Immune Deficiency Foundation

Health Insurance Toolkit

for Patients with Primary Immunodeficiency Diseases and Their Families
Immune Deficiency Foundation

Health Insurance Toolkit

for Patients with Primary Immunodeficiency Diseases and Their Families
Having the tools you need to select the right healthcare plan for you and your family is very important. The passage of the Affordable Care Act (ACA), also known as the healthcare reform law, has led to significant changes in the way individuals and families can receive healthcare coverage. Historically, those affected by chronic conditions had limited opportunities to obtain healthcare coverage in the individual market. The ACA created Health Insurance Marketplaces (formerly referred to as Exchanges), which are intended to be transparent and competitive markets where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state will have a Marketplace/Exchange in 2014 that will offer a variety of health plan options presented in four categories (tiers) – Bronze, Silver, Gold and Platinum. In the Marketplace, you can compare coverage options based on price, benefits, quality and other features important to you.

Regardless of how you and your family obtain your health insurance plan, it is ultimately your responsibility to choose the plan that is right for you. It is essential to understand your family’s healthcare needs and the medical services used most often in order to properly evaluate your plan options. The selection of an appropriate health plan can affect both your health and your finances.

The Immune Deficiency Foundation (IDF) is pleased to offer this toolkit to provide you with information, facts, resources and worksheets to help you choose the best possible options for you and your family. This toolkit reflects rules and protections already in place under the ACA and those, which take effect in 2014. For unfamiliar acronyms or terms, see the *Glossary of Commonly Used Healthcare Acronyms and Terms* that begins on page 15.

This toolkit will be regularly updated with the most current information. For the most updated version, please go to http://primaryimmune.org/services/patient-insurance-center/idf-health-insurance-toolkit.

The IDF Insurance Toolkit is adapted from the Personal Health Insurance Toolkit produced by the American Plasma Users Coalition’s (A-PLUS) State Exchange Project. Special thanks to the following organizations for their assistance with content development:

- Georgetown Health Policy Institute
- Alpha - 1 Association
- Caring Voice Coalition
- Immune Deficiency Foundation
- National Hemophilia Foundation
- Patient Services, Inc.
About the Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF) is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. IDF was founded in 1980 by parents of children with primary immunodeficiencies and their physicians. At that time, there were few treatments for primary immunodeficiency diseases, almost no educational materials for patients, no public advocacy initiatives, and little research being done. In the past thirty-three years, IDF has pursued an aggressive agenda to remediate these problems and has made tremendous strides in the following areas:

• Helping the patient and professional communities gain a broader understanding of primary immunodeficiency diseases through comprehensive education and outreach efforts;
• Promoting, participating in, funding and supporting research that has helped characterize primary immunodeficiency diseases and given healthcare providers substantially improved treatment options for the care of patients with primary immunodeficiency diseases;
• Addressing patient needs through public policy programs on local, national and international levels by focusing on issues such as insurance reimbursement, patient confidentiality, SCID newborn screening, preventing genetic discrimination, ensuring the safety and availability of immunoglobulin therapy, and maintaining and enhancing patient access to a full range of treatment options;
• Establishing supportive networks of patients and professionals to ensure that the needs of patients with primary immunodeficiency diseases are recognized and addressed.

In the United States, approximately 250,000 people are diagnosed with a primary immunodeficiency disease, and many more go undetected. Representing a group of more than 200 different rare disorders, primary immunodeficiencies are often difficult to diagnose. While not contagious, these diseases are caused by hereditary or genetic defects, in which part of the body’s immune system is missing or functions improperly. These individuals live throughout the country and experience a number of problems, which have been documented by IDF. These patient problems include:

• Difficulty in finding specialized healthcare by immunologists or care providers knowledgeable about immunodeficiency
• An inordinate delay in reaching proper diagnoses
• Problems with availability of appropriate treatment
• Difficulties financing healthcare and treatment
• Finding instructional materials about the specific diseases
• Educating the community and those with whom they come in contact about their disease and particular needs
• Lack of peer support and connection to others with whom they can share experiences

The goal of IDF is to address these issues and help affected individuals to overcome these difficulties, thereby enabling them to live healthy and productive lives.

