

MANIFESTO

THE PATIENT'S PARLIAMENT

THEME HEALTH DATA

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THE PATIENT'S PARLIAMENT MANIFESTO

**STOP
TALKING,
SHARE
OUR
HEALTH
DATA**

“For me, it has literally been a matter of life and death that my health data has not been shared between healthcare providers.”

Participant at this year's Patient's Parliament

DEAR POLITICIANS,

In May, the EU Commission launched a European Health Data Space for people and research. The goal, according to the Commission, is to lay the foundation for secure and reliable access to health data. The focus is on people themselves gaining control of their own data. The proposal is welcome. The fact that your healthcare provider has access to data about you helps to play a big role in enabling you as a patient to receive the best healthcare. Sometimes the information is downright vital.

But, in Sweden, we patients are in practice responsible for passing our healthcare information between different healthcare providers. However, there is no requirement for healthcare providers to share health data with each other. Patients should not need to function as messengers.

Of course, we patients must have power over our data, but we do not necessarily need to own it. Responsibility for our health data should instead rest with those who have the tools to assess the information: the healthcare providers.

Healthcare professionals must have access to the information required to provide the right care. Only then can we have equal, innovative and patient-safe healthcare. As simple as that. Therefore, this year's Patient's Parliament has been about the importance of enabling access to health data regardless of healthcare provider.

For the fourth year in a row, the Patient's Parliament has been held and this year presenters came from the majority of Sweden's patient organisations at national, regional and local level. Together, we have discussed what needs to be done for access to health data regardless of health care provider, to become a reality.

This spring Sweden holds the presidency of the EU. Those of us who represent patient organisations believe and hope that health data will be high up on the agenda.

We hope that you will push the issues that more than 40 patient organisations consider to be important both in Sweden and at EU level. Here you can view the five reform proposals that were presented during the Patient's Parliament 2022. We hope you will take them to heart and listen to the patient's voice.

We patient organisations are happy to be a constructive party in discussions about the future of healthcare. Through this manifesto, we want to invite dialogue.

Together we can increase the participation of patients and create better health and medical care.

The Patient's Parliament's advisory group

The advisory group consists of Astma- och Allergiförbundet, Blodcancerförbundet, Bröstcancerförbundet, Huvudvärksförbundet, Neuro, Reumatikerförbundet, The Swedish Heart and Lung Association and Rare Diseases Sweden in cooperation with Novartis.

THE PATIENT'S PARLIAMENT REFORM PROPOSAL

"The Patient's Parliament is needed because the voice of patients needs to be stronger"

Lise Lidbäck,
Chairperson, Neuro

"A common digital infrastructure is not the goal, but the remedy."

Jakob Forssmed (CD),
Minister for Health and
Social Affairs

"Everyone wants to have structured data, but no-one wants to create it. It is one of the big challenges today, and working together is of course key but what is also needed is clarification of the division of responsibilities."

Max Herulf, Chief Medical
Officer Swedish E-health
Agency

1

GIVE HEALTHCARE STAFF ACCESS TO THE INFORMATION REQUIRED TO PROVIDE THE RIGHT HEALTHCARE

In Sweden, you as a patient are in practice currently responsible for passing on your healthcare information between different healthcare providers. However, there are no requirements for healthcare providers to share health data with each other. You as a patient should not have to act as messenger. Healthcare professionals must have access to the information required to provide the right care. Only then can we have equal, innovative and patient-safe healthcare. As simple as that.

2

INTRODUCE LEGISLATION THAT MAKES HEALTHCARE PROVIDERS OBLIGED TO SHARE HEALTH DATA

The basic rule should be that health data must be shared by healthcare providers in both the private and public sector and at a both regional and municipal level. However, the patient must also have the right to restrict and supplement the access to their health data. In this way, we can assure ourselves that the information accompanies and belongs to the patient.

3

CREATE A COMMON DIGITAL INFRASTRUCTURE FOR HEALTHCARE

Today, we have a situation where the same information often needs to be documented a number of times in order for the various medical record systems to interact. With a common digital infrastructure where the system has the same technical, semantic and organisational conditions, the same data can instead be used by healthcare providers throughout the country and important information does not need to be lost on the way as happens many times today.

4

SHIFT RESPONSIBILITY FOR SHARING OF HEALTH DATA TO A NATIONAL PLAN

Today, the regions procure different systems for health data that function in various ways and also have different rules for how data is to be shared. When access to health data varies between different healthcare providers and places in the country, patient safety is compromised and healthcare becomes uneven. By shifting the responsibility for health data matters from the regions, we can safeguard the sharing of health data functioning in the same way for all patients throughout the country.

