



## SCIENTIFIC FINAL REPORT

### Two- and three-year projects and postdoctoral projects

Registration number, Östersjöstiftelsen: 2016-0022

Project manager: Maria Josephson (Björk)

Project title: *Medicin, makt och motstånd: THX-konflikten och svenskt-tyskt utbyte under efterkrigstiden*

#### 1. The three most important results of the project and what conclusions can be drawn from them

##### **Cancer: patients' situation and the state of clinical research.**

Perhaps the most important result of the project is that it contributes new knowledge of the norms and practises of clinical research, and about the situation for terminally ill cancer patients in Sweden during the decades after WW2. The project illuminates the consequences of clinical research being almost completely unregulated at the time.

Patients, including children, were often subjected to various treatments without their knowledge or consent. The project also shows that in the absence of rules and regulations for clinical research and pharmaceutical trials, doctors' and researchers' personal and professional preferences and interests generated an informal system where experimental drugs, including THX, quickly could reach critically ill patients.

Another result of the empirical analysis is that it demonstrates that terminally ill cancer patients' needs were neglected and ignored by the medical establishment and the health care system, thus creating a patient group susceptible to the promises of new experimental treatments offered by actors in the peripheries of conventional medical science.

**Conclusions:** Clinical cancer research during the decades after WW2 was not only irregular and quite unsophisticated, but it also allowed for experimental and potentially dangerous substances to reach patients through the informal system of professional actors within it.

##### **Patient organisations, anti-establishment movements, and medical science**

THX; the experimental cancer drug invented by Vet. Med. Dr. Elis Sandberg, became the centre of a controversy between patients and the Swedish medical authorities that lasted for decades. The project shows how Sandberg's patients; mostly older people from the rural parts of Sweden, formed a movement that preceded the 1968-movement in Sweden. Sandbergs patients organised in 1965, and became loud critics of the medical establishment, the ideals and authorities of conventional medical science and health care. The persistent lobbying of the THX movement generated a new law (Lagen om naturmedel för injektion, 1981).

As described in the projects' publications, the THX movement also brought into light the difficult situation for dying and incurable cancer patients, and thereby started a debate about the care of the dying in Sweden. The THX movement hereby paved the way for two different but connected, and hitherto under-researched, developments in Swedish health



care: the formation of the field of palliative care and palliative medicine, and a more accepting attitude towards complementary and alternative medicine (CAM).

**Conclusions:** The THX movement effectively influenced leading actors within the Swedish medical authorities to act against flaws within the system, such as the lack of care for chronically and terminally ill patients. The project also illuminates the part played by the THX movement for the changing attitudes towards complementary and alternative treatments in Sweden.

### **Exchange of patients and knowledge**

The project shows that consistent reporting in the press about the conflict surrounding THX and Elis Sandberg appear to have increased the demand for THX. Patients travelled far, even from abroad, to come to Aneby and receive treatment. From the beginning of the 1970s' and onwards reports reached the international press. Physicians from all over Europe came to Aneby to learn how to make THX and went home to set up their own THX-clinics. Most of these physicians came from West Germany, where hundreds of THX-clinics were operating in the beginning of the 1980s'. Particularly the clinic in Bad Harzburg became influential. Swedish patients started to travel to Germany to receive treatment when access to the extract in Sweden was scarce. Swedish THX-clinics only offered THX. Patients paid a small fee and some received treatment for free. In Germany clinics often offered THX as a part of a variety of alternative, complementary or experimental treatments, to full price paying patient-consumers. Visits to German clinics made some Swedish patients openly question the Swedish legislation on CAM-medicine.

The project illuminates how THX in Sweden became constructed as a treatment that was not perceived of as CAM, but rather almost a conventional drug. When THX crossed borders and entered new geographical and cultural contexts the extract was reframed and sometimes introduced as a CAM-product.

In addition, the project shows how different kinds of knowledge travelled in different directions. Patients brought new knowledge of CAM-medicine and a less regulated health care system home to Sweden from Germany. German physicians returned from Aneby with knowledge of how to manufacture THX, and in many cases made it a lucrative business. **Conclusion:** Knowledge is not a constant, rather something constantly renegotiated in relation to cultural context. Knowledge travels in different directions with different kinds of carriers and is influenced by the carriers' different agendas.

## **2. The project's contribution to the international research frontline**

The project contributes to several research fields. First, the project has generated new knowledge of the treatment and care of cancer patients in Sweden, thereby adding to a field of research within the history of medicine inquiring into the consequences of the rapid development of health care and medical research after WW2, which has grown during the recent years.

The project also contributes to the international research field studying patients' movements and organisations. As shown in the project the THX-movement had similarities



with some contemporary patient movements in the US and Italy, but also differences connected to their Swedish political context.

An important research field related to the project is controversy studies related to science and technology. The project illuminates the discrepancy between the sometimes-rigid theoretical framework of controversy studies and actual controversies regarding medical science and practise. As shown in the project, conflicts about medicine and health care are messy, sometimes too messy to be analysed within the strict framework of controversy studies without significant loss of empirical value. The project hereby contributes a critique of the theoretical framework of controversy studies.