For more information, contact IDF: 800-296-4433 or www.primaryimmune.org.
Table of Contents

Private Health Plan Comparison Guide .......................................................... 5
   Overview of the IDF Health Insurance Toolkit including questions to be asked when
   choosing a health plan.

Getting Started ......................................................................................... 7
   Identifies the materials needed and outlines the process to be followed in order
   to evaluate your health plan options.

Personal Health Experience Stat Sheet ..................................................... 9
   How to create a record of your (or your family’s) health experiences for the past 12
   months.

Health Plan Cost Comparison Worksheet .................................................. 11
   Worksheet that, combined with your personal health experience stat sheet, is used to
   compare the cost of your various plan options as they relate to your specific benefit
   needs.

Glossary of Commonly Used Healthcare Acronyms and Terms .................. 15
   Glossary and acronym list defining various healthcare terms, plan types, healthcare
   systems and health-related government agencies.

FACT SHEETS

Making Benefits Easier to Understand: Summary of Benefits and Coverage (SBC) and
Uniform Glossary ......................................................................................... 33
   Health insurance issuers and group health plans are required to provide you with a
   Summary of Benefits of Coverage to help you better understand and evaluate your
   health insurance choices. This section explains what is required and provides a link
   containing a sample SBC.

What If I Am Denied Coverage? Appeals and Grievances .......................... 35
   If you are denied coverage of healthcare claims, this section will help you understand the
   appeals process.

I Have Coverage, What Does the ACA Mean to Me? Individual Mandate ....... 37
   Under the ACA, starting in 2014, you must be enrolled in a health insurance plan that
   meets basic minimum standards. If you aren’t, you may be required to pay a penalty.
   This is often referred to as the “individual mandate.” Exempt from this are people with
   very low income for whom coverage is unaffordable, or for other reasons, including
   religious beliefs. This section includes a chart that illustrates the various ways individuals
   can comply with the requirements of the mandate.

Does My Current Plan Meet ACA Requirements? ...................................... 39
   Not all plans are required to comply with ALL provisions of the ACA. In this section the
   ACA standards for health plans are outlined and a chart is provided to illustrate to which
   plans each provision applies.
Table of Contents (cont.)

Where Do I Go for Help With Insurance Questions and/or Problems........................................ 41
Under the ACA various consumer assistance programs have been developed to help consumers understand their insurance options and to assist with enrollment, appeals, etc. This section identifies the various resources available to consumers having problems or questions about health insurance.

What Is the Health Insurance Marketplace? Marketplace Primer ........................................ 43
The Marketplace is intended to be a one-stop-shop or no-wrong-door way to explore health plan options available in your state. This section serves as a primer to explain the Marketplace.

What Level of Coverage is Available through the Marketplace? Standardized Health Plans: Four Levels of Coverage......................................................................................... 47
Under the ACA health plans can provide four levels of coverage, sometimes referred to as “metal tiers.” This section explains the difference between these tiers and the cost shares associated with each.

What If I Can’t Afford Coverage? Subsidies to Buy Coverage in the Health Insurance Marketplace...................................................................................................................... 49
Under the ACA, individuals who purchase coverage through a Health Insurance Marketplace may be eligible for financial assistance if their household income is less than 400% of the federal poverty level and they do not have “minimum essential coverage.” This section provides information about what types of assistance are available and rules regarding eligibility.

Consumer Resources.................................................................................................................. 51
List of nonprofit and government resources.
Private Health Plan Comparison Guide

Determining which health plan is most appropriate for your needs can often be a difficult process whether it is an individual or family policy offered through your employer (a group health plan) or one you acquired as an individual. There are many things to consider when reviewing your options. These considerations fall under two categories: cost and benefit design. Most people first consider the cost of a plan when making a decision. Our goal is to provide you with a tool to help you compare and evaluate the cost and benefits of various plans that may be offered to you by an employer or an insurance Marketplace in your state. Questions typically asked by people when choosing a plan include:

- What is the monthly/annual premium for the plan?
- What is the total of my yearly out-of-pocket costs, including medical and prescription co-pays, deductibles and coinsurance?
- Does it cover all the services I need?
- Are my physicians in network?
- Are there annual limits on the number of visits for any particular service? (For example, physical therapy is often limited to a certain number of visits per year.)
- Are out-of-network benefits available? What percentage of the cost am I responsible for if I receive out-of-network care?
- Am I covered if I get sick/need treatment out of state?