5

LET US PATIENT ORGANISATIONS BE A CONSTRUCTIVE PART OF THE DISCUSSIONS ABOUT ACCESS TO HEALTH CARE DATA REGARDLESS OF HEALTHCARE PROVIDER

Sharing of health data is ultimately a matter of the patients' right to equal and patient-safe healthcare. We patient organisations are sitting on a great knowledge about how patients currently perceive the current supply of information within healthcare and have a lot to contribute to the discussions about access to health data. Unless there is a focus on patient's perspective early in the work for increased sharing of health data, there is a risk that fundamental perspectives will be lost.



THE PATIENT'S PARLAMENT REFORM PROPOSAL

- 1 Give healthcare professionals access to the information required to provide the right healthcare.
- 2 Introduce legislation that makes healthcare providers obliged to share health data.
- 3 Create a common digital infrastructure for health data.
- 4 Shift the responsibility for the sharing of health data to a national plan.
- 5 Let us patient organisations be a constructive part in the discussions about access to health data regardless of healthcare provider.

SHARED HEALTH DATA - A PRESSED ISSUE

- Proposal for regulation on the European Health Data Space
- Sweden's presidency of the Council of the EU in spring
- The patient's voice about health data – an investigation by Vinnova
- Health data as a national interest – legislation for interoperability
- The Tidö Agreement

A lot is happening in the matter of health data both in and outside Sweden. This year's theme for The Patient's Parliament is based on current events in the area.

PROPOSAL FOR REGULATION OF THE EUROPEAN HEALTH DATA SPACE

In May 2022, the EU Commission presented its proposal for a regulation with an associated announcement of the European Health Data Space.

The purpose of the Commission's proposal for a regulation is partly to give individuals within the EU greater control of their health data, and partly to make it easier to share and gain access to different types of health data. This applies to both healthcare (primary use) and for, among other things, research, innovation and decision-making (secondary use).

Within the EU, this would mean that people gain direct access to their health data and that they can share their health data with healthcare professionals throughout the EU and across borders. As the proposal looks today, it means that people gain control of their health data and can add information, correct inaccurate information, restrict access for changing and receiving information about how the data is used and for what.

Through the health data space, a strong regulatory framework is established for the use of health data for research, innovation, public health, decision-making and regulation according to the EU Commission. Researchers, innovators, public institutions and industry gain access to large amounts of high-quality health data under strict conditions.

The EU Commission's proposal will be discussed in the Council and the European Parliament. The proposal has been referred by the Government and referrals have been received from authorities, regions, municipalities and organisations through the EU.

SWEDEN'S PRESIDENCY OF THE COUNCIL OF THE EU IN THE SPRING

Sweden is president of the Council of the EU from 1 January-30 June 2023. The Government writes on its website that the proposal regarding regulation on the European Health Data Space will be negotiated and possibly adopted during Sweden's presidency.

In Sweden, the Swedish E-health Agency assists the Ministry of Health and Social Affairs in negotiations on the regulation as an expert authority during the presidency. The proposal has major consequences upon healthcare and for business; everything from innovation to complex regulatory aspects and in turn impact on market and business models.





**THE PATIENT'S VOICE
ABOUT HEALTH DATA
– AN INVESTIGATION BY VINNOVA -
SWEDEN'S INNOVATION AGENCY**

The report highlights what patients in Sweden today know about health data, what they want more knowledge about and what they see is important for them to feel safe to share their health data.

Patients want to have more knowledge about how, by whom and for what purpose health data are used. The majority want to be able to access health data through an easily-accessible digital portal like "Mina sidor" on 1177 and consider that there should be more functions in order that a patient is able to contribute to their medical records. Several patients emphasise that all health data should be gathered in one place, so that it is easily possible to have an overview regardless of who the health care provider is. They should also be described in a way that the patient can easily understand. Patients also want to be able to change or report where data shared with healthcare is incorrect. Patients also emphasise that they want to be able to share their own health data with healthcare and that health data must also be able to be shared between different regions and healthcare providers if the patient agrees to this. Many patients emphasise the importance of making health data usable, and that there is a strong desire that their own health data is used to contribute to better healthcare and is not simply collected for the sake of it.

The report was produced in the spring of 2022 by Ramboll on behalf of Vinnova and working groups within the Government's collaboration programme Health and Life Science. The report is mainly based on a questionnaire survey that was actively distributed in February 2022 to individuals in municipalities, regions, patient boards, patient organisations and authorities via email as well as in social media. In total, 583 people have answered the questionnaire which provides an indication of the awareness and knowledge patients have about health data. By having health data as the theme during this year's Patient's Parliament, patient organisations were given the opportunity to further highlight the issue, as they together represent over 500,000 members, more information on the theme could be collected and raised to a new level.

**HEALTH DATA AS A NATIONAL INTEREST
– LEGISLATION FOR INTEROPERABILITY**

In July 2022, the Government commissioned a special investigation to analyse and propose suitable and socio-economically effective measures in order to bring about a better and more secure information supply of health data between systems and actors. Interoperability refers to the ability of our different systems, usually in a computer context, to work together and be able to communicate with each other.



