2014, 2015 and 2016
IDF National Health Insurance Surveys
Introduction

- The Patient Protection and Affordable Care Act (ACA) became law in March 2010. The goal of the law is to make healthcare more affordable and accessible for millions of Americans who either do not have access to or cannot afford health insurance.

- However, the decentralized nature of the healthcare marketplaces makes it difficult to project what types of issues or challenges persons with PI may face in obtaining their IgG therapy.

- In order to capture the impact ACA may have on those with PI, as well as to describe in general the health insurance experiences of those impacted by PI, IDF conducted a series of web-based surveys of persons with PI in our database in 2014, 2015 and 2016: IDF National Health Insurance Surveys.
Methodology

- The IDF Survey Research Team and other IDF Staff developed the IDF National Health Insurance Survey questionnaires. Each of the three individual surveys contained about 53 main questions, with an average completion time of approximately 25 minutes.

- The 2014, 2015 and 2016 IDF National Health Insurance Surveys were designed to measure how the ACA impacted public and private health insured persons with PI. Survey questions focused on:
  - Out of pocket costs, cost sharing, premium costs
  - Annual limits
  - Essential health benefits
  - Access to preferred therapy- product, site of care and mode of infusion
  - Ability to access specialists

Each of the survey study protocols were individual and independently reviewed by Schulman IRB Associates. All three surveys received exemptions from IRB review and approval.
Field Period and Completed Surveys

- IDF 2014 National Health Insurance Survey
  - In field: November 14, 2014 – December 4, 2014
  - 9,133 e-mail invitations delivered
  - 1,417 surveys completed

- IDF 2015 National Health Insurance Survey
  - In field: December 4, 2015 – December 31, 2015
  - 10,532 e-mail invitations delivered
  - 1,504 surveys completed

- IDF 2016 National Patient Survey
  - In field: November 30, 2016 – January 15, 2017
  - 11,198 e-mail invitations delivered
  - 1,414 surveys completed

The following slides will present data from the 2014, 2015 and 2016 IDF National Health Insurance Surveys
Topics

- **Type of Insurance Coverage and Access to Care**
- **Perception of Quality of Care**
- **Costs of Health Insurance**
- **Immunoglobulin Replacement Therapy**
- **General Health and Well-being**
- **Demographics**
- **Conclusions**
Type of Insurance Coverage and Access to Care
## Health Insurance by Type

<table>
<thead>
<tr>
<th>Type</th>
<th>% 2014 N=1402</th>
<th>% 2015 N=1481</th>
<th>% 2016 N=1395</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer sponsored group plan</td>
<td>57</td>
<td>55</td>
<td>52</td>
</tr>
<tr>
<td>COBRA</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Individual policy plan</td>
<td>7</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Medicare</td>
<td>10</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Medicare Supplemental</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Medicare Advantage</td>
<td>3</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Medicare due to disability</td>
<td>6</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Medicaid</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>SCHIP</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>State Exchange/Marketplace</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Federal Exchange/Marketplace</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>TRICARE</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Veterans Policy</td>
<td>0.2</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td>Not sure</td>
<td>0.6</td>
<td>0.5</td>
<td>0.4</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

In 2014, 2015 and 2016 over 98% of persons with PI with PI were insured

Q7b. What is this person's main type of health insurance?
Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private or Public Pay Health Insurance

<table>
<thead>
<tr>
<th>“Private Pay”</th>
<th>“Public Pay”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer sponsored</td>
<td>Medicare</td>
</tr>
<tr>
<td>COBRA</td>
<td>Medicare-disability</td>
</tr>
<tr>
<td>Individual policy</td>
<td>Medicaid</td>
</tr>
<tr>
<td>Medicare Supplemental</td>
<td>SCHIP</td>
</tr>
<tr>
<td>Medicare Advantage</td>
<td>TRICARE</td>
</tr>
<tr>
<td>State Marketplace</td>
<td>Veterans Policy</td>
</tr>
<tr>
<td>Federal Marketplace</td>
<td></td>
</tr>
</tbody>
</table>

Q7b. What is this person's main type of health insurance?
Base: All Insured Persons with PI, Other Insurance and Not Sure/Don't Know Insurance not included

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Had Problems Seeing Any Healthcare Specialists Due to Health Plan Rules

Q17a. Since January 2014/2015/2016 as a result of your health plan’s rules, has the person with PI had any problems seeing any healthcare specialists?