For those affected by primary immunodeficiency disease, there are often additional, more specific questions you must ask that relate to what benefits are covered and how, such as:

- Is immunoglobulin (Ig) therapy covered? If so, is it a part of major medical or a pharmacy benefit?
- Do I have a choice of site of care (hospital, home infusion, physician’s office)?
- Do I have a choice of administration of therapy, i.e. subcutaneous (SCIG) or intravenous (IVIG)?
- What is my out-of-pocket cost for my Ig therapy?
- Are supplies and nursing services covered?
- Do I need a referral to see a specialist?
- What services require prior authorization?
- Is Ig therapy subject to a restrictive formulary?
- Will I be required to switch from my current Ig product to another product?
- Does the plan provide a case manager to assist me with navigating my benefits?

Answers to some of these questions, relative to cost and generally covered benefits, can be found by reviewing a plan’s summary of benefits, drug formulary list and provider network directory. However, sometimes you will need to find out more information from the plan to get all of the information you need. While this is often considered a tedious process, it is one of the most important steps you can take to ensure that a plan meets your needs. It is better to know everything you can about your plan before you pick it than finding out problems and hidden costs after you have made a decision.

It is important to remember that... **Once you choose a plan, you cannot change until the next open enrollment period** unless you experience a qualifying life event.
Getting Started

Step 1 – Complete the Personal Health Experience Stat Sheet (page 9). This document was designed to identify and quantify the health services used by you and your family in the previous 12 months, providing you with a list of benefits your new plan should include.

Step 2 – Have a copy of the Glossary of Commonly Used Healthcare Acronyms and Terms (page 29) at hand.

Step 3 – Collect from your Human Resources representative, insurance agent, or Marketplace the following documents for each health plan being offered (Note: often you will be provided a link to this information on the insurance carrier’s website).

A. Benefit Summary – Health insurers and group health plans are required to provide you with an easy-to-understand summary of a health plan’s benefits and coverage. For more information on what should be included in your benefit summary, please see the “Fact Sheets” section of this toolkit.

B. Drug Formulary – Health insurers maintain a formulary (sometimes referred to as a Preferred Drug List or PDL), which is a list of prescription drugs, both generic and brand name, that are covered through your health plan. Formularies classify drugs by different cost tiers that define the plan member’s co-payment (co-pay) amount and/or coinsurance levels. Typically, generic drugs require the lowest co-pay from plan members.

C. Provider Network Booklet – A provider network is a group of providers (such as physicians, hospitals, skilled nursing facilities, pharmacy or other licensed, certified institutions, or health professionals) that have contracted with the health plan to provide healthcare services to plan members at agreed upon billing rates. Depending on the plan’s design, members who receive care from a provider not included in the network may have less or no coverage for that provider and/or service received. It is important to note that many insurers offer several different plan options, each of which may have a different provider network. It is important to review the provider network for each plan.

D. Health Savings Account or Flexible Spending Account – If your employer provides either of these programs, printed copies of the details will be helpful. A Health Savings Account is a medical savings account available to individuals enrolled in a high-deductible health plan that meets certain federal rules for out-of-pocket costs. The funds contributed to an account are not subject to federal income tax at the time of deposit. Healthcare Flexible Spending Accounts are employer-established benefit plans that reimburse employees for specified medical expenses as they are incurred. The employee contributes funds to the account through a salary reduction agreement and is able to withdraw the funds set aside to pay for medical bills.

