

Health Insurance & Primary Immunodeficiency Diseases:

A 2014 Immune Deficiency Foundation Survey



iDF Immune
Deficiency
Foundation

About the Immune Deficiency Foundation and Primary Immunodeficiency Diseases

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 disease (PI) through advocacy, education and research. There are approximately 250,000 people who are diagnosed with PI in the US¹, and thousands more go undetected.

Governed by a Board of Trustees – and supported by a Medical Advisory Committee comprised of some of the world's leading clinical immunologists, as well as hundreds of grassroots volunteers and a compassionate, professional staff – IDF has provided individuals and their families with vital knowledge by:

- Helping the patient and medical community gain a broader understanding of PI through education and outreach efforts;
- Promoting, participating, and funding research that has helped characterize PI and given patients and physicians substantially improved treatment options;
- Addressing patient needs through public policy programs by focusing on issues such as insurance reimbursement, patient confidentiality, ensuring the safety and availability of immunoglobulin therapy, and maintaining and enhancing patient access to treatment options.

Contributors to this Report

The 2014 IDF National Health Insurance Survey was designed and implemented by the staff at the Immune Deficiency Foundation with consulting and analysis support from C. Alan Lyles, M.P.H., Sc.D., Senior Research Associate of the Schaefer Center for Public Policy. Principals include Christopher Scalchunes, M.P.A., Vice President of Research IDF; Mrs. Marcia Boyle, President & Founder IDF; Tiffany Henderson, Ph.D., Survey Research Analyst IDF; and, Lawrence LaMotte, M.P.A., Vice President Public Policy IDF.

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Background

Primary immunodeficiency diseases (PI) represent a group of more than 300 rare, chronic, genetic, diseases in which there is a defect in the human immune system. The human immune system is a network of many different, interrelated, processes and components that work together to provide defense against infection. To function properly, the immune system must detect and protect against a wide variety of pathogens—viruses, bacteria and fungi. The immune system also must be able to distinguish foreign pathogens from a body's own tissues which need to be protected. When any component or part of this process is absent or does not function properly the result is a susceptibility to severe, persistent, unusual or recurrent infections². Unfortunately, far too many patients are not diagnosed and treated for their PI prior to the onset of permanent functional impairments caused by these infections³. These impairments must be addressed and treated on their own accord in addition to the underlying primary immunodeficiency. The various treatments for PI diseases include immunoglobulin (Ig) replacement therapy, bone marrow transplantation, gene therapy, and gamma interferon treatments.

Frequently, primary immunodeficiency diseases are complicated by autoimmune and inflammatory conditions. It is recognized that different forms of PI have been linked to specific autoimmune complications, such as inflammatory bowel disease, thrombocytopenia, rheumatoid arthritis and dermatomyositis^{4,5}.

Healthcare utilization for this population tends to be high, with correspondingly high medical and health insurance related costs.

Given these circumstances, healthcare utilization for this population tends to be high, with correspondingly high medical and health insurance related costs. The financial burden on patients with these diseases can often be extreme. For many, these diseases and co-morbid conditions necessitate multiple visits to numerous specialists, along with a dependency on life-long therapies or drugs that are needed to keep the patient healthy and maximize patient health outcomes⁶.

As such, the primary immunodeficient community is vulnerable to changes or disruptions in how healthcare is delivered and paid. Recent history suggests that even small changes to healthcare or health insurance policies can have a negative impact on those with PI. In 2006 the Immune Deficiency Foundation (IDF) conducted three different national surveys in order to quantify reports from patients and healthcare providers that Medicare reimbursement for intravenous immunoglobulin (IVIG) was insufficient. These surveys included a national survey of patients from the IDF database, a survey of hospital pharmacists, and a national survey of immunologists conducted with the American Academy of Asthma, Allergy and Immunology (AAAAI). The results from these surveys indicated that Medicare recipients had more difficulty obtaining IVIG infusions and suffered more health problems than patients with private insurance⁷.

Recent history suggests that even small changes to healthcare or health insurance policies can have a negative impact on those with PI.

With the passage of the Affordable Care Act into law, many of its provisions are of benefit to those with PI. However, some outcomes and policies may have unintended consequences, not only for those insured under the Federal or State Marketplaces but also those insured through private health insurance. The decentralized nature of the healthcare marketplaces and far-reaching changes to healthcare under ACA make it difficult to project what types of issues or challenges patients may face.

In order to capture what impact the ACA may have on patients, IDF decided to conduct a survey of patients in our database for 2014, 2015 and 2016. It is our hope that the data from this series of surveys will help better inform policymakers as to the experience of those in the primary immunodeficiency community, as healthcare reform evolves over the next few years. Findings from the 2015 and 2016 Health Insurance surveys will be discussed in a later report; this report describes our findings from the 2014 survey.

Survey Methodology

The survey questionnaire was developed by IDF staff in consultation with Dr. Alan Lyles and with Hart Health Strategies, IDF's public policy consultant. An online survey research instrument was developed, piloted, refined and fielded. All self-identified patients and caregivers of patients with PI in IDF's patient database with a valid e-mail address (N=9,133) received an email invitation on November 14, 2014 to participate. A reminder e-mail was sent to non-respondents on November 20, 2014 and a final request sent November 26, 2014. A total of 1,417 surveys were completed, 149 surveys were partially completed, 32 respondents only answered the first or second question and 20 indicated they were not a person or a caregiver of person with a primary immunodeficiency disease. Only the data collected from the 1,417 completed surveys will be reported.

Demographics

A strong majority (73%) of the respondents with valid data was provided by the person with a primary immunodeficiency, while *parent/caregiver* respondents represented a substantial percentage (24%), with *Both* being less common (3%).

Survey respondents were geographically dispersed: South (36%), Northeast (17%), and approximately equal numbers in the Midwest (24%) and West (22%). Respondents were predominately female (68%) and represented a broad span of ages (average = 43.5 years). Age when diagnosed with a PI is bimodal, with 25% being 13 years or younger, half being 37 or younger and 25% being above age 51. A majority of the survey sample is White, non-Hispanic (92%) with modest representation by other race/ethnicities.

Few respondents were unemployed and looking for work (3%), though 19% were *Disabled/Too ill* to work and 13% were *Retired*. They were 55% *Employed* (46% full-time and 9% part-time). As a group, the respondent sample is better educated than the general US population⁸. Ninety percent have some education beyond high school (vs. 58% for the general population), 54% started or completed college (vs. 47% for the general population) and 36% have graduate and/or professional degrees (vs. 12% for the general population) (Appendix 1.0).

Ninety-five percent of the 1,417 persons who provided responses indicated a specific PI diagnosis, most commonly Common Variable Immunodeficiency (61%), then Hypogammaglobulinemia (11%), IgG Subclass Deficiency (7%) or Agammaglobulinemia (5%).

Key Findings: Type of Insurance Coverage

Just 1% of the 1,417 respondents who provided an answer reported that the person with PI in their household currently does not have health insurance. Those without insurance reported "the policies the patient can have are too expensive" (n=8) or "[the patient] had insurance but lost it" (n=4). This is in strong contrast to the experience of the U.S. population as a whole, in which 16.3% of adults were uninsured at the time of interview in 2014.