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Does the person have access to a PI Specialist

Q15a. Does this person have access to an immunologist who specializes in primary immunodeficiency
Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Why doesn’t the person have access to a PI Specialist

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Q15b. Why doesn’t this person have access to an immunologist who specializes in primary immunodeficiency?
Base: All Insured Persons with PI who Did Not Have Access to a PI Specialist

- Can’t find PI immunologist
- Immunologist is too far away
- Current Dr is sufficient
- Dr no longer covered by health insurance
- Dr not in health insurance network
- Other

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Why doesn’t the person have access to a PI Specialist
Private vs. Public

Q15b. Why doesn’t this person have access to an immunologist who specializes in primary immunodeficiency?

Base: All Private or Public Insured Persons with PI who Did Not Have Access to a PI Specialist

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Perception of Quality of Care
Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would receive high quality and safe medical care?

**Base:** All Private and Public Insured Persons with PI

**2014**
- Very or Somewhat Confident: 49%
- Somewhat Confident: 46%
- Not very confident: 10%
- Not at all confident: 3%

**2015**
- Very or Somewhat Confident: 46%
- Somewhat Confident: 41%
- Not very confident: 9%
- Not at all confident: 4%

**2016**
- Very or Somewhat Confident: 44%
- Somewhat Confident: 42%
- Not very confident: 11%
- Not at all confident: 3%

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private: Receive High Quality and Safe Medical Care

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Public: Receive High Quality and Safe Medical Care

2014 Very or Somewhat Confident: 81%
2015 Very or Somewhat Confident: 82%
2016 Very or Somewhat Confident: 78%
Very to Somewhat Confident Receive High Quality and Safe Medical Care

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Overall: Receive the Most Effective Drugs

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...
Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private: Receive the Most Effective Drugs

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Insured Persons with PI with Private Insurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Public: Receive the Most Effective Drugs

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Insured Persons with PI with Public Insurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would receive most effective drugs?

Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Overall: Receive the Best Medical Technology

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private: Receive the Best Medical Technology

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Insured Persons with PI with Private Insurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Insured Persons with PI with Public Insurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Base: All Private and Public Insured Persons with PI
Overall: Be Able to Afford the Care Needed

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would…

Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private: Be Able to Afford the Care Needed

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Base: All Insured Persons with PI with Private Insurance
Public: Be Able to Afford the Care Needed

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Base: All Insured Persons with PI with Public Insurance

2014 Very or Somewhat Confident: 66%
2015 Very or Somewhat Confident: 68%
2016 Very or Somewhat Confident: 66%
### Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

**Base: All Private and Public Insured Persons with PI**

<table>
<thead>
<tr>
<th>Year</th>
<th>Overall</th>
<th>Private</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>N=1361</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td></td>
<td>N=1062</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=299</td>
<td>66%</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>N=1444</td>
<td>70%</td>
<td>70%</td>
</tr>
<tr>
<td></td>
<td>N=1086</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=358</td>
<td>68%</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>N=1364</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td></td>
<td>N=1010</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=354</td>
<td>66%</td>
<td></td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Overall: Satisfaction with Quality of Healthcare Received

Q21. Overall, how would you rate your satisfaction with the quality of the healthcare the person with PI receives?

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Private: Satisfaction with Quality of Healthcare Received

Q21. Overall, how would you rate your satisfaction with the quality of the healthcare the person with PI receives?

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Public: Satisfaction with Quality of Healthcare Received

Q21. Overall, how would you rate your satisfaction with the quality of the healthcare the person with PI receives?

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Very to Somewhat Satisfied with Quality of Healthcare Received

Q21. Overall, how would you rate your satisfaction with the quality of the healthcare the person with PI receives?
Base: All Private and Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q7i. Please rate your satisfaction with the persons current health insurance coverage.

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
### Satisfaction with Private Health Insurance

<table>
<thead>
<tr>
<th>Year</th>
<th>Very or Somewhat Satisfied (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>86%</td>
</tr>
<tr>
<td>2015</td>
<td>82%</td>
</tr>
<tr>
<td>2016</td>
<td>86%</td>
</tr>
</tbody>
</table>

**Source:** IDF 2014, 2015 and 2016 Health Insurance Survey

Q7i. Please rate your satisfaction with the persons current health insurance coverage.