Step 4 – Begin using your Health Plan Cost Comparison Worksheet (page 11). One way to evaluate your potential plan cost is to base your review on your prior year’s medical experience. Using the information included on your Personal Health Experience Stat Sheet, the plan’s summary of benefits, and drug formulary list, fill in each section that applies on the worksheet.
It is important to remember that unexpected medical needs often arise. Their costs are often unpredictable. The IDF Health Insurance Toolkit is designed to provide you with a general idea of the predictable costs associated with your health plan based on your family’s known health situations. While these documents may answer many of the questions important to choosing the appropriate plan, there may be some questions that require additional resources. To answer these questions, begin by contacting your human resources/benefits administration department, broker or your health plan’s customer service representative. There are many resources available to consumers who need additional help. For more information and/or a list of available resources, you can contact IDF at 800-296-4433 or visit www.primaryimmune.org.

You may find that you have the option to choose between multiple plan types and designs such as HMO, PPO, POS or EPO (see Glossary for explanations.). The IDF Health Insurance Toolkit was developed to assist you in evaluating your plan options. The Health Plan Cost Comparison Worksheet (page 11) was designed to help in performing a side-by-side comparison of your plan options by helping to identify covered benefits and out-of-pocket costs associated with each. The chart can be used in two ways: to make general comparisons between health plans or highlight the costs and benefits specific to your individual needs.
Personal Health Experience Stat Sheet

Choosing a healthcare plan can be very confusing. There are many things to consider; two of the most important are cost and benefit design. When trying to determine your potential out-of-pocket (OOP) costs, it is important to determine which benefits you (and your family, if you are all on the same policy) typically use and how often you use them. This will help you project your out-of-pocket costs for the upcoming benefit year. The easiest way to do this is to ask yourself the following questions:

In the past 12 months, I have:
1. Visited my primary care physician
   Spent $__________ in out of pocket costs (OOP) ________ time(s).
   a) Spouse has visited his/her primary care physician ________ time(s).
   b) Child(ren) have visited their primary care physician ________ time(s).
   Spent $__________ (OOP) ________ time(s).
2. Been seen by a specialist
   Spent $__________ (OOP) ________ time(s).
   a) Spouse ________ time(s).
   b) Child(ren) ________ time(s).
3. Visited an ER
   Spent $__________ (OOP) ________ time(s).
   a) Spouse ________ time(s).
   b) Child(ren) ________ time(s).
4. Purchased ____________ prescriptions (including for my family) at my local pharmacy.
   a) What was the name of the medication(s)?
   b) Was it recurring (or maintenance) medication or was it for a one time use?
5. Number of immunoglobulin therapy treatments __________________________
   IV or SC?
   Spent $__________ OOP ________ time(s).
6. Been admitted to a hospital for an overnight stay
   a) Spouse ________ time(s).
   b) Child(ren) ________ time(s).
7. Needed home health services (such as nursing care including IVIG infusions) ________ time(s).
   a) Spouse ________ time(s).
   b) Child(ren) ________ time(s).
8. Visited an urgent care center
   a) Spouse ________ time(s).
   b) Child(ren) ________ time(s).
The following is a list of all doctors (including specialists) and facilities that I / my family used in the past 12 months:

Primary Care Physician(s):

Specialist(s):

Urgent Care Center(s):

Lab Facility:

Hospital Facility:

Ophthalmologist:

Dentist:

Retail Pharmacy:

Specialty Pharmacy:

Other:
# Health Plan Cost Comparison Worksheet

### Healthcare Plans (put each plan name offered in separate column for this comparison)

<table>
<thead>
<tr>
<th>Plan Name(s)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan type (EPO, HMO, PPO, POS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the plan(s) require you to choose a primary care physician (PCP)?</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, is your current PCP in-network?</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

### Financial (deductible/coinsurance/annual limits)

<table>
<thead>
<tr>
<th>Annual Deductible (In-Network):</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annual Deductible (Out-of-Network):</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
</tbody>
</table>

| Is the deductible included in the out-of-pocket maximum? | Yes / No | Yes / No | Yes / No |
| Are any services covered before the deductible is met? | Yes / No | Yes / No | Yes / No |
| Co-insurance (i.e. 80% plan pays/20% OOP, 70/30) | % | % | % |

<table>
<thead>
<tr>
<th>Annual Out-of-Pocket Maximum:</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
</tbody>
</table>

| Does the plan(s) have annual limits?¹ | Yes / No | Yes / No | Yes / No |
| If so, what are the limits? | $ | $ | $ |

