for the most part did not have much of a political agenda, but were more akin to mutual aid societies or social clubs. However, in 1936, the Royal Board of Medicine—the government agency responsible for the healthcare sector—proposed new legislation concerning the management of tuberculosis. The proposal contained a number of measures that many patients and doctors perceived as overly coercive, mainly the suggestion that 'bullheaded germ-carriers'[34] should be forcibly admitted to sanatoria. As a reaction to the proposal, a group of former and current patients from the Stockholm area formed the After-Care Committee of the Lung-Sick.[35] This committee made formal appeals to state authorities and key medical experts to reconsider the proposed legislation, and were successful in having some of the more coercive aspects removed from the bill.[36]

Since the start, the After-Care Committee had toyed with the idea of founding a national organisation. Perhaps inspired by the way that many sanatorium clubs used magazines to communicate and gather funds, they decided to finance the organisation with a national paper. *Status*, its purposefully ambiguous name having connotations both to the medical jargon of the sanatoria and the situation of the tuberculosis patients as a social group, was first issued in 1938. It had a broad social policy profile and high literary ambitions, not limited to the tuberculosis question. Even in the first issue, some of the most prominent Swedish authors at the time contributed essays and short stories.[37] Although the majority of the articles in the first volume concerned tuberculosis and in particular the proposed tuberculosis law, there were also pieces on more general healthcare issues and other illnesses.[38] *Status'* high ambitions and wide scope proved to be a successful concept, and in the following year, the committee launched the DLR. By the end of 1939, 51 sanatorium clubs and four convalescent clubs—that is, clubs for former sanatorium patients—had joined the national organisation.[39] For the most part, then, the base consisted of sanatorium inpatients, and one important task for the new organisation was to mobilise support outside of the institutions. Erik Frithioff, recently appointed president of the DLR, presented his idea for this new phase of the organisation on the first page of *Status'* 1940 November issue. Building 'a net of convalescent clubs all over the country'[40] was, he explained, the most important activity if they were to fulfil the aims of the organisation. In his vision, every town should have a convalescent club, and the rural areas should be covered as well through forming clubs across a

[34]'Syfte och mål', *Status* 1, no.1 (1938): 3–4.

[35]In Swedish: De lungsjukas eftervårdskommitté. Cf. Inaugural meeting minutes, 13 December 1936, SE/RA/730195/A1a/3.

[36]Annual report of the after-care committee for 1937, SE/RA/730195/A1a/3; Annual report of the after-care committee for 1938; DLR annual report 1939; cf. Jenny Björkman, 'Frihet under ansvar. En jämförelse av anmälningsplikten för veneriskt sjuka och tuberkulösa, 1900–1920', *Socialvetenskaplig tidskrift* 8, no. 1–2 (2001), 40–53.

[37]Ivar Lo-Johansson (1901–1990), a leading representative of the proletarian literature movement, and Hasse Zetterström (1877–1946), a well-known newspaper columnist.

[38]Johannes Sandrén, 'Sjukhuset av första klass', *Status* no. 1938, 7, 4, 6; 'Kiseldammet tvingas på knä. 'Problemet silikosis' snart ur världen hos oss.', *Status* 1938, 6, 8.

[39]Erik Ransemar, *En föreningsrörelse i folkhälsans tjänst: Riksförbundet för hjärt-och lungsjuka 1939–1989* (Stockholm, 1989), 81.

[40]Erik Frithioff, 'Ett starkare riksförbund', *Status* 1940: 3.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

few neighbouring parishes. Through these local clubs, the DLR would be able to reach out to all lung sick in Sweden, not just the sanatorium patients. Frithioff's appeal was heard, and through local initiatives and with the aid of the central organisation, the network he had envisioned materialised. One example of how this was done was the formation of the Uppsala convalescent club. In August of 1941, the patients at the Central Sanatorium in Uppsala met with a representative from the patient club at the nearby Vattholma sanatorium and two 'representatives of the convalescents', likely former patients. They elected an interim board and chose two delegates to travel to Stockholm and request support from the DLR.[41] A month later, Frithioff came to Uppsala and spoke to the interim board about the purpose and aims of an organisation like the one they were about to form. Patient clubs at sanatoria, he explained, were merely engaging in entertainment and were unable to voice grievances since the chief physician was 'an actual dictator, and anyone who complains might very well be expulsed from the sanatorium'.[42] Convalescent clubs, on the other hand, had a 'greater task': to work for 'social justice for those who have been afflicted by the disease'.[43] Besides this motivational address, the DLR also provided a template for the statutes, and a first financial contribution to get the new club off the ground.[44] Frithioff and other DLR representatives regularly made visits like these to towns all across Sweden and helped with setting up convalescent clubs.[45] By 1942, there were fourteen such clubs, and in 1949 there were around 70, some of which were organised in regional umbrella organisations.[46]

In the 1940s, the DLR launched several activities that served to establish the organisation as an authority and key player in the field of social policy. Despite the sometimes-confrontational tone towards the medical profession and other authorities, the DLR were keen on collaborating with them. From 1943, they organised a series of 'welfare work conferences' that brought together politicians, physicians, key officials from government and local authorities, social workers, and union and business representatives in a 'forum for open exchange of ideas in the tuberculosis question'.[47] The initiative came from the Skövde convalescent club, which formed in the summer of that year and by September had 400 members—an example of the efficiency of the DLR umbrella structure to mobilise in local communities. The conference had around one hundred attendees, and was chaired by the mayor (Figure 1). Amidst talks by the governor and prominent local businessmen, as well as the chief physician from a nearby sanatorium, Erik Frithioff delivered a forceful address on the social situation of the lung sick, and brought up all of the main positions of the DLR regarding the need for vocational training and combatting discrimination.[48]

[41]Uppsala convalescent club meeting minutes, 8 August 1941, SE/FAC/313 A1:1.
[42]Uppsala convalescent club meeting minutes, 10 September 1941, SE/FAC/313 A1:1.
[43]Ibid.
[44]Uppsala convalescent club meeting minutes, 24 September 1941, SE/FAC/313 A1:1.
[45]For example, 'Förbundsordföranden på turné i Norrland', *Status* 1942, 13; 'Förbundets tjugoförsta konvalescentförening bildad', *Status* 1942, 11; 'Två nya konvalescentföreningar bildade', *Status* no. 10 (1943): 9; 'Konvalescentförening bildad i Ljusdal', *Status* 1948, 21.
[46]'Konvalescentföreningar anslutna till De Lungsjukas Riksförbund', *Status* 1942, 10; 'Konvalescentföreningar anslutna till De Lungsjukas Riksförbund', *Status* 1949, 31.
[47]DLR annual report 1947–1948, 6, SE/RA/730195/B1/1.
[48]'Uppmärksammad socialvårdskonferens i Skövde', *Status* 1943, 5–6.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Fig. 1. Attendees at the welfare work conference in Skövde, 19 September 1943 (*Status* no. 10 1943, p. 6)

