



Providing Enhanced Medical Support for Patients with Primary Immunodeficiency Disorders (PID): A Patient-Guided Intervention to Ensure Patient Engagement During a Global Pandemic and Beyond

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The Survey

In 2021, the American Academy of Allergy, Asthma and Immunology (AAAAI) partnered with the Immune Deficiency Foundation (IDF) and AXDEV, a performance company specializing in evaluation and assessment, to solicit input from PID patients about the gaps they have experienced seeking care for immunodeficiency conditions. A Steering Committee made up of allergist/immunologists and patients associated with IDF drafted a survey addressing:

- Diagnosis
- Interprofessional collaboration
- Treatment and management
- Patient-provider communication
- Use of Telehealth

The survey was distributed by IDF to their community of PID patients, and over 300 patients submitted responses.

The Participants

Adult Patients' Diagnoses (n=308) PID patients over the age of 18	Age	Gender Identity
<ul style="list-style-type: none"> – 56% (n=173) common variable immunodeficiency (CVID) – 14% (n=44) hypogammaglobulinemia, IgG subclass deficiency or selective IgA deficiency – 17% (n=53) both of the above – 12% (n=38) other 	<ul style="list-style-type: none"> – 44% 61 or older – 35% 46-60 – 27% 31-45 – 3% 18-30 	<ul style="list-style-type: none"> – 84% female – 16% male – 1% gender non-conforming

Provider Most Involved in Diagnosis	Provider Most Involved in Treatment
<ul style="list-style-type: none"> – 63% Immunologist or Allergist – 15% Other – 8% Pulmonologist – 6% Infectious disease physician – 5% Primary Care Physician – 4% Hematologist – 1% Mental Health Provider 	<ul style="list-style-type: none"> – 80% Immunologist or Allergist – 8% Primary Care Physician – 6% Hematologist – 4% Infectious Disease Physician – 2% Other

The Findings

Diagnosis

Patients report long delays in diagnosis

- 41% (124/302) of adult sample reported that it took over **21 years beyond the onset** of their first symptom to receive a final PIDD diagnosis
- 59% (179/304) reported that their PIDD was **initially diagnosed as a different disorder** (e.g., allergy, bacterial or viral infection, chronic sinusitis, Crohn's disease)

Patients report the following potential reasons for long delays based on their experiences:

- **HCPs do not ask patients about their full range of symptoms**
 - 42% (126/302) of adult sample *disagreed with the statement: When I initially consulted with a health care professional, they asked about the full range of symptoms I have been experiencing.*
- **HCPs tend to dismiss signs and symptoms of PIDD**
 - 76% (226/296) *agreed or strongly agreed with: I have experienced more than one healthcare professional completely dismissing my primary immunodeficiency related symptoms.*
 - This is true even for patients who have common signs and symptoms of PIDD. Participants with the following symptoms *agreed or strongly disagreed with this statement: "I have experienced more than one healthcare professional completely dismissing my primary immunodeficiency related symptoms."*
 - 91% Unexplained illness
 - 85% Recurrent pneumonia
 - 83% Chronic nasal or ear drainage
 - 81% Breathing problems
 - 80% Autoimmune disorders

Treatment and Management

- 91% (278/304) of adult patients reported that the severity of their symptoms worsened over time

Patient-Provider Communication

% of patients disagreeing or strongly disagreeing that HCPs explained to them how the following factors affect the severity of their PIDD

- 65% Environmental factors
- 60% Lifestyle
- 57% Another health condition

Telehealth

60% of adult patients reported perceived benefits associated with telehealth; some reported perceived limitations

- 25% provides **little to no support for mental health**
- 21% provides **little to no opportunities for discussions on quality of life**