Base: All Insured Persons with PI with Private Insurance

![Bar chart showing satisfaction levels across years](chart.png)
Satisfaction with Public Health Insurance

Q7i. Please rate your satisfaction with the person's current health insurance coverage.
Base: All Insured Persons with PI with Public Insurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Very to Somewhat Satisfied with Health Insurance

Q7i. Please rate your satisfaction with the persons current health insurance coverage.
Base: All Private or Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Overall: Very to Somewhat Confident or Satisfied with...

Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q8. Do you know how much you pay for your health insurance premium each month?

Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Costs of Health Insurance
# Monthly Premium Cost

**Source:** IDF 2014, 2015 and 2016 Health Insurance Survey

**Q9.** Please tell us how much you pay for your health insurance premium(s) each month.  
**Base:** All Insured Persons with PI who Know the Amount of Their Monthly Premium

<table>
<thead>
<tr>
<th>Year</th>
<th>2014 N=1008</th>
<th>2015 N=1063</th>
<th>2016 N=1031</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average</strong></td>
<td>$413.53</td>
<td>$421.78</td>
<td>$446.90</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>$300.00</td>
<td>$300.00</td>
<td>$292.00</td>
</tr>
</tbody>
</table>
Knowledge of Yearly Deductible

Q10b. Do you know how much your health insurance deductible is?
Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
# Yearly Deductible

Q11. Please tell us how much your total yearly deductible(s) are for your insurance plan(s). Base: All Insured Persons with PI who Know the Amount of Their Yearly Deductible

<table>
<thead>
<tr>
<th></th>
<th>2014 N=866</th>
<th>2015 N=882</th>
<th>2016 N=857</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>$2018.51</td>
<td>$2134.60</td>
<td>$2155.99</td>
</tr>
<tr>
<td>Median</td>
<td>$1450.00</td>
<td>$1500.00</td>
<td>$1500.00</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q12. Does your insurance have a maximum out-of-pocket amount you must pay each year before your health insurance plan pays 100%?

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
### Max Out-of-Pocket

**Q13.** What is the maximum amount of your yearly, out-of-pocket expenses for healthcare?

**Base:** All Insured Persons with PI who Know the Amount of Their Max Out-of-Pocket Expenses

<table>
<thead>
<tr>
<th>Year</th>
<th>Average ($)</th>
<th>Median ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014 N=808</td>
<td>$4366.34</td>
<td>$4000.00</td>
</tr>
<tr>
<td>2015 N=819</td>
<td>$4688.52</td>
<td>$4290.00</td>
</tr>
<tr>
<td>2016 N=806</td>
<td>$4599.57</td>
<td>$4000.00</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Co-pay or Coinsurance for Ig Therapy

Q46. Do you currently have a co-pay for Ig therapy, or do you have coinsurance for Ig therapy? Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
### Monthly Cost for Ig Therapy

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>$223.10</td>
<td>$453.32</td>
<td>$346.20</td>
</tr>
<tr>
<td>Median</td>
<td>$69.00</td>
<td>$80.00</td>
<td>$100.00</td>
</tr>
<tr>
<td>Don’t Know the Cost</td>
<td>16%</td>
<td>23%</td>
<td>21%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coinsurance</th>
<th>2014 N=233</th>
<th>2015 N=190</th>
<th>2016 N=183</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>$651.71</td>
<td>$562.41</td>
<td>$573.61</td>
</tr>
<tr>
<td>Median</td>
<td>$333.00</td>
<td>$355.00</td>
<td>$300.00</td>
</tr>
<tr>
<td>Don’t Know the Cost</td>
<td>33%</td>
<td>43%</td>
<td>41%</td>
</tr>
</tbody>
</table>

**Q47a.** How much is your monthly co-pay for Ig therapy treatment?  
Base: All Insured Persons with PI Currently Receiving Ig Therapy who Have a Co-pay

**Q48c.** How much do you have to pay for the person's coinsurance for each month of Ig therapy treatment?  
Base: All Insured Persons with PI Currently Receiving Ig Therapy who Have Coinsurance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q28a. Since January 2014/2015/2016/2016, were there times the person (or parent/caregiver of the person) with PI had problems paying or was unable to pay for medical bills?
Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Since January 2014/2015/2016, was there any time when the person ____ because of out-of-pocket costs?