### Preventive Care²

| Annual physical exam copays and/or co-insurance | $ | $ | $ |
| Annual routine pediatric care copays and/or co-insurance | $ | $ | $ |
| Annual immunizations³ copays and/or co-insurance | $ | $ | $ |

### Major Medical

| Do you have a copy of the plan’s provider list? | Yes / No | Yes / No | Yes / No |

(Worksheet continued on next page)
<table>
<thead>
<tr>
<th>Plan Comparison (continued from page 12)</th>
</tr>
</thead>
</table>

**In-Network**

**Please note:** cost shares may vary when using out-of-network providers

If permitted, indicate plan’s percentage of cost for out-of-network services

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>%</th>
<th>%</th>
</tr>
</thead>
</table>

**Outpatient Care** *(ongoing co-pays after deductible is met)*

- Annual physician’s office visit co-pays
  - $  
  - $  
  - $

- Annual specialist’s office visit co-pays
  - $  
  - $  
  - $

- Annual surgical expense
  - $  
  - $  
  - $

- Annual Laboratory services expense
  - $  
  - $  
  - $

**Hospital Care Charges** *(inpatient services)*

- Annual physician’s and surgeon’s services expense
  - $  
  - $  
  - $

- Semi-private room and board copay and/or co-insurance
  - $  
  - $  
  - $

- Annual prescription drugs and medications expenses
  - $  
  - $  
  - $

**Emergency Care**

- Emergency room copay and/or co-insurance
  - $  
  - $  
  - $

- Urgent care center copay and/or co-insurance
  - $  
  - $  
  - $

**Maternity Care**

- Annual prenatal and postnatal care co-pays
  - $  
  - $  
  - $

- Hospital services expense (mother and child)
  - $  
  - $  
  - $

**Substance Abuse**

- Inpatient: _____ visits allowed per calendar year
  - Annual copay and/or co-insurance
    - $  
    - $  
    - $

- Outpatient: _____ visits allowed per calendar year
  - Annual copay and/or co-insurance
    - $  
    - $  
    - $

**Mental Health**

- Inpatient: _____ visits allowed per calendar year
  - Annual copay and/or co-insurance
    - $  
    - $  
    - $

- Outpatient: _____ visits allowed per calendar year
  - Annual copay and/or co-insurance
    - $  
    - $  
    - $

*(Worksheet continued on next page)*
# Plan Comparison (continued from page 13)

<table>
<thead>
<tr>
<th>Pharmacy Benefit (do you have a copy of the plan’s drug formulary list?)</th>
<th>Yes / No</th>
<th>Yes / No</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yearly deductible (pharmacy)</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Co-pay Tier 1 (generics)</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Co-pay Tier 2 (brand/preferred)</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Co-pay Tier 3 (brand/non-preferred)</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Co-insurance Tier 4 (% of cost share or co-pay dollar amount)</td>
<td>$ or %</td>
<td>$ or %</td>
<td>$ or %</td>
</tr>
<tr>
<td>If your plan(s) has a specialty tier with coinsurance is there maximum OOP cost for each prescription?</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Is there a yearly out-of-pocket maximum?</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Is immunoglobulin covered under the pharmacy benefit?</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Do you have more than one choice of pharmacy provider?</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

## Other (if offered)

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chiropractic copays and/or co-insurance</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Short-term rehabilitation: inpatient copays and/or co-insurance</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Short-term rehabilitation: outpatient copays and/or co-insurance</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Skilled nursing facility (SNF) annual expense</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Home healthcare annual expense</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Hospice care: inpatient annual expense</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Hospice care: outpatient annual expense</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Durable medical equipment (DME) annual expense</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td><strong>Total Estimated Annual Cost per Plan</strong></td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
</tr>
</tbody>
</table>