Following the success in Skövde, the DLR held several conferences according to the same concept across the country each year, so that each region would regularly have a venue for discussing concerns around the lung-sick and their social situation in the respective area. Another recurring event, started in the same year, was the annual welfare work course. This course was intended for active members and offered an overview of the social policy and welfare landscape, in order to better equip them to guide and support members, effectively collaborate with authorities, and lead study groups and courses in their local communities.[49]

As mentioned, even the very first attempt by DLR's predecessor organisation to affect policymaking had been remarkably successful. During the 1940s, likely supported by the intense efforts to engage in social policy discourse, its influence grew as it regularly provided comments on government inquiries, a key feature of Swedish policymaking. New legislation is frequently preceded by an inquiry by an appointed individual or commission, which makes recommendations and then solicits comments from relevant organisations, institutions, or authorities.[50] Being asked to comment on an inquiry constitutes a recognition as being a relevant political stakeholder. Beginning in 1940, the DLR was regularly asked to comment on inquiries regarding, for example, social services, health insurance, and pensions.[51] This was a source of pride: *Status* explained in 1940

[49]DLR annual report 1947–1948, 9–10, SE/RA/730195/B1/1.

[50]Rune Premfors, 'Governmental Commissions in Sweden', *American Behavioral Scientist* 1953, 26, 623–42.

[51]Meeting minutes for the DLR executive committee, 27 March 1940, SE/RA/730195/A3a/1; 'Invalidpensionären bör ej få det sämre ställt än ålderspensionären!', *Status* 1946, 7–8; DLR annual report 1947–1948, 13; DLR annual report 1949–1951, 26–28, SE/RA/730195/B1/1.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

that the fact that the Ministry of Health and Social Affairs had solicited their comments on an inquiry meant that 'the Federation … has been officially recognised by His Royal Majesty'.[52] In addition to offering comments, the DLR had a seat in one government commission, the influential Committee for the Partially Able, and in several local committees for the partially able or for tuberculosis care.[53]

Besides lobbying and education, the DLR also moved towards becoming a provider of healthcare services. Many patients, who were no longer in need of sanatorium treatment but nevertheless required some level of care, ended up in old-age homes. This was considered medically inappropriate, demeaning, and counterproductive as they lacked rehabilitation resources.[54] Since the 1930s, the DLR and its local organisations repeatedly petitioned for the creation of specialised facilities, 'convalescent homes', especially for the lung sick.[55] They had success in a few places, where local authorities created institutions that prepared the residents for re-entering society with appropriate diet, occupational therapy, and study groups. However, the slow pace of establishing these homes frustrated the organisation, and in the late 1940s some local chapters became directly involved in founding new homes, while the central organisation simultaneously set up a fund for acquiring a facility of their own. These initiatives came to fruition in the first years of the 1950s, when some regional organisations together with local authorities created foundations for the operation of convalescent homes and finally, in 1956, the DLR opened its own facility in the small northern community Undersåker.[56] Altogether, this made up eight homes that were fully or in part managed by the DLR, with altogether 181 beds and over 30,000 overnight stays annually (Figure 2). The facilities were approved by the health insurance authorities, so that the convalescents could receive assistance in paying the fees. In addition, there were a limited number of spaces offered free of charge based on individual hardship after an assessment by the DLR in collaboration with the NAAT.[57] Besides the convalescent homes, the DLR also operated

[52]'Riksförbundets verksamhet under år 1940', *Status* 1941, 11–12; The inquiry in question was not officially a government inquiry, as it was done under the auspices of the NAAT. It was, however, done in close collaboration with the government, with several officials involved, and went through the same referral process as government inquiries. See Gustaf Neander et al., *Utredning angående förbättrad tuberkuloseftervård* (Stockholm: Esselte, 1939).

[53]'Partially able', in Swedish 'partiellt arbetsför' or, literally, 'partially able to work', was at this time the official term for people with disabilities. The Committee for the Partially Able was appointed in 1943 and issued seven reports until 1948. It is considered to have significantly contributed to shaping ideas and policies regarding disability in Sweden, see Kent Ericsson and Patricia Ericsson, *Att sätta prägel på sin vardag: Om säsongssamtal som ett arbetssätt inom handikappomsorg* (Pedagogiska institutionen, Uppsala, 2004); Kent Ericsson, 'Den svenska handikappreformen och 1946 års normaliseringsprincip', *Handikapphistorisk Tidskrift* 2005, 13, 36–50; and Marie-Louise Larsson-Severinsson, Olov Andersson, and Magnus Tideman, *Det relativa handikappbegreppets framväxt och etablering* (Högskolan i Halmstad, 2009); The DLR occupied a seat on the inquiry from 1947, appointed through the Joint Committee for the Partially Able, a collaborative effort initiated by the DLR and consisting of various organisation for the disabled. Cf. DLR annual report 1947–1948, 11–13, SE/RA/730195/B 1/1.

[54]Johannes Sandrén, 'De lungsjuka bort från ålderdomshemmen', *Status* 1946, 6, 30.

[55]'De lungsjuka i Malmö få konvalescenthem?', *Status* 1938, 12; 'Från förbundsarbetet', *Status* 1943, 9; Johannes Sandrén, 'Tuberkuloseftervården i Stockholm', *Status* 1945, 3–4; 'Norrbottens landsting anslår 220,000 kr. till omskolning av lungsjuka', *Status* 1946, 12.

[56]DLR annual report 1949–1951, 23; DLR annual report 1951–1953, 1953, 15–17, SE/RA/730195/B1/1; 'Konvalescenthemmet i Undersåker önskedrömmen för lungsjuka', *Status* 1956, 10–11.