The intention is to increase patient safety, operate a more patient-centred kind of healthcare and reduce the duplication of work for the health and medical care professionals as well as provide better conditions for developing and improving medical treatments, ways of working and health-promoting preventative initiatives.

The appointed investigator is Annemieke Ålenius who will also submit the legislative proposals that the investigation considers justified. The assignment will report no later than 30 April 2024.

THE TIDÖ AGREEMENT

During the year that has passed and similarly during the work on this year's Patient's Parliament, a new government was appointed. In October, the Tidö Agreement between the Moderate Party, Christian Democrats, Liberals and Sweden Democrats was published. In the Tidö agreement, it appears that the parties want to implement a uniform and common digital infrastructure for the Swedish healthcare system that replaces and supplements the existing infrastructure of the 21 regions.

"Likt infrastrukturen för den avreglerade apoteksmarknaden ska sjukvården använda en enhetlig digital infrastruktur. Hälsodata blir tillgänglig i hela vårdkedjan för all vård, både kommunal vård, regional sjukvård och tandvård, oavsett vårdhuvudman. Den digitala infrastrukturen ska skapa förutsättningar för en innovativ och marknadsdriven utveckling där patientsäkerheten är i fokus. Samspel behöver ske med såväl offentliga som privata aktörer. Frågan om detta kräver författningsändring ska prövas."

THE PATIENT'S PARLIAMENT 2022

**SHARED
HEALTH
DATA
REGARDLESS
OF HEALTH-
CARE
PROVIDER**

IN DECEMBER 2022, the fourth Patient's Parliament took place. It is an arena for and by patient representatives, where an advisory group consisting of eight different patient organisations has worked together throughout the year on issues related to theme, speakers and design. During 2022, the advisory group consisted of Astma- och Allergiförbundet, Blodcancerförbundet, Bröstcancerförbundet, Huvudvärksförbundet, Neuro, Reumatikerförbundet, The Swedish Heart and Lung Association and Rare Diseases Sweden in cooperation with Novartis.

ON THE THEME OF ACCESS TO HEALTH CARE regardless of healthcare provider, patient and sector organisations within life science, politicians and experts gather for a unique occasion where patients and patient organisations steer the agenda and discussion. Since 2019, the Patient's Parliament has been a forum for engagement, exchange of knowledge and influence where the focus is on the patient's voice and increased patient participation.

DURING THE PATIENT'S PARLIAMENT 2022 there was an opportunity to participate both physically and digitally. The popular influence forum, a form of interactive workshop, formed an important part of the programme. During the influence forum, the pressing issue related to accessible health data regardless of healthcare provider was discussed.

THE PATIENT'S PARLIAMENT 2022 WAS HOSTED BY Andreas Norlén, Speaker of the Parliament, Jakob Forsmed (CD), Minister for Health and Social Affairs, Lena Hallengren (S), Group Leader in the Swedish Parliament and former Minister for Health and Social Affairs, Anders W Jonsson (C), Member of the Swedish Parliament and health care policy spokesperson, Karin Rågsjö (Left), Member of the Swedish Parliament and healthcare policy spokesperson, Malin Sjöberg Högrell (Lib), Health and Medical Care Regional Councillor in Region Uppsala, Jimmy Loord (CD), Opposition Councillor with responsibility for health and medical care in Region Kalmar County, Max Herulf, Chief Medical Officer of the Swedish E-health Agency and Magnus Isacson, Chairperson of The Swedish Association of General Practice (SFAM).

PARTICIPANTS FROM THE ADVISORY GROUP included Caroline Åkerhielm, Chairperson of Rare Diseases Sweden, Gustav Hadin, Vice Chairperson of the Swedish Headache Association, Inger Ros, former Chairperson of The Swedish Heart and Lung Association, Lise Lidbäck, Chairperson of Neuro Sweden, Lise-lott Eriksson, Chairperson of the Swedish Blood Cancer Association, Lotta Håkansson, Chairperson of the Swedish Rheumatism Association, Mikaela Odemyr, Chairperson of the Swedish Asthma and Allergy Association and Susanne Dieroff Hay, Chairperson of the Swedish Breast Cancer Association, as speakers.

The Patient's Parliament was moderated by Karin Klingenstierna.



"The Patient's Parliament has become stronger during the year and has become the pressure group it should be."

Karin Rågsjö (Left Party), Member of the Swedish Parliament and healthcare policy spokesperson

"The Patient's Parliament is a meeting place that makes it possible for those who may not normally have time to meet to sit down and perhaps find new areas of collaboration. But above all, decisionmakers who visit the Patient's Parliament have reason to think about what perspective they should have when talking to patients."

Lena Hallengren (S), Member of the Swedish Parliament, former Minister for Health and Social Affairs



THE PATIENT'S PARLIAMENT 2022 IN FIGURES

200

participants

40

participating patient organisations

180 000

exposures in social media

THE PATIENT'S PARLIAMENT

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