



## FORENINGEN FOR BIVIRKNINGSRAMTE - COVID-19 VACCINATION

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### **Comment to ACIP – Experiences of Vaccine-Injured Patients and Systemic Barriers to Recognition and Care (Denmark)**

**Submitted by: Anette Lindberg Friedrichsen, Chair**  
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(Foreningen for Bivirkningsramte efter COVID-19 vaccination)

<https://bivc19vac.dk/en/>

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#### **Introduction**

This comment is submitted to inform ACIP about the real-world situation faced by individuals who developed serious and persistent health problems after COVID-19 vaccination, with a specific focus on the experience in Denmark.

Our association represents individuals who were previously healthy, often younger and with healthy lifestyle and strong immune system. They developed severe and often chronic conditions after vaccination. Their experiences highlight systemic gaps in safety monitoring, recognition, diagnosis, treatment and compensation for covid vaccine-related injuries.

These issues are not unique to Denmark and are increasingly reported by patient organizations under our organisation *Covid Vaccine Injury Alliance* <https://www.covidvaccineinjuryalliance.org> and researchers worldwide.

#### **Patient outcomes and long-term illness**

In June 2025 our association conducted a patient survey among vaccine-injured individuals. The results illustrate the severity and persistence of the condition.

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Key findings from the survey include:

- **94 % of patients are still not recovered** several years after vaccination.
- Patients have been ill for an average of **1,388 days (almost four years)** at the time of the survey.
- Many suffer from multi-system symptoms including neurological, cardiovascular and autoimmune complications.

A striking pattern in the survey is the **temporal relationship between vaccination and symptom onset**:

- **38 % developed symptoms the same day as vaccination**
- **84.6 % developed symptoms within the first week**

These findings strongly suggest that a subgroup of patients experience **persistent vaccine-associated syndromes**, often referred to in the literature as **Post-Acute COVID-19 Vaccination Syndrome (PACVS)**. Yet they are denied acknowledgment and compensation.

## **Lack of recognition and medical care**

Despite severe and disabling symptoms, the majority of patients report limited access to diagnosis and treatment.

Survey results show:

- Only **29 % are receiving treatment within the public healthcare system**
- **62 % are paying privately for treatment**, despite often reduced income due to illness.

The absence of structured care pathways means many patients are:

- left without diagnosis
- referred repeatedly between specialists
- or told their symptoms are psychological and denied treatment

This lack of clinical recognition creates significant barriers to treatment and recovery.

## Severe underreporting of adverse events

The same survey highlights substantial underreporting of vaccine adverse events.

- **78 % of patients reported their adverse event themselves**
- **Only 32 % say their physician reported the event.**

This gap is particularly concerning because physicians were under **mandatory reporting obligations during the COVID-19 vaccination rollout.**

Underreporting creates a distorted safety signal and undermines pharmacovigilance systems that depend on accurate reporting.

## Structural data gaps in national health systems

A critical systemic issue identified in Denmark is that **vaccine injuries are not registered with diagnostic codes in national health registries.**

Because research recruitment and surveillance systems rely on diagnoses and coded health data, this means:

- patients with vaccine injuries cannot be reliably identified in the registries
- their health outcomes are not systematically studied
- they are even being recruited for new vaccine trials
- studies done on these insufficient data is misleading

This lack of registry coding also makes it impossible to determine the **true incidence of long-term vaccine injuries.**

## Findings from the Danish national Covid evaluation, (VIVE)

The independent national evaluation of Denmark's COVID-19 response conducted by **VIVE**, commissioned by the Danish Parliament, also highlights systemic shortcomings.

The report concluded that authorities should have given **greater priority to investigating and addressing vaccine side effects**, including earlier clarification of responsibility and better follow-up of adverse events.

Instead, many vaccine-injured patients experienced:

- lack of recognition
- lack of treatment pathways
- and prolonged bureaucratic disputes regarding responsibility.

These systemic failures contribute to erosion of public trust in health authorities.

## The human consequences

The absence of recognition and medical care creates a vicious cycle for affected patients:

lack of diagnosis → lack of registry data → lack of research → lack of treatment → lack of compensation.

As a result, many patients remain invisible within official health statistics despite severe disability.

This has profound personal and societal consequences, including:

- loss of employment
- financial hardship
- mental health impacts
- shorter lifespan
- and long-term healthcare needs.

## Recommendations for ACIP and global health authorities

Based on these experiences, we respectfully urge ACIP and other public health authorities to consider the following measures:

1. **Establish standardized diagnostic codes** for vaccine-associated chronic syndromes.
2. **Ensure long-term follow-up of vaccine adverse events**, especially in previously healthy individuals.
3. **Create dedicated clinical programs** for diagnosis and treatment of vaccine-injured patients.
4. **Improve pharmacovigilance systems** by addressing underreporting among healthcare providers.
5. **Guarantee transparent communication about risks and uncertainties** in vaccination programs.
6. **Include patient organizations in safety evaluations and policy discussions.**

## Conclusion

Vaccination remains an important public health tool. However, ethical vaccination policy must also recognize and support the individuals who experience serious adverse outcomes.

Ignoring these patients does not strengthen trust in vaccines — it undermines it.

Transparent recognition, research and care for vaccine-injured individuals are essential both for justice and for maintaining confidence in public health programs.

Sincerely

Anette Lindberg Friedrichsen, chair

*former competition rower, but now Pfizer covid vaccine injured since November 2021*

*(Heart inflammation, Heart failure, lungs damaged, inflammation in lymph nodes, Angio oedema, ongoing systemic reaction, neuropathy and POTS)*