[57]DLR annual report 1953–1955, 41–43, SE/FAC/313/F2:1; DLR annual report 1959–1961, 14–17, SE/RA/730195/B1/1.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

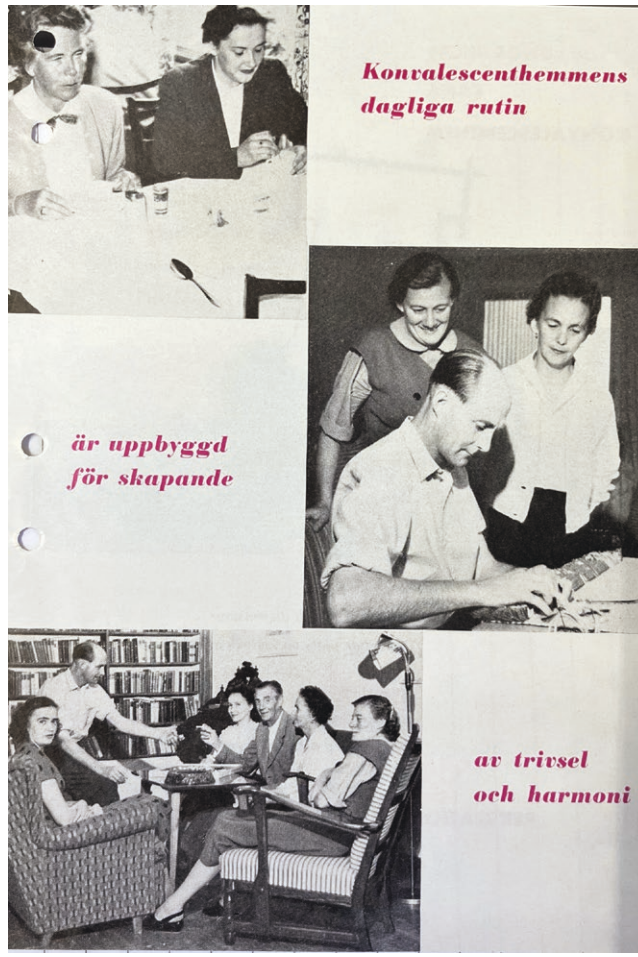

Fig. 2. From a brochure on DLR convalescent homes, circa 1956: 'The daily routine at the convalescent homes is built for creating comfort and harmony' (SE/FAC/313/F3/1)

two sheltered workshops where formerly lung-sick could work with manufacturing and bookbinding (Figure 3).[58]

During the two decades since 1936, when the predecessor organisation formed, the DLR expanded vastly in terms of its size, scope, and influence. According to an overview from 1955, the number of members—22,375—was equivalent to nearly 40 per cent of all tuberculars in the country.[59] The organisation was respected, deeply integrated in the social policy and healthcare landscape, and successful in implementing its agenda for how tuberculosis should be managed. Yet, stagnation was becoming noticeable. As both *Status*' circulation and the number of members began to drop, the board noticed that shorter stays at the sanatoria seemed to impede the activities in the patient clubs,

[58]Ransemar, *En föreningsrörelse*, pp. 70–72.

[59]DLR annual report 1953–1955, SE/FAC/313/F2:1.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Fig. 3. Map of Sweden with the DLR resources depicted: local clubs (blue dots), convalescent homes (house icons) and sheltered workshops (factory icon). From a 1965 information brochure (National Library of Sweden, document ID 50001000806643)

and that the convalescent clubs were having a harder time recruiting, given a growing sense that tuberculosis was becoming a problem of the past.[60]

Disassembling Lung Disease

When the DLR formed, they thought of 'lung disease' as equivalent with tuberculosis. In other words, being 'lung sick' was not just having any kind of pulmonary disease, but

[60]DLR annual report 1957–1959, 11; DLR annual report 1959–1961, 10, 27, SE/RA/730195/B1/1.; DLR board meeting minutes, 10 May 1956, SE/RA/730195/A3 a/8, 137.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

specifically tuberculosis. Conversely, speaking of tuberculosis meant the pulmonary form and not skeletal, genitourinary, or any of the other extrapulmonary manifestations of the disease. They were not alone in using the term in this way. Infection control legislation for tuberculosis only applied to pulmonary TB until 1939 and among physicians, we find the same synonymous treatment of lung disease and tuberculosis. For example, there were two competing professional associations, the Tuberculosis Physicians Association (TPA) and the Sanatorium Physicians' Association.[61] As the names suggest, the dividing line was the place of employment, not the disease in focus, and both of them considered themselves primarily focused on pulmonary tuberculosis or in other words lung disease. However, as the incidence of TB was dropping, the coherence of the concept became increasingly questioned. Among the physicians, this caused some turmoil as they began groping for a new definition of their field. The TPA, which despite the name had previously defined its scope as 'the study of lung disease and especially pulmonary tuberculosis', dropped the reference to other diseases of the lung in 1941 and reinvented itself as studying tuberculosis in all its manifestations. However, this did not last long and in 1956, they reintroduced other forms of pulmonary disease, and chose the new name Lung Physicians' Association.[62] This example serves to show how the reduced incidence of tuberculosis made ambiguities in the illness concept that had previously not been visible come to the fore and demand more specific definitions.

The first DLR statutes defined its objective as working for the interests of 'the lung-sick', without any closer specification of who that referred to.[63] Initially, the definition was built in to the organisational structure, since it was a conglomerate of sanatorium patient clubs. Only patients at the sanatoria, in other words people with pulmonary tuberculosis, could be members of those clubs. When convalescent clubs became more common in the 1940s, the definition did not seem to cause much trouble at first either. The DLR produced a set of standard statutes to facilitate the formation of such clubs, and here, for the first time, laid out conditions for membership. In the executive committee, there was some discussion about possibly allowing 'non-lung sick persons' to serve on the boards, but this was to make it possible to appoint prominent local persons, like city officials, not to organise other patient groups.[64] Ultimately, the decision was to stay with the principle of only allowing 'lung sick person[s] not presently admitted at a hospital or sanatorium'[65] as active members. The first impulse to question the definition came instead from Einar Ljunggren, a surgeon specialising in genitourinary tuberculosis. Since the 1930s, Ljunggren had actively lobbied for this form of the disease receiving more attention and resources. He lectured on the topic at the TPA, petitioned the Board of Medicine, and initiated an NAAT inquiry on the topic.[66] In 1946, he published an

[61]Sanatorieläkareföreningen and Tuberkulosläkareföreningen. Neither organisation used an abbreviation.
[62]Allan Beskow, *Tuberkulosläkarföreningen - Lungläkarföreningen 1912–1957–1967: En återblick på den vetenskapliga verksamheten* (Tranås, 1988), 6–13.
[63]DLR statutes, 1939, SE/RA/730288/EI/101 No. 1177.
[64]Meeting minutes for the DLR executive committee, 26 October 1941, SE/RA/730195/A3a/1 Vol. 4, 42–47.
[65]'Förslag till stadgar för lokalavdelning av De Lungsjukas Riksförbund', 1941, SE/RA/730195/A3a/1 Vol 4, 48–53.
[66]Beskow, *Tuberkulosläkarföreningen*, 96–98; Ola Brandt, 'Rävlanda sanatorium', *Status* 1958, 5; NAAT board meeting minutes, 7 June 1943, SE/RA/730288/A II/24.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

appeal in *Status* for patients with genitourinary and other types of TB to be admitted as members.