---

1. For any plan issued after 9/23/12, the annual limit can be no less than $2 million, unless the plan receives a waiver from the rule. For any plan issued after 01/01/14, annual dollar limits are prohibited.
2. For a complete list of preventive services for which there is no co-pay allowed under the ACA, go to: [http://www.healthcare.gov](http://www.healthcare.gov).
3. The ACA bans co-pays for recommended vaccines for adults and children.
4. For group plans and individual policies created or issued after 3/23/2010, the ACA bans higher co-pays or coinsurance for out-of-network ER services.
5. The Mental Health Parity and Addiction Equity Act prohibits plans from imposing higher deductibles or co-pays or tighter limits on visits than are allowed for medical services in the plan.
Glossary of Commonly Used Healthcare Acronyms and Terms

Healthcare and Insurance Related Acronyms

ACA: Affordable Care Act
ACO: Accountable Care Organization
APTC: Advanced Premium Tax Credit
AV: Actuarial Value
CAC: Certified Application Counselor
CAP: Consumer Assistance Program
CCIIO: Center for Consumer Information and Insurance Oversight
CDC: Centers for Disease Control and Prevention
CHC: Community Health Center
CHIP: Children’s Health Insurance Program
CMS: Centers for Medicare & Medicaid Services
COB: Coordination of Benefits
COBRA: Consolidated Omnibus Budget Reconciliation Act
CO-OP: Consumer Operated and Oriented Plan
CSR: Cost-Sharing Reduction
DME: Durable Medical Equipment
ECP: Essential Community Provider
EHB: Essential Health Benefits
EMR: Electronic Medical Record
EOB: Explanation of Benefits
EPO: Exclusive Provider Organization
EPSDT: Early Periodic Screening, Diagnostic & Treatment Services
ERISA: Employee Retirement Income Security Act
ESI: Employer-sponsored Insurance
FFM/FFE: Federally Facilitated Marketplace/Federally Facilitated Exchange
FFS: Fee-for-service
FPL: Federal Poverty Level
FQHC: Federally Qualified Health Center
FSA: Flexible Spending Account
HCR: Health Care Reform
HCBS: Home and Community-Based Services
HHS: U.S. Department of Health and Human Services
HIPAA: Health Insurance Portability and Accountability Act
HIM/HIX: Health Insurance Marketplace/Health Insurance Exchange
HMO: Health Maintenance Organization
HRP: High Risk Pool
HRSA: Health Resources and Services Administration
HSA: Health Savings Account
HDHP: High Deductible Health Plan
IPA: In-Person Assisters Program
LTC: Long Term Care
MAGI: Modified Adjusted Gross Income
MA: Medicare Advantage
MLR: Medical Loss Ratio
OEP: Open Enrollment Period
OON: Out of Network
Glossary of Commonly Used Healthcare Acronyms and Terms

OOP: Out of Pocket
PBM: Pharmacy Benefit Manager
PCIP: Pre-existing Condition Insurance Plan
PCORI: Patient-Centered Outcomes Research Institute
PCP: Primary Care Provider
PDP: Prescription Drug Plan under Medicare Part D
POS: Point-of-Service Plan
PPO: Preferred Provider Organization
QHP: Qualified Health Plan
SBC: Summary of Benefits and Coverage
SBM/SBE: State Based Marketplace/State Based Exchange
SEP: Special Enrollment Period
SHOP: Small Business Health Options Program
SNF: Skilled Nursing Facility
SPM/SPE: State Partnership Marketplace/ State Partnership Exchange
SPP: Specialty Pharmacy Provider
SSDI: Social Security Disability Income
SSI: Supplemental Security Income
TPA: Third Party Administrator
UCR: Usual, Customary and Reasonable Charges

Glossary of Commonly Used Healthcare Terms

340B Program: The 340B Drug Pricing Program enables eligible health care organizations (known as covered entities) to purchase drugs from manufacturers at reduced prices. It is called 340B since that is the section of the Public Health Service Act that establishes the program.

Accountable Care Organization (ACO): A group of healthcare providers that gives coordinated care for chronic disease management with the goal of improving the quality of patient care. The “organization’s” payment is tied to achieving healthcare quality goals and outcomes that result in cost savings. ACOs can include various types of doctors – primary care, specialists, etc. – as well as other medical providers (nurses, physician’s assistants, etc.) and institutions (hospitals, multi-physician practices).

Accreditation: If a health plan provided in the Marketplace/Exchange is approved, this is the “seal of approval” given to the plan by an independent organization to show that the plan meets national quality standards.