There was a low general level of understanding rules on coverage policies obtained through an Insurance Exchange. This is likely due to the high level of existing coverage in the surveyed population and low knowledge generally of insurance coverage specifics. Of the 25 respondents that indicated they had coverage through a State Insurance Exchange, 24 indicated the type of metal plan (Platinum n=7; Gold n=5; Silver n=7; Bronze n=2). The results are small and similar with the 16 indicating a Federal Insurance Exchange (Platinum n=3; Gold n=7; Silver n=4; Catastrophic n=1; Don't Know/Not Sure n=1).

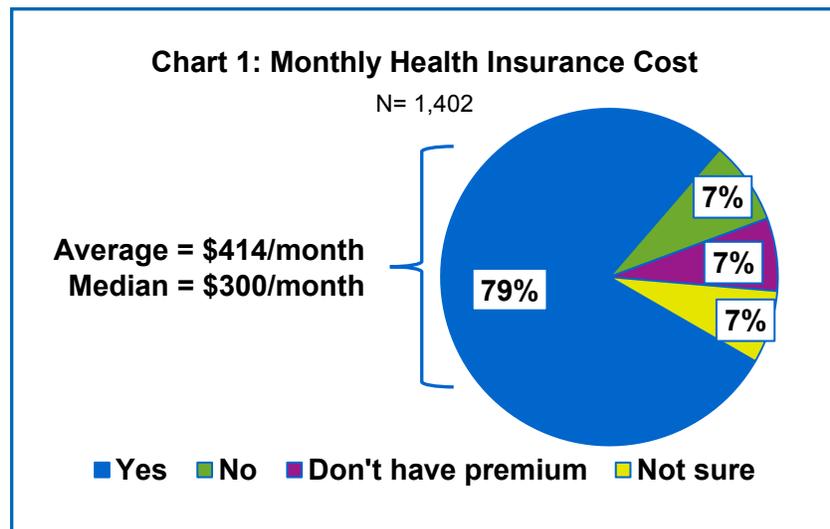
The most common source from which the patient receives health insurance coverage is an Employment-Based Family Plan (37%), then Employment-Based Individual Only (17%), then Government Health Insurance (16%). Just 6% purchase their policy directly from an insurance company. The main type of health insurance is quite varied (**Table 1**), with most having an employer sponsored group plan (57%) and few having their insurance through an Insurance Exchange (3%). These findings demonstrate patients in the IDF database are active participants in insurance market and generally have not obtained insurance through the Affordable Care Act Exchanges.

Table 1 Type of Insurance	%
Employer Sponsored	57
COBRA	3
Individual policy plan	7
Medicare*	10
Medicare Supplemental	2
Medicare Advantage	3
Medicare Disability*	6
Medicaid*	3
SCHIP*	1
State Exchange/Marketplace	2
Federal Exchange/Marketplace	1
TRICARE*	2
Veterans Policy*	0.2
Not sure	1
Other	2
* = "public pay"	

Key Findings: Costs of Health Insurance

The distribution for those reporting a value for their monthly premium is skewed right, meaning many pay above the average amount for their premiums. The median monthly payment of health insurance premiums was \$300, though 25% of respondents pay above \$500 per month (**Chart 1**). These amounts are consistent with nationally reported premium data for employer-based health insurance, although the national data show variations between HDHP/SO (lower) and HMO, PPO and POS products⁹. Premiums are, however, only part of the total patient cost responsibilities and can be misleading – the total of premiums, deductibles and cost-sharing (co-payment and/or coinsurance) is the relevant amount.

For those who did report how much their total annual deductible(s) was for their insurance plan(s), the range is from \$1 - \$20,000. For half, the deductible was \$1,450 or less but for 25% the deductible was at least \$3,000 (**Chart**

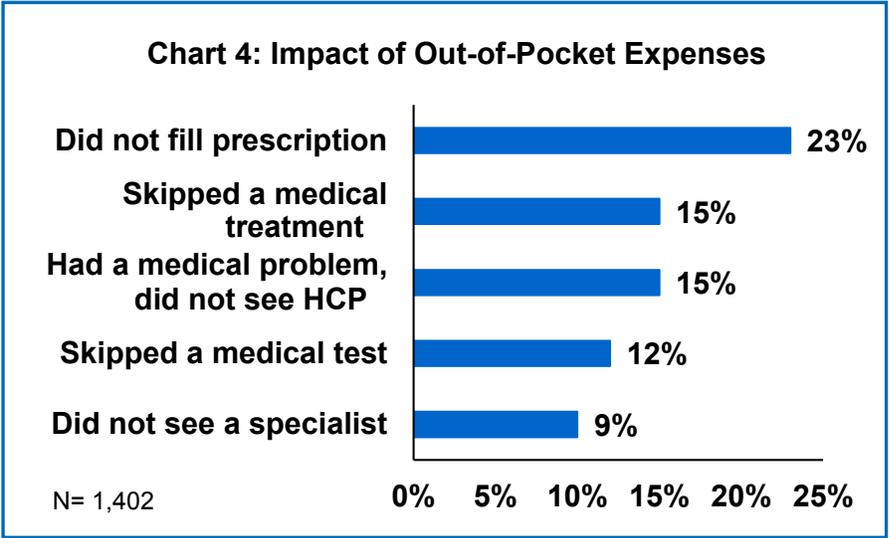
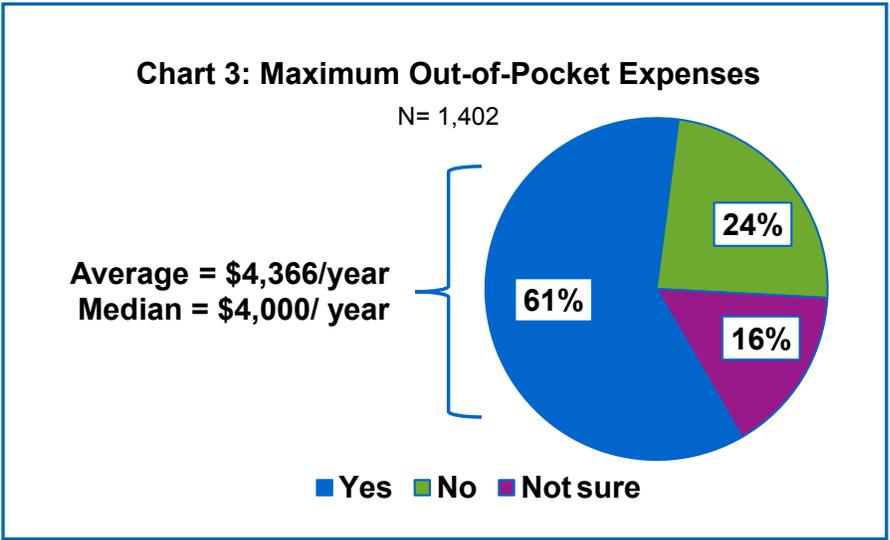
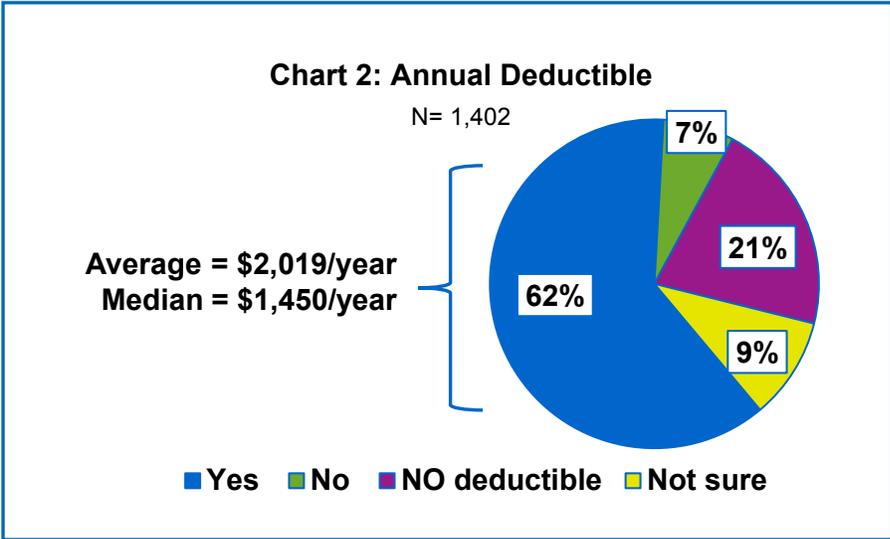