> Why is it 'The National Federation of the Lung Sick' and not for example 'The National Federation of the Tuberculars'? The former name is in reality downright misleading in that the Federation only includes patients with *tuberculous lung diseases* and not other *disabling lung diseases* such as asthma. This, however, I find rather irrelevant, since in colloquial terms a lung sick person makes one think primarily of someone with pulmonary tuberculosis. I find it far more serious that the thousands of people in our country, who suffer from tuberculosis in other organ systems, for example in the skeleton or the genitourinary tract … are not being affiliated with the 'National Federation of the Lung Sick'.[67]

Ljunggren went on to describe the symptoms and consequences of genitourinary tuberculosis, explaining that there were about 500 cases annually in Sweden and that their problems and interests were the same as for those with TB of the lungs, which was why they should be allowed to join the DLR.[68] While there are no traces of the idea being pursued further in *Status* or the organisation at this point, Ljunggren's efforts resulted in a special ward for genitourinary tuberculars at the Rävlanda sanatorium near Gothenburg from 1948.[69]. At the following DLR congress, the Gothenburg regional organisation motioned to change the statutes so that this group could be included in the organisation. They suggested to change the name and objectives throughout, to be either the National Federation of Tuberculars or the National Federation of the Lung and Kidney Sick, arguing that '[t]he treatment for pulmonary and genitourinary tuberculosis is quite similar and the genitourinary tuberculars have the same difficulties as we do with housing, work, and other conditions'.[70] The DLR board, however, argued that a change in the terminology would harm the organisation, which was already well-established under its current name. Instead, the congress voted to amend the standard statutes for the local clubs to allow 'lung sick, formerly lung sick, or persons who have or have had genitourinary tuberculosis'[71] to become members.

Including a further patient group, who were technically not 'lung sick' but nevertheless had a similar collective experience of sanatorium care, was uncontroversial and apparently of little consequence to the movement as a whole. However, when the stagnation in the DLR started to become noticeable after 1955, the question came up again and the organisation's leadership began exploring ways to expand the base. Board member Ture Edbom initiated the discussion and suggested changes in the statutes to clarify the definition of 'lung sick'. What Edbom had in mind was the opposite of Ljunggren's suggestion. Instead of defining the scope as all forms of tuberculosis, he suggested that any disease of the lungs and airways—as long as it was debilitating to one's financial or social condition—should be included. Edbom argued for the necessity of these changes due to the noticeable decline in tuberculosis morbidity, which reduced the pool of potential members, but also because of shorter sanatorium stays and reduced frequency

[67]Einar Ljunggren, 'De Lungsjukas Riksförbund bör omfatta alla tuberkulösa', *Status* 1946, 7.
[68]Ibid.
[69]Brandt, 'Rävlanda Sanatorium'.
[70]DLR congress protocol, 23 August 1953, SE/RA/730195/A3 a/6, 337.
[71]DLR statutes 1953, 19, SE/FAC/313 B:1.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

of persistent disabling effects. When patients spent less time in the sanatorium, the patient club lost appeal and significance, which affected the willingness to continue the engagement after discharge. Improved social conditions and fewer lasting disabilities also meant less incentive to organise. However, expanding the organisation also had risks. Previously, the members had all had similar needs, and there had been, with the sanatoria, 'natural units … on which to build local organisations'.[72] Changing the scope brought the potential of administrative disarray and conflict over budget and priorities between different patient groups. Therefore, Edbom suggested an expansion, but only to carefully selected patient groups that were as similar to the tuberculars as possible, in the sense that they were or had been patients at a sanatorium or had a debilitating lung condition.[73]

When delegates to the 1957 congress debated—and eventually approved—Edbom's suggestion, it became clear that it in some ways came post facto. At least one other group of lung sick, silicosis sufferers in Borlänge, had already joined the DLR.[74] Along with the previously affiliated genitourinary patients, this was still only a very slight change in terms of actual numbers. In 1959, the Borlänge club had 28 members and the Rävlanda sanatorium club 53. At the same time, the overall number of members had declined by about 2,500 since the decision to expand the base.[75]

In the intervening time, another group had caught the eye of the DLR leadership. Weeks after Edbom submitted his proposal to the board, the National Federation Against Asthma and Other Allergic Diseases (RAAS) held its inaugural meeting in Uppsala and the DLR decided to approach them.[76] The RAAS had 1,700 members and was growing, making them a highly attractive group to incorporate into the DLR, and initially they expressed some interest in joining.[77] Between 1957 and 1960, the two organisations engaged in repeated attempts to negotiate the terms of a merger, but ultimately never came to an agreement.[78] The failure was probably due to multiple factors. The RAAS was apprehensive about being engulfed in a much bigger organisation and in particular losing its independent magazine.[79] More fundamentally, however, the organisations had different cultures and profiles. The DLR was strongly committed to remaining a grass-roots organisation by and for the lung sick and was built mainly for political advocacy. The RAAS, on the other hand, sought out engagement from medical professionals in running the operations and was primarily aimed at fundraising for research, while being much less radical in their political advocacy.[80]

[72]Ture Edbom, 'Behöver underlaget för DLR:S verksamhet vidgas?', 1956, SE/RA/730195/A3 a/8, 247.

[73]Ibid, 246–50.

[74]DLR congress protocol, 28 July 1957, SE/RA/730195/A3 a/8, 583–86.

[75]DLR annual report 1957–1959, 10, 12, SE/RA/730195/B1/1.

[76]Minutes from meeting between RAAS and DLR, 20 October 1956, SE/RA/730195/A3 a/8, 326f.

[77]Meeting minutes of the DLR executive committee, 26 July 1957, SE/RA/730195/A3 a/8, 502; RAAS annual report 1957–1958; RAAS annual report 1958–1959, SE/RA/739039/B/B2/1.

[78]Meeting minutes of the RAAS executive committee, 19 June 1957, SE/RA/739039/A/A2/1; RAAS board meeting minutes, 10 November 1958; RAAS board meeting minutes, 14 May 1960, SE/RA/739039/A/A1/1.

[79]Meeting minutes of the RAAS executive committee, 10 December 1958, SE/RA/739039/A/A2/1.

