The Immune Deficiency Foundation (IDF) conducted surveys of persons with primary immunodeficiency diseases (PI) and their caregivers to gain insight on availability of care through health insurance in 2014, 2015 and 2016.

**Satisfaction with Insurance**

The majority of respondents were satisfied with their insurance plans.

The results of 2014, 2015 and 2016 Health Insurance Surveys are based on respondents connected with IDF and may represent those with better than average coverage and experience.

**When Health Plans Interrupt Treatment**

In recent years, the number of respondents reporting problems seeing a healthcare specialist as a result of their health plans rules has been on the rise:

- **39%** of respondents who skipped or delayed an infusion in 2016 reported this being due to problems with their health insurance.

Timely immunoglobulin (Ig) replacement therapy is critical for many persons with PI, yet insurance problems are a common cause for interruption of Ig therapy.

- **21%** of respondents (2014, 2015 and 2016) reported that as a result of their health plan’s cost-sharing rules, the person with PI had problems affording visits to healthcare providers.
How do those with primary immunodeficiency diseases (PI) rate the quality of the care they’re receiving? The Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and caregivers found that generally, respondents are confident in their ability to receive appropriate medical care. Respondents with private insurance tend to be more confident than those with public insurance.

The results of 2014, 2015 and 2016 Health Insurance Surveys are based on respondents connected with IDF and may represent those with better than average coverage and experience.

**DEFINITIONS**

**PRIVATE**
Any health insurance policy purchased by an employer or an individual from a private insurance company regardless of any public funding.

**PUBLIC**
An insurance plan or policy that is subsidized by federal or state funds and is administered by a public entity, such as Medicare, Medicaid and Tricare.

**SATISFACTION WITH QUALITY OF CARE**

<table>
<thead>
<tr>
<th>Year</th>
<th>Private</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>87%</td>
<td>85%</td>
</tr>
<tr>
<td>2015</td>
<td>86%</td>
<td>83%</td>
</tr>
<tr>
<td>2016</td>
<td>87%</td>
<td>80%</td>
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</table>

**CONFIDENCE IN RECEIVING THE MOST EFFECTIVE DRUGS**

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>2014</td>
<td>85%</td>
<td>76%</td>
</tr>
<tr>
<td>2015</td>
<td>84%</td>
<td>76%</td>
</tr>
<tr>
<td>2016</td>
<td>84%</td>
<td>72%</td>
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</table>

**CONFIDENCE IN RECEIVING THE BEST MEDICAL TECHNOLOGY**

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>2014</td>
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<td>75%</td>
</tr>
<tr>
<td>2015</td>
<td>86%</td>
<td>78%</td>
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<tr>
<td>2016</td>
<td>85%</td>
<td>74%</td>
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</table>

**CONFIDENCE IN RECEIVING HIGH QUALITY AND SAFE MEDICAL CARE**

<table>
<thead>
<tr>
<th>Year</th>
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<th>Public</th>
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</thead>
<tbody>
<tr>
<td>2014</td>
<td>90%</td>
<td>81%</td>
</tr>
<tr>
<td>2015</td>
<td>89%</td>
<td>82%</td>
</tr>
<tr>
<td>2016</td>
<td>88%</td>
<td>78%</td>
</tr>
</tbody>
</table>

**DESPITE HIGH CONFIDENCE AND SATISFACTION, HEALTH PLAN RULES MAY DISRUPT TREATMENT**

39% of respondents who skipped or delayed an infusion in 2016 reported this being due to problems with their health insurance.

**WHAT DOES IT MEAN?**

Despite many persons with PI having high confidence in their insurance coverage and quality of healthcare, significant challenges remain.
From access to specialists, life-long therapies or drugs, the financial burden on persons with primary immunodeficiency diseases (PI) can be extreme. The Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and caregivers looked into current costs of care.

The Immune Deficiency Foundation (IDF), founded in 1980, is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency through advocacy, education and research.

The results of 2014, 2015 and 2016 Health Insurance Surveys are based on respondents connected with IDF and may represent those with better than average coverage and experience.

The financial burden on persons with PI due to healthcare and health insurance costs is high, with many forgoing important healthcare related treatments. An increasing number, despite having health insurance, turn to outside sources of support to pay for their healthcare related expenses.


Primary Immunodeficiency Diseases

Public Policy Impacts

As the Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and their caregivers show, many people are either taking actions or being forced to take actions that are detrimental to their health, as a direct result of health insurance policies, health insurance costs and the general cost of medical care.

Type of Health Insurance

Private

Any health insurance policy purchased by an employer or an individual from a private insurance company regardless of any public funding.

74%

26%

Public

An insurance plan or policy that is subsidized by federal or state funds and is administered by a public entity, such as Medicare, Medicaid and Tricare.

FINANCIAL BURDEN OF CARE

Annual medical expenses that require patients to spend more than 10% of their family’s total income are considered high burden.1, 2

Almost half of all families used more than 10% of their income to cover healthcare costs.

Confidence in ability to afford the needed care:

Since January 2016, were there times the person with PI had problems paying or was unable to pay for medical bills?

67% 70% 67% 67%

Private 2014 2015 2016

66% 68% 66% 66%

Public 2014 2015 2016

WHAT DOES IT MEAN?

In light of healthcare reform in the U.S., policy makers must consider the health and economic cost burdens placed on this vulnerable chronic disease population.

The results of 2014, 2015 and 2016 Health Insurance Surveys are based on respondents connected with IDF and may represent those with better than average coverage and experience.