2). On average these amounts are comparable to those reported nationally for employer-based health insurance, though the higher amounts reported by IDF respondents exceed the average by a substantial amount.

The 808 who reported a "maximum amount of your annual, out-of-pocket expenses for healthcare" ranges from \$0 - \$25,000, with 50% having \$4,000 or more (**Chart 3**).

Out-of-pocket costs influenced respondents' demand for medical

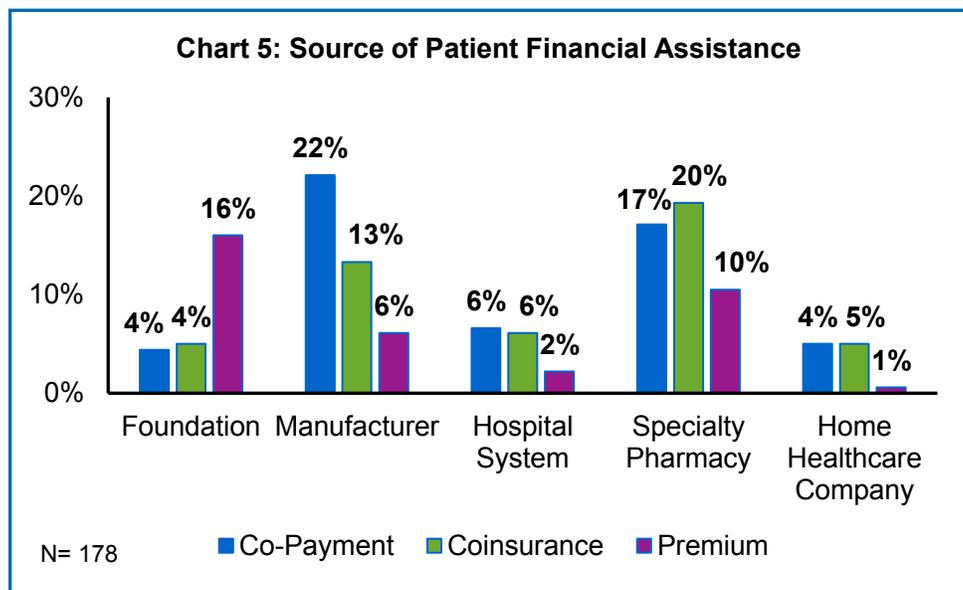
services. When asked about specific types of deferred or reduced use of medical services, almost one-quarter (23%) reported not filling or refilling a prescription. From 12 to 15% reported skipping a medical test (12%), skipping a medical treatment recommended by a doctor (15%) or having had a medical problem but did not go to a medical doctor or clinic (15%) (**Chart 4**).



These findings are comparable with national results from the Commonwealth Fund’s Biennial Health Insurance Survey, 2014; however, the consequences for a community of persons with primary immunodeficiency can be both more severe and costlier¹⁰.

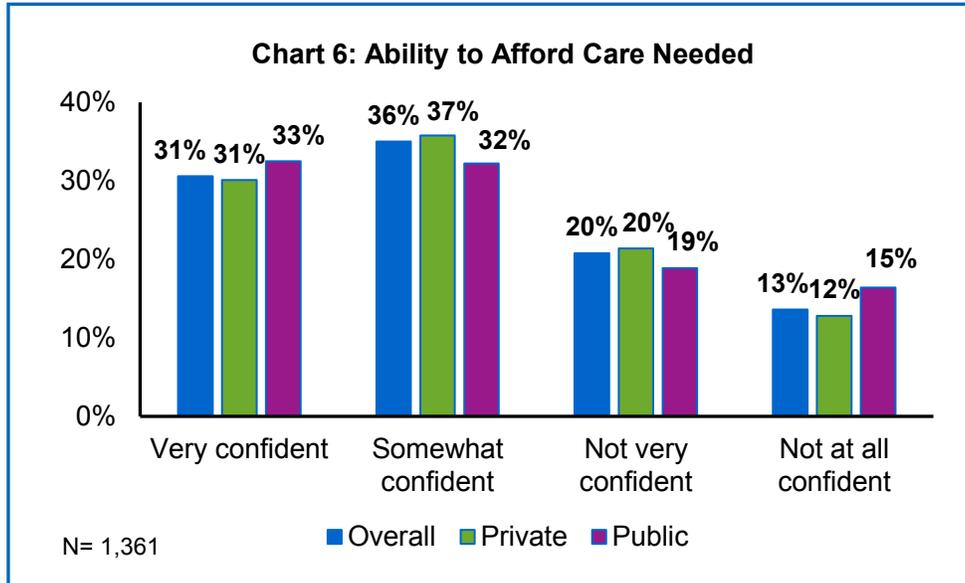
The continuing rise of high deductible health insurance suggests that total cost-sharing by persons insured under employer policies will also rise.

The increase in health insurance cost has forced many patients to seek financial assistance. Information on financial assistance for the person with PI was reported by 83% of the sample. Of those, 15% reported receiving some type of financial assistance (n=178). For respondents who reported that the person with PI is currently receiving financial assistance for co-pay, coinsurance or health insurance premium expenses, most often, when provided, comes from a Manufacturer or Specialty Pharmacy (**Chart 5**).



Affordability of the Care Needed: The experience and concerns among respondents is reflected in the large proportion who believe a serious illness might be unaffordable. Although 67% continued to be confident, they were less confident that they would be able to afford the care needed. More than with the other three questions in this series, 33% were either *Not very confident* (20%) or *Not at all confident* (13%) that they would be able to afford the care needed (**Chart 6**).