[80]'Det nya riksförbundet. Tillkomst, ändamål, uppgifter.', *Allergia* 1957, 1, 4; Minutes from meeting between RAAS and DLR, 25 April 1958, SE/RA/739039/A/A2/1; DLR board meeting minutes, 20–21 October 1956, SE/RA/730195/A3 a/8.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

When the DLR assembled in Gothenburg for their 1961 congress, it was obvious that all attempts to halt the decline of their organisation by expanding the scope to other diseases of the lung had failed. More and more local clubs had disbanded or were struggling, and the board had given up hope of ever reaching an agreement with the RAAS.[81] A committee had produced a new proposal to revise the statutes, which included a passage that further emphasised the broader scope. However, before the congress, the Stockholm convalescent club submitted a brave new proposal: instead of amending the statutes with a long list of lung disorders, they proposed to rename the organisation the National Federation of the Heart and Lung Sick. Through expanding the scope to the 'heart sick', they argued, the organisation would gain not only more members but more importantly 'a very strong increase in sympathy',[82] which would be 'a big plus in our opportunities'[83] to influence social policy. After only a brief debate, the congress voted in favour of the suggestion.[84]

With this decision, a long process of reformulating the meaning of 'lung sick' came to its conclusion. A decade earlier, the term had signified not so much a disease of a particular organ, or infection with a certain germ, but a specific lived experience. It suggested someone who had been through a process of withdrawal from the rest of society, joining instead the world of the sanatorium, where relationships formed and experiences were made that fostered a sense of community. After the stay at the sanatorium, the shared experience continued: of interacting with dispensaries and poor relief institutions, of stigmatisation, and struggles to re-enter society. Being lung sick was certainly 'a way to be a person and live in society', but that kind of person was now going extinct—even among people with tuberculosis. This was not lost on the DLR, who opened the 1961 annual report with stating that 'the era of sanatoria is now approaching its end',[85] and with the decision to rebrand the organisation later the same year, an antiquated disease concept approached its end as well.

Making Heart Disease

At the same time, cardiology was on the rise in Sweden, as was cardiac disease. Ironically, the higher standard of living that was conducive to the decline of infectious diseases like TB contributed to this increase through rising life expectancy and lifestyle changes. The DLR was not alone in needing to come to terms with this shift. There had been vast systems built around lung disease: institutions, organisations, and careers that all needed to be reoriented, and in many cases, it was heart disease they turned to. For example, the DLR's professional counterpart, the NAAT, changed its name to the National Association Against Tuberculosis and Other Endemic Diseases[86] in 1956, and then again to the National Association Against Heart and Lung Disease in 1960. Many surgeons, who had developed thoracic surgery techniques in the sanatoria, turned to cardiac surgery instead

[81]DLR annual report 1959–1961, 8–9, SE/RA/730195/B1/1.
[82]DLR congress protocol, 28 July 1961, 43, SE/RA/730195/A1a/1.
[83]Ibid.
[84]Ibid, 29–44.
[85]DLR annual report 1959–1961, 3, SE/RA/730195/B1/1.
[86]In the Swedish original, the title uses the term 'folksjukdom' which is difficult to translate. It literally means 'people's disease' but denotes a disease that is widespread and recognised as a public health threat. We have chosen to translate it to 'endemic'.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

as the patients ran out.[87] In other words, the DLR's decision was far from unique, and closely aligned with the direction that many of its important partners were heading in. Nevertheless, shifting from tuberculosis to heart disease was not ubiquitous. In Norway, DLR's counterpart also changed its name and orientation to include cardiac disease in 1961, but the Danish and Finnish tuberculosis patient organisations instead reoriented their focus towards lung disease in general.[88] Professional and charitable organisations in other countries also chose different paths. The German Zentralkomitee zur Bekämpfung der Tuberkulose maintains its name and orientation to this day, while in Great Britain, the National Association for the Prevention of Tuberculosis changed its name to the Chest and Heart Association in 1959.[89]

However, the term 'heart disease' had a marked difference from 'lung disease'. The latter was a general-sounding term that in fact signified something very specific: pulmonary tuberculosis and a path from sanatorium to dispensary. Heart disease was instead an umbrella term for a broad set of pathological conditions, treatment modalities, and patients, centred around one of the organs involved. There was no institution or otherwise shared experience similar to that of the lung sick that could make the 'heart sick' into a group behaving as such. Instead, this became the task of the new DLR.

After deciding to organise the heart sick in 1961, the DLR was faced with the challenge of where to find them and what to do with them. In 1936, it had been an easy task to find the lung sick, since they were already gathered at the sanatoria. Now, the organisation appeared not even to have a very specific idea of what, exactly, they meant by their new name and objective. What they did have, however, was an infrastructure that they had spent the last decades building up for the lung sick. The congress had taken place at the end of July, and in early September, the central DLR office began issuing instructions to all local chapters on how to reach out to and organise the heart sick in their communities. While still using the old letterhead, they sent out templates for lectures and pleas to organise and advertise courses and public meetings about cardiac disease.[90] In order to facilitate a nationwide outreach campaign, the DLR leadership laid out what they expected from the local organisations:

> **INFORMATION MEETINGS**
> Should be arranged in every district. The most appropriate start is that each regional organisation arranges a large-scale information meeting in the largest town, with a lecture by a cardiac specialist. Representatives of the press, the county, the county labour bureau, the rehabilitation authority, counsellors and others whom we want to make aware of the cause should be invited. The heart sick themselves should of course also be invited through advertisements and announcements in the press. We believe that an important precondition for reaching out in the widest of circles and

[87]Nathoo, *Hearts Exposed*, 10–11.
[88]*Boserup Minde*; Skogheim, *Gå foran*; Mähonen, 'Vammaisjärjestötoiminta Suomessa'.
[89]Anna Ritchie, *Stroke Association: History Perspective 1898–2012* (Stroke Association, 2012); R. Loddenkemper et al., '125 Jahre Deutsches Zentralkomitee zur Bekämpfung der Tuberkulose e. V. (DZK)', *Pneumologie* 2020, 74, 719–41.
[90]'Cirkulär Nr. 12', 7 September 1961; 'Cirkulär Nr. 15', 16 September 1961, SE/FAC/313 E2:1.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

> quickly spreading information about our restructuring is to involve the press and having them write positive articles about meetings and get-togethers arranged by the clubs. Apart from that, there is continuous information through the local clubs, which invite heart sick persons to all of their meetings. The national office is happy to provide advice and support in planning and arranging information meetings in the districts.[91]