Base: All Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
### Actions Taken in Order to Pay for Healthcare

<table>
<thead>
<tr>
<th>Action</th>
<th>2014 N=1402</th>
<th>2015 N=1481</th>
<th>2016 N=1395</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spent less on entertainment</td>
<td>52%</td>
<td>47%</td>
<td>50%</td>
</tr>
<tr>
<td>Used credit card more often</td>
<td>40%</td>
<td>37%</td>
<td>39%</td>
</tr>
<tr>
<td>Spent less on family</td>
<td>40%</td>
<td>36%</td>
<td>38%</td>
</tr>
<tr>
<td>Spent less on groceries</td>
<td>33%</td>
<td>30%</td>
<td>32%</td>
</tr>
<tr>
<td>Postponed paying other bills</td>
<td>33%</td>
<td>31%</td>
<td>29%</td>
</tr>
<tr>
<td>Applied for government assistance</td>
<td>11%</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Took out a loan to pay medical bills</td>
<td>7%</td>
<td>6%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Q27. Since January 2014/2015/2016, have you done any of the following in order to pay for the person’s healthcare costs. Base: All Insured Persons with PI
Q17b. Since January 2014, as a result of your health plan’s costs sharing, has the person with PI had any problems affording visits to any healthcare specialists?

Base: All Private or Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Other Insurance Issues

Pay MORE for Co-pays

- 2014: 44% (N=270)
- 2015: 45% (N=277)
- 2016: 36% (N=274)

Pay HIGHER PERCENT for Coinsurance

- 2014: 29% (N=354)
- 2015: 25% (N=338)
- 2016: 21% (N=316)

Receiving Financial Assistance

- 2014: 15% (N=257)
- 2015: 20% (N=277)
- 2016: 28% (N=259)

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Q47b. Since September 2013/2014, what changes, if any, have you experienced in the amount of the co-pays for the Ig therapy?

Q48d. Since January of 2014/2015/2016, what changes, if any, have you experienced in the percent of coinsurance you have to pay?

Q50a. Is the person with PI currently receiving any financial assistance for co-pay, coinsurance or health insurance premium expenses?

Base: All Insured Persons with PI Currently Receiving Ig Therapy
Financial Burden: >10% of Household Income Spent on Healthcare

Financial Burden
Base: All Private or Public Insured Persons with PI

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q50b. What type of organization gives the person assistance and what type of payment do they help with?
Base: All Insured Persons with PI Currently Receiving Ig Therapy who Receive Financial Assistance

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Immunoglobulin Replacement Therapy
Q42. Does the person’s insurance plan cover both SCIG and IVIG?  
Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Health Plans and Dosage Limitations

Q44. Does the person's health insurance limit the amount of grams of immunoglobulin the patient receives, or does the patient receive the FULL amount of immunoglobulin prescribed by the doctor? Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Q51a. Since January 2014, due to health plan rules, has the person ever had a problem in getting his/her regular infusion?
Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Due to Health Plan Rules...

Q51b. Since January 2014, which of the following events, if any, has the person experienced due to health plan rules? Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Delayed or Skipped Ig Therapy in Past Year

Q45a. Since January 2014/2015/2016, has there been a time when the person skipped or delayed their Ig therapy?
Base: All Insured Persons with PI Currently Receiving Ig Therapy

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Reasons Why Ig Therapy was Delayed or Skipped in Past Year

Q45c. What reason(s) did the person with PI have for skipping or delaying their Ig therapy? Base: All Insured Persons with PI Currently Receiving Ig Therapy Whom Delayed or Skipped Ig therapy in the Past Year

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
General Health and Well-being
**General Health**

**Adults with PI**
- 2015: N=1167
- 2016: N=1146

2015 Excellent to Very Good: 17%
2016 Excellent to Very Good: 16%

**Children with PI**
- 2015: N=337
- 2016: N=268

2015 Excellent to Very Good: 34%
2016 Excellent to Very Good: 34%

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Q1a_pt. In general, would you say your health is: . . . .
Q1a_chld. In general, would you say their health is: . . . .
Base: All Respondents
Quality of Life

Source: IDF 2014, 2015 and 2016 Health Insurance Survey

Q1b_pt. In general, would you say your quality of life is: . . . .
Q1b_chld. In general, would you say their quality of life is: . . . .

Base: All Respondents

Adults with PI
- 2015 Excellent to Very Good: 29%
- 2016 Excellent to Very Good: 29%

Children with PI
- 2015 Excellent to Very Good: 46%
- 2016 Excellent to Very Good: 49%

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Physical Health

Q1c_pt. In general, how would you rate your physical health? . . . .
Q1c_chld. In general, how would you rate their physical health? . . . .
Base: All Respondents

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Mental and Emotional Well-being

Q1d.pt. In general, how would you rate your mental health, including your mood, and your ability to think? . . . . .