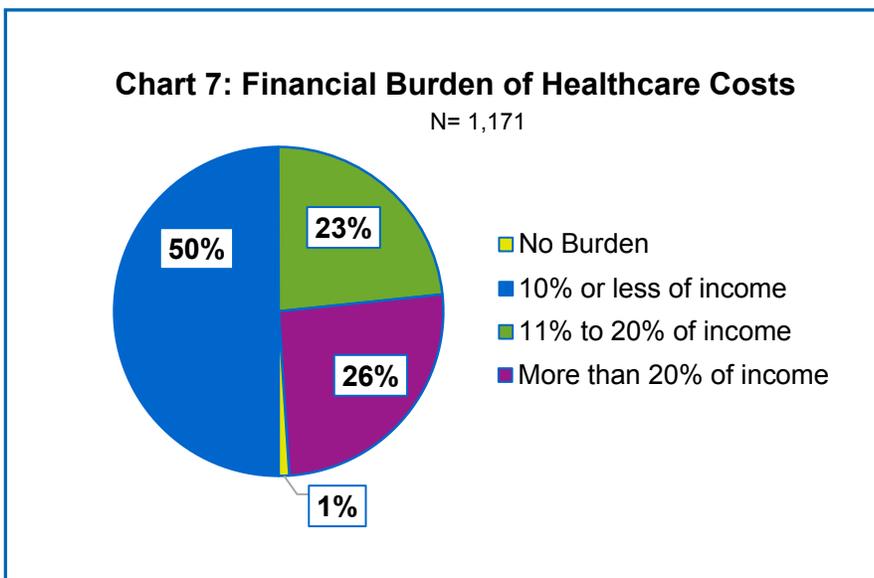
These trends are worrisome as almost 36% of respondents reported having problems paying or were unable to pay medical bills. Since January 2014, 28 respondents had to declare bankruptcy due to the person’s medical bills.



Financial Burden of Healthcare: Even with health insurance, many families still shoulder a large burden of out-of-pocket costs to pay for the care they need. For this reason, the financial burden of out-of-pocket medical costs were examined. In the 2014 IDF National Health Insurance Survey, information about each patient’s monthly premium, monthly co-pay or coinsurance for immunoglobulin therapy and maximum out-of-pocket annual expenses were collected. Additionally, the range for the patient’s household income was obtained (e.g., \$0 to \$24,999; \$50,000 to \$74,999). The formula to determine the financial burden of healthcare is below:

$$\begin{array}{l}
 \text{Annual Medical Expenses} \\
 \text{(e.g., premium, co-pay or coinsurance for therapy, out-of-pocket costs)}
 \end{array}
 \div
 \text{Annual Income}
 =
 \text{Financial Burden of Healthcare}$$

Annual medical expenses are divided by annual income and the resulting value is the portion of family income that pays for the patient’s healthcare. Annual medical expenses that require patients to spend more than 10% of their family’s total income are considered *high burden*^{11,12}. Using the average of each income range to approximate

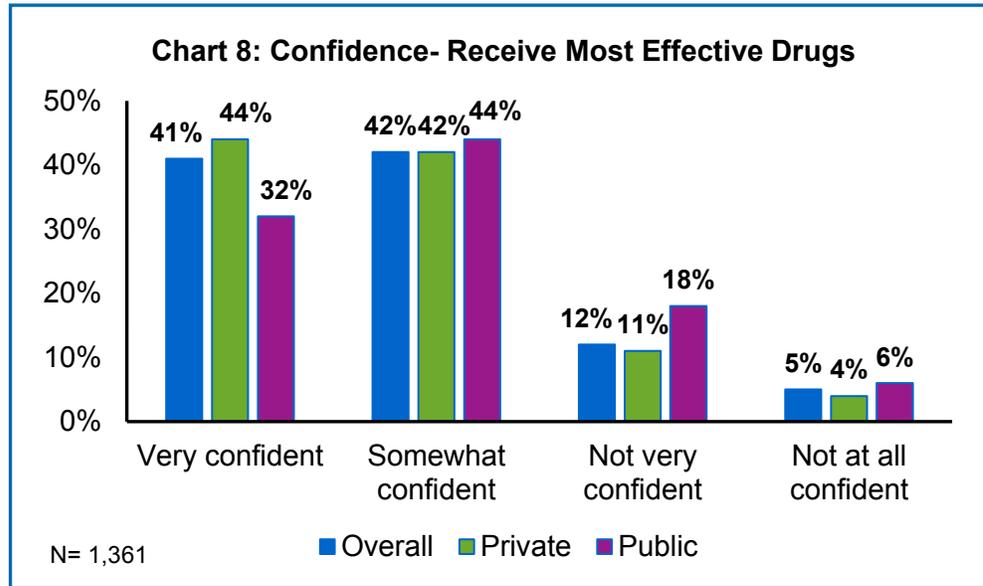


each patient’s family income, together with the patient’s reported medical expenses, the financial burden of healthcare was determined (**Chart 7**). Close to half of all patients’ (49%) medical expenses are more than 10% their family’s total income (11% to 20% of income, 23%; more than 20% of income, 26%). Exactly 50% of patient medical expenses are 10% or less of their family’s income. Only 1% of patients experience no financial burden due to healthcare costs.

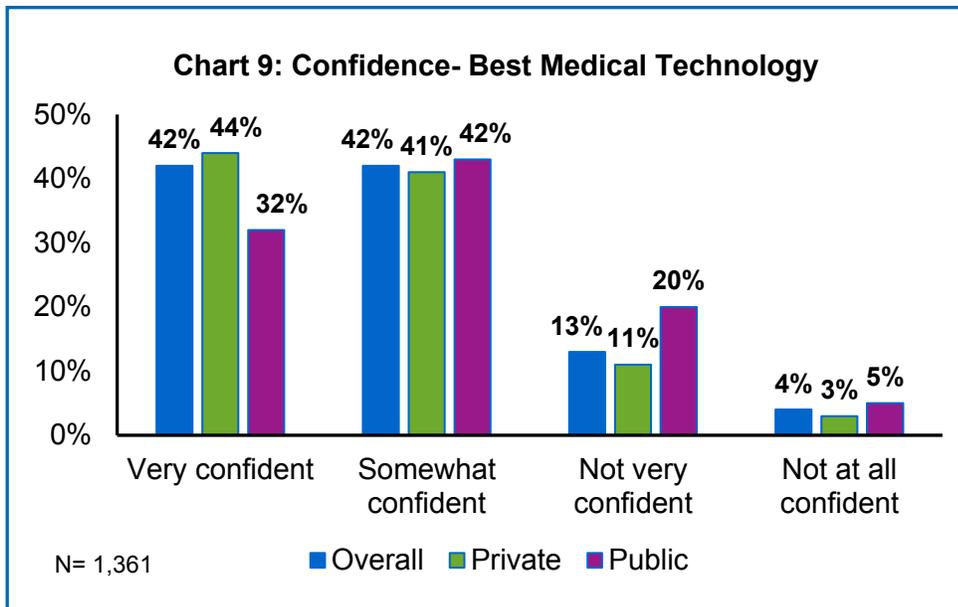
Key Findings: Perception of Quality of Care

Most Effective Drugs:

A minority of respondents (17%) were *Not very confident* or *Not at all confident* that they would receive the most effective drugs but the overwhelming majority (83%) were either *Very confident* (41%) or *Somewhat confident* (42%) that they would receive the most effective drugs. When the insurance source is



considered, the average confidence that the patient with PI would receive the most effective drugs differs. Privately insured are slightly better than *Somewhat confident* but persons receiving insurance from Government sources were between *Somewhat confident* and *Not very confident* (**Chart 8**).