### **3. The contribution of the research to the knowledge of the Baltic Sea Region and Eastern Europe**

The project's main contribution to knowledge about BSR and EE consists of its results regarding circulation of knowledge and ideas between Sweden and West Germany. As shown the knowledge circulated in connection to THX was on the one hand practical; how to make THX, on the other general; patients learned and experienced that a different system of health care and medicine was possible. It seems likely but would require a completely different study to be certain, that THX-patients with experience of THX-treatment from Germany, influenced the Swedish debate about CAM.

### **4. New research questions that the project has led to**

The project has led to several new research questions, of which three will be mentioned here. First, it has led my attention to the history of death and dying in Sweden: what has been perceived of a good death, why, and in what ways do the answers differ over time and between patients, health care staff and policy makers? Second, it has led to new questions about patienthood in a transforming health care system: in what ways have expectations on patients changed during and after the golden age of the welfare state? Third, the project has also led to new questions about the development of clinical research and clinical science: how did the shift towards Big Science play out in Sweden, where human as well as monetary resources were limited?

### **5. Dissemination of the results of the project within and outside the research community**

The project has generated great interest, within and outside the research community. Due to the pandemic conference attendance has been limited. Therefore, greater effort has been made to contribute to the public debate about topics related to the project, such as disease, illness and medicine in society.

The project has generated a monograph published by Norstedts bokförlag, which is one of the leading publishing houses in Sweden. The monograph *Lex THX* has generated great interest and has been the subject of articles and episodes in several daily newspapers, journals and podcasts during the fall of 2022, and continue to do so. During the spring/summer of 2023 the PI will attend two major conferences to present the project's results: Nordic Medical History Congress in Helsinki, where the PI will give one of the



keynote lectures, and Svenska Historikermötet i Umeå where the PI will partake in a panel discussion about popular history writing and present the monograph.

## **Publications**

### **Monograph**

Lex THX. Historien om Sveriges största medicinska konflikt och den märkvärdige veterinären som skapade den (Norstedts bokförlag, 2022).

<https://www.norstedts.se/bok/9789113117713/lex-thx>

### **Peer reviewed articles**

Historien om THX – hur en veterinärmedicinare från Småland skapade Sveriges största medicinska konflikt genom tiderna, *Svensk Medicinhistorisk tidskrift*, 2020, vol. nr. 24, nr. 1, s. 105 - 120.

En ”medborgerlig” patientrörelse. Samhällssyn och maktkritik hos den svenska THX-rörelsen under 1970-talets andra hälft, *Scandia. Tidskrift för historisk forskning*, 2018, vol. 84, nr. 1, s. 36 – 60. <https://journals.lub.lu.se/scandia/article/view/17584/17738>

### **Book chapters**

Veterinären som folkets vetenskapsman. Kalvthymus och gettarmar mot cancer, i *Humantimalt. Oss djur emellan i medicin och samhälle förr och nu*, red. Motzi Eklöf (Exempla förlag, 2020), s. 101 – 108.

En ”folklig” medicinsk moral? Konfliktlinjer kring cancermedlet THX ca 1965 – 1971 i Sverige, i *Medicinska moraler och skandaler. Vetenskapens (etiska) gränser*, red. Motzi Eklöf (Carlssons bokförlag, 2019), s. 189 – 210.

### **Popular science publications**

Den goda doden, i *Anekdot. Det digitala bildningsmagasinet*, 21/5 – 2020.

<https://anekdot.se/essa/den-goda-doden/>

Vi har glömt att det är normalt att vara långtidssjuk, *Göteborgs Posten kultur*, 11/8 – 2021.

<https://www.gp.se/kultur/kultur/vi-har-gl%C3%B6mt-att-det-%C3%A4r-normalt-att-vara-l%C3%A5ngtidssjuk-1.52669337>

### **Debate**

Man dör inte längre för att man är gammal, *Expressen kultur*, 27/3 – 2020.

<https://www.expressen.se/kultur/man-dor-inte-langre-for-att-man-ar-gammal/>

Begreppet kultursjukdom slår på dem som redan ligger, *Svenska Dagbladet*, 14/4 – 2021.

<https://www.svd.se/a/zg2qvr/begreppet-kultursjukdom-slar-pa-den-som-redan-ligger>

### **Media**

Historia Nu, podcast, dec 2022: <https://historia.nu/historia-nu/thx-i-brytpunkten-mellan-omsorg-och-kvacksalveri/>

SR, P1, Vetenskapsradion på djupet, 17/5 – 2021: <https://sverigesradio.se/avsnitt/1727018>

SR, P1, Studio Ett, <https://sverigesradio.se/artikel/medicinshistoriker-slar-ett-slag-for-konvalescensen>

### **Conferences**

Society for the History of Medicine Conference 2018, Liverpool, 11 – 13 July,

Presentation: *Patient Consumers or Patient Citizens? The THX Patient Movement in Sweden 1974 – 1978.*

Medicinshistoria idag, Medicinshistoriska nätverket, Karolinska Institutet, Uppsala universitet, 30 sept, 2019, organized.

Existential Medical Humanities, Södertörn University, November 7-8, 2019. Presentation: *Det sista halmstået. Kalvbräseextraktet THX och patienterna.*