During the fall of 1961 and the following year, the districts followed through and arranged numerous meetings according to this instruction. Perhaps the most extravagant of these events took place in the Stockholm Concert Hall on 2 October 1962. It featured speeches by two of the most prominent Swedish medics at the time, cardiologist Gunnar Biörck and heart surgeon Viking Olov Björk, and top-notch entertainment with dancing performances and well-known musical acts. Behind the event was the DLR, its two local chapters in Stockholm, and the NAAT (although the latter appears to have been involved only in funding). The organising committee sent out more than 500 personal invitations to politicians, physicians, other healthcare workers, public officials, and representatives of other NGOs, advertised in all major newspapers and distributed 4,000 advertising leaflets. Nearly two thousand people were in the audience, including several high-ranking physicians, key figures in state and local government, and many members of the press.[92] As planned, the event received significant attention in the media, with at least 35 articles published in the weeks afterwards and headlines such as 'Half a million Swedes suffer from heart disorders'[93] and 'Heart patients can live long, do not have to view life in dark colours'.[94]

Biörck and Björk complemented each other in their lectures that night. Biörck, who was professor at the Karolinska institute, a prolific writer on medical and social issues, and an influential voice in healthcare policy debates, focused on prevention and made a point of showing statistics that suggested that food rationing during the war had led to decreased incidence of cardiovascular disease.[95] Björk, on the other hand, presented new surgical techniques and argued for the need for specialised clinics to provide advanced care for heart disorders.[96] His career was archetypal for the development of cardiology in the mid-20th century, having started with the surgical treatment of tuberculosis, then training in London where he treated injured soldiers, and subsequently becoming a pioneer of cardiac surgery in Sweden.[97] After the physician and the surgeon, the chief of the

[91]'Cirkulär Nr. 2', 16 January 1962, SE/FAC/313 E2:1.

[92]'Lista för inbjudan till konferens i konserthuset den 2 Okt. 1962', SE/RA/730195/F 5/1.

[93]*Hallandsposten* October 3, 1962.

[94]*Dagens Nyheter* October 3, 1962, cf. 'Rapport gällande informationsmöte om hjärtsjukdomar i Stockholms konserthus tisdagen den 2/10 1962', SE/RA/730195/F 5/1.

[95]Gunnar Biörck had a background in political activism on the far-right, having been one of the leading figures in the campaign to prevent Jewish physicians to flee to Sweden from Nazi persecution. In the 1960s, Biörck was already somewhat well-known, having published several books and often featured in the media. He would later become one of the most famous physicians in the country, and from 1976 a Member of Parliament for the conservative Moderaterna party. Lars Erik Böttiger, 'Carl Gunnar Wilhelm Biörck', in *The Roll of the Royal College of Physicians of London. Vol. 10*, ed. Sarah Jane Gillam and William Munk (London, 2000), 36; Ulf Högberg, *Vita rockar och bruna skjortor. Nazimedicin och läkare på flykt* (Malmö: Universus, 2013), 93–94,176–77.

[96]'Hjärtpatient kan leva länge, behöver inte se livet i svart', *Dagens Nyheter*, 3 October 1962.

[97]Francis Robicsek, 'Tribute to a Pioneer: Viking Olov Björk, 1918–2009', *The Journal of Thoracic and Cardiovascular Surgery* 2009, 137, 1309–10.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

National Labour Market Board Roland Eriksson emphasised that the heart sick, provided that they could have the right rehabilitation and support, in many cases could be financially independent. It was gratifying, he said, that the DLR and NAAT, who had done so much to fight tuberculosis, would now 'make their services and resources available to the heart sick'.[98]

One of those resources were the convalescent homes. On the back of the program for the evening, the NAAT advertised their luxury telegram templates, an important source of funding for them, while the DLR informed about the homes. They promised 'Recreation–Rest // Aftercare–Preventive care in a relaxing environment and scenic areas',[99] and that there was financial support available. However, for heart patients the latter was still only a partial truth, as the DLR were in the midst of negotiations with the funders—the NAAT and regional authorities—to extend their subsidies for stays at the convalescent homes to people with heart disease. By early 1963, most counties had decided to provide such funds.[100] Yet, while the formal obstacles had been removed, still relatively few people with heart conditions came to stay.

Bringing people with cardiac disease into the convalescent homes became a process that was symptomatic of the challenges of bringing the heart sick into the DLR, and overall of the transformation in the organisation. Initially there had been some concern about the old fear of germs making it unlikely that any other patients would want to house together with tuberculars.[101] That does not appear to have posed much of a problem, but it became very obvious that other patient groups could not simply be brought into structures built for the particular kind of people that the lung sick had been. Besides people with cardiac disease, the homes also admitted asthmatics, but the staircases and the smoking in the dining halls proved to be problematic for them and the heart sick.[102] In addition, the cardiac patients were not 'convalescent' in the same manner as the former sanatorium patients. Whereas the lung sick had needed primarily social support, like the opportunity to study and participate in occupational therapy while they recovered, patients who had been discharged with a heart condition were physically in worse shape. The homes did not have nurses or other medical staff, and were not equipped to handle the emergencies which were prone to happen with the cardiac cases.[103] At the same time, tuberculosis had changed as well. The treatment was shorter, meaning that their condition was also frailer after leaving the hospital, and the disease now mainly affected older and socially marginalised groups. This diminished the

[98]'Informationsmöte om hjärtsjukdomarna, Stockhoms konserthus tisdagen den 2 Okt. 1962', SE/RA/730195/F 5/1.
[99]'Program vid informationsmöte om hjärtsjukdomarna', 1962, SE/RA/730195/F 5/1.
[100]'Cirkulär Nr. 4', 19 March 1963, SE/FAC/313 E2:1.
[101]Meeting minutes from convalescent home conference, 24 November 1957, SE/RA/720195/A3 a/9.
[102]Meeting minutes from convalescent home conference, 13 November 1965, SE/RA/730195/Ö1a/2; Letter from Einar Hiller to John Gärdin and Harald Holm, 29 June 1966, SE/RA/730195/Ö1a/5.
[103]John Larsson, 'PM angående driften vid Fjällfarargårdens konvalescenthem', 31 December 1964; Annual meeting minutes for the Fjällfarargårdens convalescent home, 10 April 1965; Annual report of the Fjällfarargårdens convalescent home for 1966, 1967, SE/RA/730195/Ö1a/2.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

potential clientele and presented new challenges in housing people with addictions and other multimorbidities.[104] Eventually, these problems lead to the decision to close three of the convalescent homes in the late 1960s and early 1970s.[105]