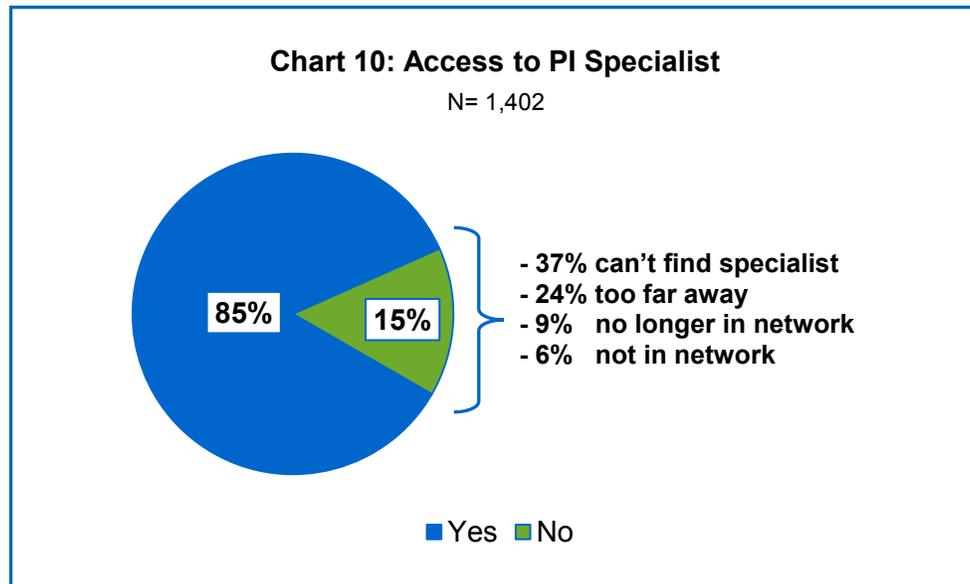


Best Medical Technology:

The majority (84%) was confident whereas 17% lacked confidence. Thirteen percent were either *Not very confident* or *Not at all confident* (4%). Privately insured are slightly better than *Somewhat confident*, but persons receiving insurance from Government sources were between *Somewhat confident* and *Not very confident* (**Chart 9**).

Access to Specialty Care:

A substantial majority of respondents (85%) have access to an immunologist who specializes in primary immunodeficiency (**Chart 10**). This immunologist is in-network for 87% of them, out-of-network for 7%, and 6% did not know or were unsure.



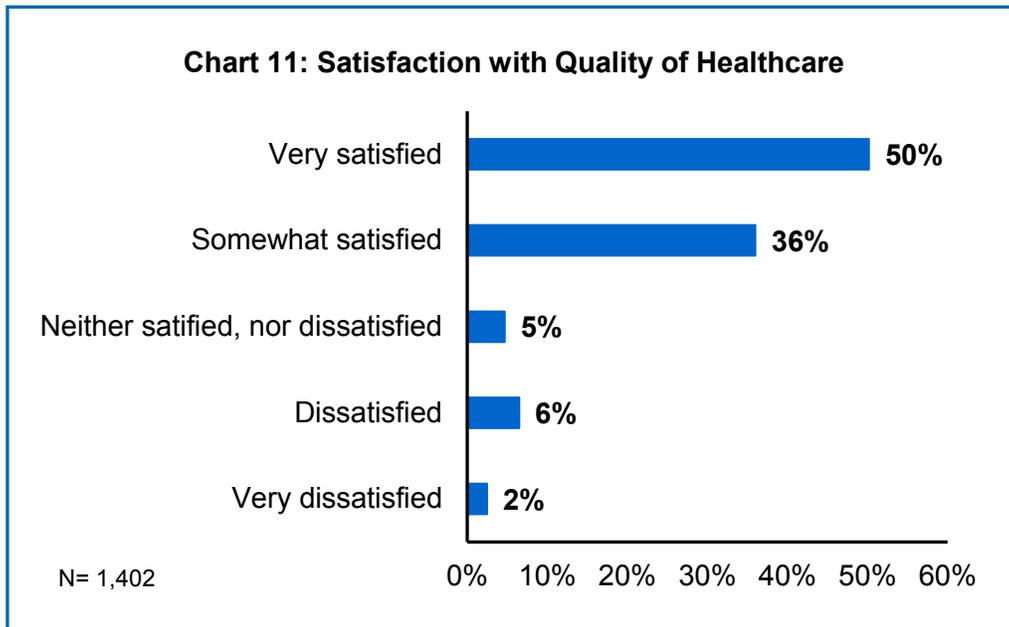
For those not having access to an immunologist who specializes in primary immunodeficiency, the leading reasons why they do not were *Can't find an immunologist who specializes in primary immunology* (37%), followed by *The immunologist is too far away to be convenient* (24%) and *The immunologist is no longer covered by health insurance* (9%). 187 (13%) of respondents reported that the patient with PI has had problems seeing a healthcare specialist since January 2014. Additionally, 294 (21%) reported that as a result of their health plan's cost-sharing rules, the person with PI has had problems affording visits to healthcare specialist.

These responses indicate that even though the patient with PI is mostly able to see healthcare specialists, there are problems with affording that access.

21% of the respondents reported that as a result of their health plan's cost-sharing rules, the person with PI has had problems affording visits to healthcare specialists.

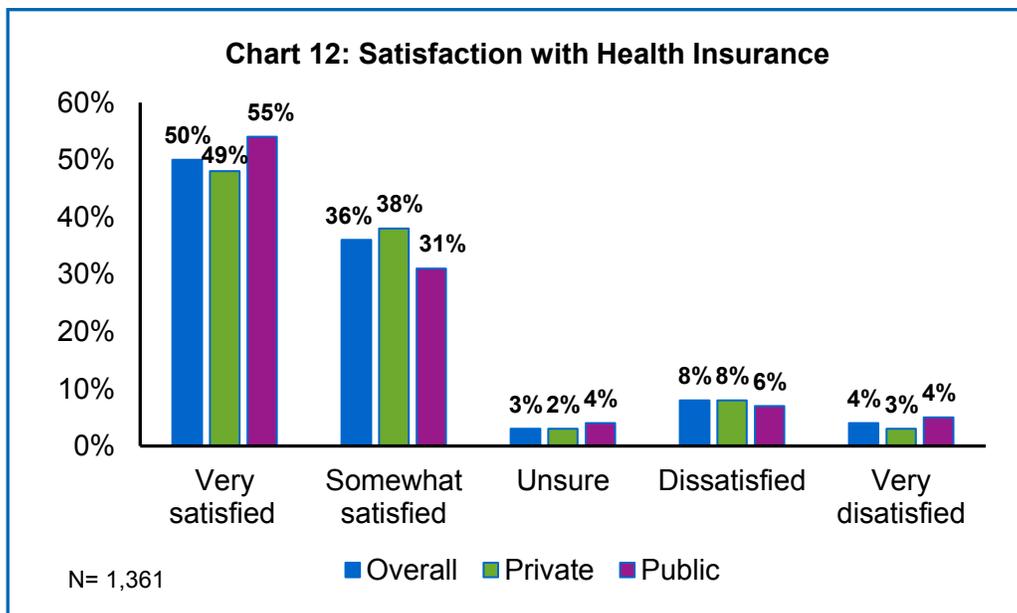
Satisfaction with the Quality of Healthcare:

86% were either *Very satisfied* (50%) or *Somewhat satisfied* (36%) with the quality of the healthcare the person with PI receives, while 9% of respondents were either *Dissatisfied* (6%) or *Very dissatisfied* (2%) (**Chart 11**).