Q1d.chld. In general, how would you rate their mental health, including their mood, and their ability to think? . . . . .

Base: All Respondents

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
### Demographics: Age and Gender

<table>
<thead>
<tr>
<th>Age</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 14</td>
<td>11%</td>
<td>10%</td>
<td>8%</td>
</tr>
<tr>
<td>15 to 24</td>
<td>12%</td>
<td>11%</td>
<td>9%</td>
</tr>
<tr>
<td>25 to 34</td>
<td>9%</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>35 to 44</td>
<td>12%</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>45 to 54</td>
<td>19%</td>
<td>19%</td>
<td>20%</td>
</tr>
<tr>
<td>55 to 64</td>
<td>22%</td>
<td>24%</td>
<td>27%</td>
</tr>
<tr>
<td>65+</td>
<td>14%</td>
<td>16%</td>
<td>18%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>31%</td>
<td>28%</td>
<td>27%</td>
</tr>
<tr>
<td>Female</td>
<td>68%</td>
<td>71%</td>
<td>73%</td>
</tr>
<tr>
<td>Other</td>
<td>0.1%</td>
<td>0.3%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Refused</td>
<td>1%</td>
<td>0.4%</td>
<td>0.1%</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
## Demographics: Race/Ethnicity and Location

### Race or Ethnicity

<table>
<thead>
<tr>
<th>Race or Ethnicity</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian/Alaskan Native</td>
<td>1%</td>
<td>1%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0.4%</td>
<td>0.4%</td>
<td>1%</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>2%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>92%</td>
<td>92%</td>
<td>91%</td>
</tr>
<tr>
<td>Two or more races</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

### Location

<table>
<thead>
<tr>
<th>Location</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast</td>
<td>17%</td>
<td>18%</td>
<td>16%</td>
</tr>
<tr>
<td>Midwest</td>
<td>24%</td>
<td>24%</td>
<td>26%</td>
</tr>
<tr>
<td>South</td>
<td>36%</td>
<td>37%</td>
<td>37%</td>
</tr>
<tr>
<td>West</td>
<td>22%</td>
<td>21%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
# Demographics: Employment

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>46%</td>
<td>43%</td>
<td>42%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>9%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Unemployed, looking for work</td>
<td>3%</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Student</td>
<td>5%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3%</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>Disabled/too ill to work</td>
<td>19%</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>Retired</td>
<td>13%</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>3%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
## Demographics: PI Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=1417</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agammaglobulinemia</td>
<td>5%</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Ataxia Telangiectasia</td>
<td>0%</td>
<td>0%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Chronic Granulomatous Disease</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Common Variable Immunodeficiency</td>
<td>61%</td>
<td>63%</td>
<td>62%</td>
</tr>
<tr>
<td>Combined Immunodeficiency</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Complement Deficiency</td>
<td>0.4%</td>
<td>1%</td>
<td>0.4%</td>
</tr>
<tr>
<td>DiGeorge Anomaly</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0%</td>
</tr>
<tr>
<td>Hereditary Angioedema</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0%</td>
</tr>
<tr>
<td>Hyper IgE Syndrome</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Hyper IgM Syndrome</td>
<td>0.4%</td>
<td>0.3%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Hypogammaglobulinemia</td>
<td>11%</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td>IgG Subclass Deficiency</td>
<td>7%</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Selective IgA Deficiency</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Severe Combined Immunodeficiency</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Severe Congenital Neutropenia</td>
<td>0%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Specific Antibody Deficiency</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Wiskott-Aldrich Syndrome</td>
<td>0.4%</td>
<td>0.3%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Not Sure/ Do Not Know</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Source: IDF 2014, 2015 and 2016 Health Insurance Survey
Conclusions
Take Away

- Between 2014, 2015 and 2016, IDF members have remained relatively well insured and are still generally satisfied with the healthcare they receive; however…
  - Substantial minority of persons have issues with access to care and affording access to care
  - Those with private insurance report more confidence in access to care and satisfaction with care received
  - Close to 50% of households are spending more than 10% of their household income on Healthcare expenses
  - Healthcare costs have risen for persons with PI since 2014
  - Additionally, reliance on financial assistance has risen as well since 2014
Thank You!