Clearly, the DLR was in need of a new knowledge base in order to work effectively with the heart sick, and for this, they also had historical experience to draw from. In 1938, before officially forming as DLR, the aforementioned After-Care Committee conducted a survey of the living conditions of the lung sick, which they presented to the national poor relief authority.[106] A larger survey followed in 1943, which revealed that nearly 70 per cent of the respondents were unemployed post-sanatorium treatment, compared to less than one in ten before being admitted. Other issues addressed included housing conditions, vocational training, and public poor relief.[107] Further surveys were conducted in 1954 and 1955 regarding conditions at the sanatoria and the status of former sanatorium patients in relation to the newly approved general public health insurance.[108] After the decision to expand to heart disease, the organisation decided to launch a new inquiry in order to get to know their potential new base. This time, they recruited the renowned professor in social medicine Gunnar Inghe to lead the work and secured funding from the NAAT.[109] In its initial phase, the investigation included 48 DLR members from Stockholm, and the focus was similar to the previous surveys: their financial situation, housing conditions, access to healthcare and social services, and medical expenses.[110] In other words, the making of the new patient collective was modelled on the knowledge of the existing one, as the social and financial challenges of the sick or convalescent came to conceptually bond the two groups together. A second, large-scale study followed but was not finished until 1976.[111] In the meantime, the DLR developed a program for their new focus group on an ad hoc basis. In a brochure from 1964, they declared that

> [o]ld endemic diseases are pushed back but new ones emerge. Especially concerning is the increase in cardiac and vascular diseases. The tougher pace in labour and the faster beat of time involve greater strain on the heart and vessels than most of us can bear. Half a million people in Sweden have heart disease. 200 000 of them are of working age. There is data to suggest that the increase is greater in middle aged than in elderly people. A large proportion of hospital beds are occupied by people with heart troubles.[112]

[104]Annual report of the Alsborg Helgevärma convalescent home for 1963, 18 March 1964; Annual report of the Alsborg Helgevärma convalescent home for 1964, 24 February 1965; Annual report of the Alsborg Helgevärma convalescent home for 1965, 24 March 1966, SE/RA/730195/Ö1b/1; Meeting minutes for Fjällfararegårdens executive committee, 17 February 1962; Annual meeting minutes for the Fjällfarargårdens convalescent home, 14 March 1964; Larsson, 'PM angående driften Vid Fjällfarargårdens Konvalescenthem', SE/RA/730195/Ö1a/2.

[105]DLR annual report 1967–1970, 6; DLR annual report 1973–1976, 14, SE/RA/730195/B1/1.

[106]Martin Engvall, letter to the After-Care Committee, 28 October 1938, SE/RA/730195/F2/1; DLR annual report 1939, SE/RA/730195/F1/1.

[107]'Riksförbundets utredning lämnar intressanta uppgifter om de lungsjukas levnadsförhållanden', *Status* 1943, 5–6, 12, 31.

[108]'1954 års sanatorieutredning', SE/RA/730195/F2/9; 'Alarmerande utförsäkringsfrekvens bland sanatorievårdade tbc-sjuka', *Status* 18, 1955, 12–13.

[109]DLR annual report 1964–1967, 14–15, National Library of Sweden, 00000000071831.

[110]DLR annual report 1961–1964, 4, SE/RA/730195/B 1/1; DLR congress protocol, 30 July 1967, 2, 22–24, SE/RA/730195/A1a/1.

[111]DLR annual report 1973–1976, 16–17, SE/RA/730195/B 1/1.

[112]Brochure 'En organisation i folkhälsans tjänst', 1967, National Library of Sweden, 00000000071831. Here, the organisation also uses the difficult to translate word 'folksjukdom', which we have chosen to translate to 'endemic disease'. Cf. note 87 above.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

In this presentation, as in other material, the DLR took care to maintain their focus on labour, and emphasised that just like the lung sick, the heart sick were often relatively young, had a disability and were in need first and foremost of social rehabilitation. On the back of the brochure, they listed some of their causes and offers: courses and retraining grants (for a more suitable vocation), help to apply for public support to become self-employed, and lobbying for extended vocational rehabilitation. Another folder, from 1970, described consequences of heart disease in a way that could in most parts have been about tuberculosis in the 1940s: 'extended periods of illness, need for aftercare, life-long medicating, constant worry of relapse, readjustment to suitable work and … reduced financial standard of living'.[113]

At the same time, the information meetings had helped establish contacts with cardiologists and with people who suffered from heart conditions, who brought forth issues particular to the group. This included petitioning for free public transport and subsidies for motor vehicles, and recurring campaigns against firecrackers.[114] Instead of the convalescent homes, which were proving to be less than ideal for the heart sick, local clubs began offering physical therapy classes and 'adaptation courses' (Figure 4). The latter were targeted towards people who had suffered a heart attack, and included sessions epidemiology, symptoms and causes of heart disease, diet and lifestyle advice, guidance in the healthcare and social welfare system, physical exercise, and information about the DLR.[115] In 1972 the organisation started distributing a medical identification tag for pacemaker carriers, which was soon extended to anyone with heart disease (Figures 5 and 6), and in the same year, they began arranging 'recreation trips' to southern Europe.[116]

Despite the efforts to reach out and come up with attractive offers to the heart sick, the member base changed at a slow pace. Changing the organisation's profile did not halt the decline during the first years after the decision, and by 1969 they were down to just under 14,000, with the vast majority still being lung sick. However, when many of the targeted activities for the heart sick group started in the early 70s, both the total number of members and the proportion of the heart sick group began to grow. Finally, in 1977, the heart sick became for the first time the largest section of the former DLR.[117]

When the DLR shifted its focus to include heart as well as lung disease, the heart sick were at first inserted into a framework shaped for mid-20th century tuberculosis. Because it was built for a disease that typically affected the young, disrupting their careers and impairing their social condition, it was geared heavily towards social policy

[113]Brochure 'Osynligt Handikapp', 1970, National Library of Sweden, 00000000071831.

[114]DLR annual report 1964–1967, 19, National Library of Sweden, 00000000071831; DLR board meeting minutes, 10 September 1963; Meeting minutes for DLR body of delegates, 12 June 1971; DLR board meeting minutes, 14 December 1971; DLR board meeting minutes, 26 April 1972, SE/RA/730195/A3 a/11.

[115]'Anpassningskursen på Sundbyholm', 1972; DLR board meeting minutes, 6 February 1972; DLR board meeting minutes, 16 October 1972, SE/RA/730195/A3 a/11.

[116]'Identitetsbricka för pacemakerbärare', *Status*, 1972, 2; 'Identitetsbricka för hjärtsjuka', *Status*, 1973, 4; The first recreation trip went to Sunny Beach, Bulgaria. Later, there were also trips to destinations in Italy, Spain, and Greece. Bengt Dahlström, 'Första resan till Bulgarien blev en fin upptakt', *Status*, 1972, 12–13; DLR annual report 1976–1979, 14, SE/RA/730195/B 1/1.