Satisfaction with Health Insurance:

A November 2014 Gallup Poll reported that nationally 70% of persons with health insurance were satisfied with the healthcare system, whereas only 37% of those without health insurance were satisfied. For IDF Survey respondents, 86% reported that they were *Somewhat* (36%) or *Very satisfied* (50%) with their health insurance. However, 12% were either *Dissatisfied* (8%) or *Very dissatisfied* (4%) with their health insurance. There was more satisfaction with privately purchased health insurance (rated slightly above *Somewhat satisfied*) than with government-sourced health insurance. (Chart 12).

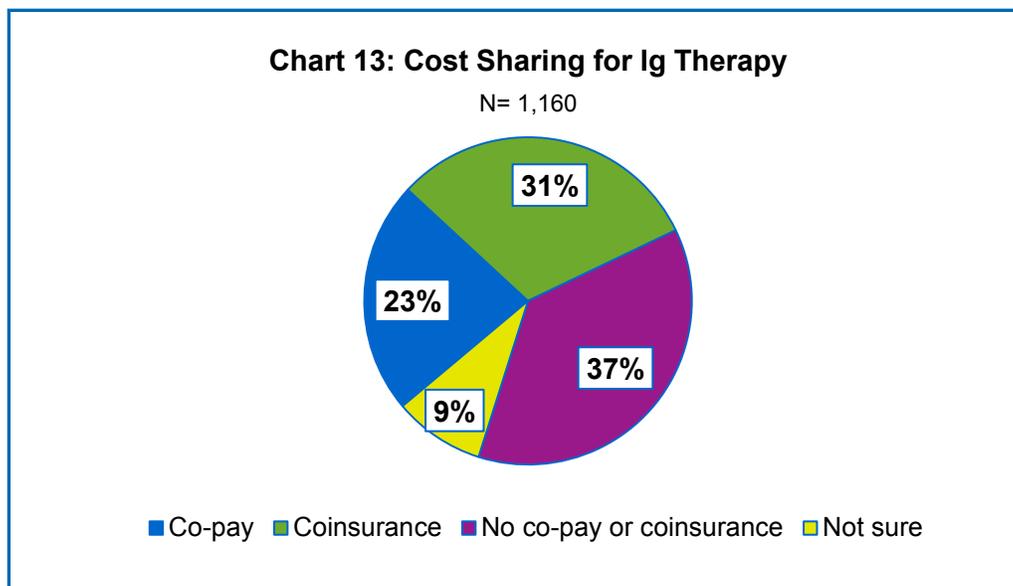


Key Findings: Immunoglobulin Replacement Therapy

An overwhelming majority (87%) of persons with PI reported being treated with immunoglobulin (Ig) replacement therapy for at least 6 months and of those, 95% (n=1,160) reported they were currently receiving Ig replacement therapy. Ig replacement therapies included intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG) and intramuscular immunoglobulin (IM) therapies. Eighty-three percent of the sample indicated a large gap in understanding their health benefits for immunoglobulin (Ig) therapy. When asked “Do you know if the person’s immunoglobulin prescription is covered under the health insurance plan’s medical benefit or pharmacy benefit”, 31% responded with *Don’t Know/Not Sure*. For 50% it is covered under the Medical Benefit and for 19% it is under the Pharmacy Benefit. Similarly, when asked if the person with PI’s insurance plan covered both SCIG and IVIG, 39% chose *Don’t Know/Not Sure*. Both SCIG and IVIG were covered for 59% of responders, but for 3% of patients both therapies were not covered.

A substantial minority of respondents (23%) reported *Moderate* and *Serious* problems understanding their health insurance prescription medicine benefits for their 2014 coverage.

Although 9% report not knowing whether they have a co-pay or coinsurance for the Ig therapy, 37% reported that they do not. For those who do have cost-sharing, 31% have coinsurance and 23% have co-payments (**Chart 13**).



When asked about the amount of their monthly co-payments, 16% selected *Don’t Know/Not Sure*. Five people chose zero as their co-payment amount and 8 chose \$10 or less. Excluding the zero amounts, the range was from \$1 - \$7,000, the average monthly co-payment was \$228.14 and 50% paid \$75 or less while 25% paid monthly co-payments of at least \$150 (**Table 2**).

Table 2: Monthly Cost of Ig Therapy

	Co-pay*	Coinsurance*
Minimum	\$1	\$15
Maximum	\$7,000	\$6,000
Average	\$228.14	\$748.02
Median	\$75.00	\$400.00
Don't know cost	16%	32%

* Zero values excluded

For those reporting having coinsurance payments, 60% of respondents indicated having a 20% coinsurance payment. Almost three-quarters of the respondents (73%) reported coinsurance of 20% or less. However, 5% of respondents pay more than 30% for their coinsurance.

An almost equal percent of respondents with co-payments (n=270) reported they pay more since September 2013 (44%) or that there have been no changes in co-payments (41%). About 7% pay less for their co-payments since September 2013, while 8% *Don't Know or are Not Sure*.

When asked about changes since January 2014 in the percent of coinsurance paid, most of those responding (n=354) reported either no changes (57%) or that they were *Not Sure/Don't Know* (12%). For respondents that reported a change in coinsurance, 29% reported paying more, while only 2% reported paying less.

44% of those with co-pays had higher Ig therapy co-pays in 2014 than in 2013

29% of those with coinsurance paid more in coinsurance for Ig therapy in 2014 than in 2013

Immunoglobulin & Health Insurance Policies:

In seeking to understand whether patients with PI receive the full amount of prescribed immunoglobulin therapy, participants were asked if the patient's health insurance limits the amount of grams of immunoglobulin the patient receives. According to 63% of those responding, health plans did not limit the number of grams of prescribed immunoglobulin they could receive, however 3% reported they were limited by health insurance. As with other responses to survey questions concerning benefits coverage, a large percentage (35%) *Did Not Know/Were Unsure* if the person with PI's health insurance limits the amount of grams of immunoglobulin the patient receives.

Respondents were asked if they had skipped or delayed their Ig therapy in the past 12 months. Almost one-third (32%) reported skipping or delaying their Ig therapy during this time. When those who skipped therapy were asked how many times they had done so since January 2014, the responses ranged from 1 to more than 26. One (26%), two (30%) or three (17%) skipped doses accounted for 74% of skipped doses. Conversely, 9% of those who skipped doses missed more than 8.

The most frequent reason for those who had skipped or delayed receiving their Ig therapy (n=372) was *Had problems with health insurance company/coverage* (40%), followed by *Scheduling conflict* (28%), *Was too sick for Ig therapy* (20%) and *My part of the cost of therapy was too expensive* (12%) and 9% *Side-effects were too great* (**Chart 14**). Fifty-two percent of those that delayed or skipped an infusion did so as a result of problems with their insurance or inadequate coverage from their health insurance.

Fourteen percent of respondents stated the patient experienced at least one problem in the past year when attempting to receive their regular Ig therapy due to health insurance plan rules. For these individuals, 39% reported delayed infusions, 23% were denied Ig therapy, 17% had reimbursement problems, 13% had to change their site of care for infusion and 9% cancelled infusions (**Chart 15**).

Chart 14: Delayed or Skipped Ig Therapy in Past Year

N= 1,160

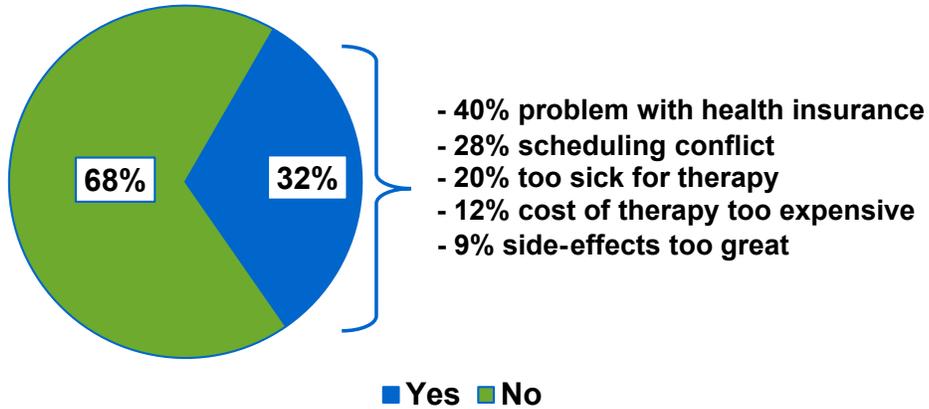
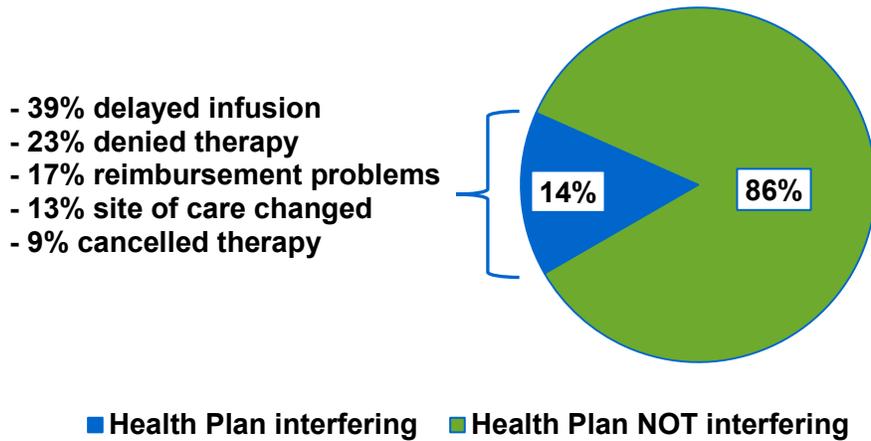


Chart 15: Health Plan Rules Interfering with Regular Ig Therapy

N= 1,160



Conclusions

The first Health Insurance & Primary Immunodeficiency Diseases: A 2014 Immune Deficiency Foundation Survey provides insight into some of the challenges in health insurance coverage for persons with PI, the type of care they receive and their satisfaction with their care. Of those surveyed, almost all persons with PI were currently covered by some form of health insurance or health plan. Most are covered by an Employment-Based Family Plan, followed by an Employment-Based Individual Only Plan and Government Health Insurance Plans. Only 3% received their health insurance through an Insurance Exchange. Therefore, the majority of the sample had a low understanding of Insurance Exchange coverage policy rules.

Results from this survey suggest serious problems and challenges exist for persons with PI, even when they have health insurance.

Due to the high costs of healthcare, persons with PI reported:

- not going to a healthcare provider when sick
- not going to see a specialist when referred to one
- skipping the filling or refilling prescriptions
- skipping medical treatments
- skipping medical tests

Perhaps most worrying is the fact that despite having health insurance, almost one-third of the respondents stated that they skipped at least one Ig therapy session in the past year. The most common reason cited was a problem with their health insurance.

For persons with PI, these patient actions can obviously have profound, negative outcomes on the patient's health.

Out-of-pocket health insurance expenses continue to grow for this vulnerable population. Nearly one-third (26%) of patients use more than 20% of their family income to cover medical expenses. As with the general U.S. population premiums, deductibles and out-of-pocket expenses continue to rise.

- Monthly median premium: \$300
- Annual median deductible: \$1,450
- Annual median maximum out-of-pocket: \$4,000

For insured persons with PI that have a co-pay, 44% reported paying more since changes in September 2013, and for those that have coinsurance, 29% reported paying more.

Out-of-pocket costs have also affected the lives of persons with PI and their families in far reaching ways beyond their treatment, impacting their quality of life. It was reported that many have:

- spent less on entertainment,
- spent less on family, and
- spent less on groceries
- used credit cards more often to pay medical bills
- took out loans to pay medical bills
- applied for government assistance to pay for medical bills

Thankfully, the majority of persons with PI were confident in and satisfied with their current health insurance plan.

- More than 80% were confident their plan offers quality medical care, the most effective drugs, and the best medical technology.
- The overwhelming majority (more than 80%) were also very to somewhat satisfied with the quality of care and health insurance coverage.
- Not surprisingly, although more than half the sample reported being somewhat to very confident they would be able to afford the care they need, 33% were not very confident to not at all confident they could afford the care they need.
- The majority of persons with PI have access to an in-network immunologist who specializes in primary immunodeficiency.
 - o For those without access, the leading reasons why were, inability to find an immunologist who specializes in primary immunology, followed by the distance of immunologist and lastly, the immunologist is no longer covered by their health insurance.
- **Although many persons with PI have health insurance coverage and are generally satisfied with their said coverage benefits and quality of care, many are plagued by high deductibles, co-pays, coinsurance.**

Perhaps most importantly, as a direct result of health insurance policies, health insurance costs and the general cost of medical care, many patients are either taking actions or being forced to take actions that are detrimental to their health.

The long term costs associated with these actions must be taken into consideration by health insurance plans, physicians and patients as we move forward with the implementation of healthcare reform in the U.S.

Endnotes

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Appendix 1.0: Survey Demographics

Respondent type	Patient	73%
	Parent	24%
	Both	3%
Gender	Male	31%
	Female	68%
	Other/refused	1%
Geographic location	Northeast	17%
	South	36%
	Midwest	24%
	West	22%
Age	0 - 14	11%
	15 - 24	12%
	25 - 34	9%
	35 - 44	12%
	45 - 54	19%
	55 - 64	22%
	65+	14%
Ethnicity	American Indian/Alaskan native	1%
	Asian/Pacific Islander	0.4%
	Black/African-American	1%
	Hispanic or Latino	2%
	White, non-Hispanic	92%
	Two or more races	3%
	Other	1%
Employment	Employed, full-time	46%
	Employed, part-time	9%
	Unemployed	3%
	Student	4%
	Homemaker	3%
	Disabled/too ill to work	19%
	Retired	13%
	Other	4%
Education	8th grade or less	1%
	Some high school	1%
	High School/GED	8%
	1- 3 years college	24%
	4 - year college graduate	30%
	Graduate or professional	36%
Household Income	0 to \$24,999	20%
	\$25,000 to \$49,000	19%
	\$50,000 to \$74,999	17%
	\$75,000 to \$99,000	15%
	\$100,000 to \$149,000	17%
	\$150,000 or more	13%

Glossary

Affordable Care Act (ACA): The comprehensive healthcare reform law enacted in March 2010. The law was enacted in two parts: The Patient Protection and Affordable Care Act was signed into law on March 23, 2010 and was amended by the Healthcare and Education Reconciliation Act on March 30, 2010. Affordable Care Act refers to the final, amended version of the law.