[117]Ransemar, *En föreningsrörelse*, 111.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

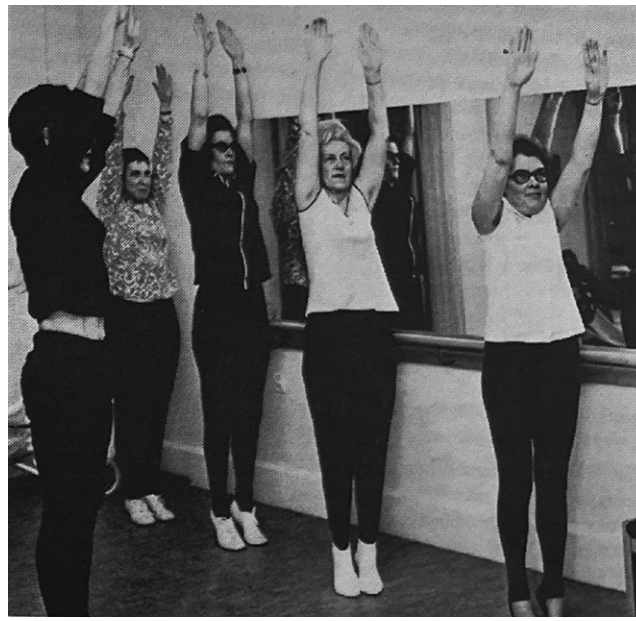

Fig. 4. Physical therapy class for DLR members, circa 1970 (DLR annual report 1967–1970, 17, SE/RA/730195/B1/1)

Fig. 5. Medical identification tag for pacemaker carriers issued by the DLR (DLR information brochure 1973, National Library of Sweden, document ID 50001000806643).

and labour issues. A heart sick person encountering the DLR would, at its meetings and in the printed material it distributed, learn foremost about the socio-economic plight affecting her kind of person, and when the organisation set out to survey their new target group, it was their finances, work life, and housing conditions they scrutinised.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Fig. 6. Medical identification tag for people with heart disease issued by the DLR (DLR information brochure 1974, National Library of Sweden, document ID 50001000806643).

However, as the organisation transitioned and the membership base shifted towards heart disease, it changed its scope. In the 1970s, the DLR branched out to engage more in the biomedical and physical aspects of healthcare and rehabilitation and this, in turn, affected the lung sick as well. In brochures and pamphlets, the DLR now presented both heart and lung disease as umbrella terms for a range of conditions that had in common that they affected a particular organ system.[118] The lung sick had ceased being those who frequented sanatoria and dispensaries, and turned into those who were afflicted with diseases of the lung.

Conclusion: Patient Organisations in the Epidemiological Transition

When the Swedish tuberculosis patient organisation incorporated the heart sick, it became one of the institutions that contributed to the making of this particular group. In the process, they interacted with other key players involved in the transition from tuberculosis to cardiovascular disease as a main public health concern. When medical experts gave lectures at the information meetings, the DLR transmitted knowledge from the expert to the people with heart disease who were present and to key public officials, and through a further institution—the press—also to wider audiences. This was not just knowledge transmission from expert to the public, but also helped lend expert status to the invited lecturers, who represented a medical field that was just being established. But the medics were not the only experts. The DLR built its own credibility and knowledge

[118]Brochures 'En halv miljon är hjärt-eller lungsjuka. Är Du en av dem?', 1973; 'Lungsjukdomar. En information från Riksförbundet för Hjärt-och Lungsjuka', 1979, National Library of Sweden, 50001000806643.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

base, through targeted studies, experiences they made in managing the heart sick in the convalescent homes, and interacting with the new members. Hence, the DLR participated on all levels of the process of 'making up' heart disease—identifying and classifying people as eligible members, participating in managing those people within their institution, generating and disseminating knowledge, and acting as experts on their condition and needs.

It was the interconnectedness of these elements that let the DLR contribute to making the heart sick a kind of person. As an example, a person with high blood pressure and someone with a congenital heart defect might both see an announcement for an information meeting in the press, sit next to each other in the audience hearing lectures about proper diet and exercise and seeing films from open heart surgeries. If they chose to become members, they could end up being among the respondents for studies on the socio-economic conditions of this group, 'the heart sick', that they now belonged to, and the data thus gathered provided a foundation for the DLR to make authoritative claims about their needs. Furthermore, through the DLR they might attend physical therapy classes, wear an identification tag, take courses that taught them—in their capacity as 'heart sick'—everything from diet to applying for housing subsidies, and even spend their vacation at a Bulgarian beach surrounded by other 'heart sick'.

Our study serves to place the active participation of patients among the factors that contributed to a transformed disease panorama in the 20th century. The epidemiological transition was an interaction of demographic, social, economic, biological, and biomedical factors, with both diet and medical policy playing a role in creating new classifications that cut the sick population into different segments. The example of how the Swedish tuberculosis patient organisation transformed into the heart and lung disease association demonstrates how patient categories are not created by the diseases themselves, but through a constellation of different conditions. In the case of 'lung disease', it was the sanatorium treatment that physically brought patients together and made them into a group of people with similar experiences and the ability and motivation to articulate common interests. However, in order for a category such as 'heart disease' to materialise as a group of people in society, a conscious effort was required. In Sweden, this was carried out in part as a dedicated campaign by tuberculosis patients, with the aim of maintaining the membership base and political relevance of their organisation.

The transformation of the DLR underlines the fact that patient organisations are not mere representatives of carriers of a certain type of biological characteristic, but are active, selective and dynamic in relation to their diseases. Hence, they are co-creators of the very disease categorisation and boundaries of the patient cohort, shaping, rather than expressing, their interests and needs.

Archival Sources

Swedish National Archives, Arninge

- Archive of the DLR (Codes SE/RA/730195)
- Archive of the NAAT (Codes SE/RA/730288)
- Archive of the RAAS (Codes SE/RA/739039)

Folkrörelsearkivet, Uppsala

- Archive of the Uppsala central organisation for heart and lung sick (Codes SE/FAC/313)

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026

Acknowledgements

This work was funded by the Swedish Research Council (2019-02984) and the European Union (ActDisease ERC-2021-STG 10104099). Views and opinions expressed are however those of the author only and do not necessarily reflect those of the European Union or the European Research Council. Neither the European Union nor the granting authority can be held responsible for them.

Downloaded from academic.oup.com/shm/article/39/3/591/8172302 by Dennis Hejhal user on 28 September 2026