Agammaglobulinemia: An almost total lack of immunoglobulin or antibodies.

Average: The sum of a series of numbers divided by the count of that series of numbers.

Bone Marrow Transplant: A bone marrow transplant is a procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells. Bone marrow is the soft tissue located in the hollow centers of most bones; the marrow contains developing red blood cells, white cells, platelets and cells of the immune system.

Catastrophic Plan: A healthcare plan that only covers certain types of expensive care, like hospitalizations. It may also include plans that have a high deductible, so that your plan begins to pay only after you have first paid up to a certain amount for covered services.

COBRA (Consolidated Omnibus Budget Reconciliation Act): A federal law that may allow you to temporarily keep health coverage if your employment ends, you lose coverage as a dependent of the covered employee, or if there is another qualifying event. COBRA requires you pay 100% of the premiums, including the share the employer used to pay, plus a small administrative fee.

Coinsurance: A form of medical cost sharing in a health insurance plan that requires an insured person to pay a stated percentage of medical expenses after the deductible amount, if any, was paid. Once any deductible amount and coinsurance are paid, the insurer is responsible for the rest of the reimbursement for covered benefits up to allowed charges: the individual could also be responsible for any charges

in excess of what the insurer determines to be 'usual, customary and reasonable.'

Co-payment: A flat dollar amount you must pay for a covered program. Example: you may have to pay a \$15 copayment for each covered visit to a primary care doctor.

Cost Sharing: The share of costs covered by your insurance that you pay out-of-pocket. Generally includes deductibles, coinsurance and copayments, or similar charges, but it does not include premiums, balance billing amounts for non-network providers, or the cost of non-covered services. Cost sharing in Medicaid and the Children's Health Insurance Program also includes premiums.

Deductible: The amount you must pay for covered care before your health insurance begins to pay. Insurers apply and structure deductibles differently. Example: under one plan, a comprehensive deductible might apply to all services while another plan might have separate deductibles for benefits such as prescription drug coverage. Some plans may also cover some services before the deductible is met, such as annual exams.

Employment-Based Insurance Plan/Policy: Coverage that is offered to an employee by an employer. Employment-based insurance plans can include family plans and individual plans.

Federal Exchange/Marketplace: Provides an organized and competitive market place for individuals and small businesses to buy health insurance. Federal Exchanges offer a choice of different health plans, which meet certain benefits and cost standards, and provide information to help consumers better understand their options. The federal government decides the Federal Exchange criteria for plan certification and participation in the exchange. The state does not have regulatory authority over plans in the Federal Exchange. All plans in Federal Exchange are separated into four metallic levels – Bronze, Silver, Gold and Platinum.

Gamma Interferon: A cytokine primarily produced by T-lymphocytes that improves bacterial killing by phagocytes; used in the treatment for Chronic Granulomatous Disease (CGD).

Gene Therapy: Treatment of genetic diseases by providing the correct or normal form of the abnormal gene which is causing the disease.

Hypogammaglobulinemia: Lower than normal levels of immunoglobulins (or antibodies) in the blood.

IgG Subclass Deficiency: The main immunoglobulin (Ig) in human blood is IgG. This is the second most abundant circulating protein and contains long-term protective antibodies against many infectious agents. IgG is a combination of four slightly different types of IgG called IgG subclasses: IgG1, IgG2, IgG3 and IgG4. When one or more of these subclasses is persistently low and total IgG is normal, a subclass deficiency is present.

Immunodeficiency: A state of either a congenital (present at birth) or an acquired abnormality of the immune system that prevents adequate immune responsiveness.

Immunoglobulin Replacement Therapy: The intravenous, intramuscular or subcutaneous injection of immunoglobulin to provide antibodies that the immunodeficient person cannot make themselves.

Individual Policy Plan: Policies for people who are not connected to job-based coverage. Individual health insurance policies are regulated under state law. Note that the phrase “individual policies” when used in this way, policies that are unconnected to employment, can be used for policies that cover a single person or multiple people (families, mother and dependent child, husband and wife, etc.).

In-Network Provider: A physician, certified nurse midwife, hospital, skilled nursing facility, home healthcare agency, or any other duly licensed or certified institution or health professional under contract with your insurance provider.

Median: The middle point of a number set, in which half the numbers are above the median and half are below.

Medicaid: A state-administered health insurance program for low-income families and children, pregnant women, the elderly, people with disabilities, and in some states, other adults. The federal government provides a portion of the funding and sets guidelines. States also have choices in how they design their program, so Medicaid programs and eligibility vary state by state and may have a different name in your state.

Medicare: A federal health insurance program for people who are age 65 or older and certain younger people with disabilities. It also covers people with End-Stage Renal Disease.

Medicare Advantage (Medicare Part C): A type of Medicare health plan offered by a private company that contract with Medicare to provide Medicare Part A and Part B benefits.

Medicare Disability: If a person qualifies for Social Security Disability Insurance (SSDI), a monthly benefit to help replace lost wages due to a permanent disability, he/she may also qualify for Medicare to cover their medical expenses.

Medicare Supplemental: Medicare Supplement Insurance. Medicare Supplement plans fill in some of the gaps in coverage in Original Medicare, such as deductibles, coinsurance, copayments, and overseas emergency health coverage. These are costs you’d normally be responsible for paying out of pocket.

Out-of-Pocket Costs: Your expenses for medical care that are not reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance and copayments for covered services plus all costs for services that are not covered.

Premium: A monthly payment you make to your insurer to get and keep insurance coverage. Premiums can be paid by employers, unions, employees or individuals or shared among different payers.

Primary Immunodeficiency Disease: A group of more than 300 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. While not contagious, these diseases are caused by hereditary or genetic defects, and, although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender. Some affect a single part of the immune system; others may affect one or more components of the system.

State Children's Health Insurance Program (SCHIP): As part of the Balanced Budget Act of 1997, Title XXI or State Children's Health Insurance Program (SCHIP) of the Social Security Act was passed in late 1997. SCHIP gives grants to states to provide health insurance coverage to uninsured children up to 200% of the federal poverty level (FPL). States may provide this coverage by expanding Medicaid or by expanding and creating a separate state children's health insurance program. The program's primary purpose is to help children in working families with incomes too high to qualify for Medicaid but too low to afford private family coverage.

State Exchange/Marketplace: State-based organizations that provide an organized and competitive market place for individuals and small businesses to buy health insurance. Like Federal Exchanges, State Exchanges offer a choice of different health plans, which meet certain benefits and cost standards, and provide information to help consumers better understand their options. Unlike Federal Exchanges, each state determines the specific criteria for State Exchange plan certification and participation within broad federal regulations and maintains local authority over managing plans in the exchange. All plans in the State Marketplace are separated into four metallic levels – Bronze, Silver, Gold and Platinum.

TRICARE: Formerly known as the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), is a health care program of the United States Department of Defense Military Health System.

Veteran's Policy: As also referred to as Veteran's Affairs (VA) health care, is a veteran-specific national health care system. The federal government owns a majority of the VA health care delivery sites, employs the VA health care providers, and directly provides the majority of VA health care services to veterans.



The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.