Actuarial Value (AV): The percentage of total average costs for covered benefits that a plan will cover. Example: if a plan has an actuarial value of 70%, on average you would be responsible for 30% of the costs of all covered benefits. However, you could be responsible for a higher or lower percentage of the total costs of covered services for the year, depending on your actual healthcare needs and the terms of your insurance policy. Under the Affordable Care Act, four health plan categories, Bronze, Silver, Gold and Platinum (sometimes called metal tiers) will be offered in the Marketplaces/Exchanges. The tiers are based on the actuarial value of providing essential health benefits to members. While two plans may be in the same metal tier, that does not mean that they will cover the same benefits in the same way - the percentages are set over the entire plan and not any individual service (See Bronze, Silver, Gold and Platinum Health Plans and Fact Sheet).
Advanced Premium Tax Credit (APTC): Also referred to as a premium tax credit, this new tax credit provided for in the Affordable Care Act helps make coverage purchased in the Marketplace/Exchanges more affordable for consumers. Advance payments of the tax credit can be used right away to lower monthly premium costs. Qualified consumers may choose how much advance credit payments to apply to their premiums each month, up to a maximum amount. If the amount of advance credit payments a consumer gets for the year is less than the tax credit due, the consumer will get the difference as a refundable credit when they file their federal income tax return. If the consumer’s advance payments for the year are more than the amount of their credit, they must repay the excess advance payments with their tax return.

Affordable Care Act (ACA): Also known as the Patient Protection and Affordable Care Act (PPACA), health care reform (HCR) and Obamacare, it is the comprehensive healthcare reform law enacted in March 2010. The law was enacted in two parts: PPACA was signed into law on March 23, 2010. It was amended by the Health Care and Education Reconciliation Act on March 30, 2010. Affordable Care Act refers to the final, amended version of the law.

Affordable Coverage (as it relates to the APTC): Employer coverage is considered affordable - as it relates to the Advanced Premium Tax Credit (APTC) - if the employee’s share of the annual premium for self-only coverage is no greater than 9.5% of annual household income. Starting in 2014, individuals offered employer-sponsored coverage that’s affordable and provides minimum value won’t be eligible for a premium tax credit if they choose to purchase health insurance in the Marketplace.

Allowed Amount: Discounted fees that insurers will recognize and pay for covered services. Insurers negotiate these discounts with providers in their health plan network. Network providers agree to accept the allowed charge as payment in full. Each insurer has its own schedule of allowed charges.

Annual Limit: A cap on the benefits your insurance company will pay in a year while you’re enrolled in a health insurance plan. Annual caps are sometimes placed on particular services such as prescriptions or hospitalizations. Annual limits may be placed on the dollar amount of covered services or on the number of visits for a particular service. After the annual limit is reached, you must pay all associated healthcare costs for the rest of the year.

Appeal: A request for a health insurer or plan to review a decision or a grievance again.

Balance Billing: The practice of billing a patient for charges not paid by his/her insurance plan because the charges exceed covered amounts. Balance billing amounts will often be charges that are above the usual and customary rates.

Benefits: The healthcare items or services covered under a health insurance plan. Covered benefits and excluded services are defined in the health insurance plan’s coverage documents. In Medicaid or CHIP, covered benefits and excluded services are defined in state program rules.

Biologic: A biologic (also known as a biological product) is a type of complex medication such as a vaccine, blood or blood product, or other treatment that mimics proteins naturally present in the body. Rather than being created chemically like drugs, biologics are based off of recombinant, cell or tissue-based proteins. Immunoglobulin replacement therapy administered intravenously or subcutaneously, is a biologic.

Biosimilar Biological Products: A biosimilar is the “follow-on” or subsequent version of a biologic. Biosimilars and biologic products have the same relationship that generic drugs have with brand name drugs, with an important distinction that due to their complexity, biosimilars are not identical to the original biologic product.
**Bronze Health Plan**: A plan in the health insurance Marketplace/Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 60%.

**Care Coordination**: The process of organizing your treatment across several healthcare providers. Medical homes and Accountable Care Organizations (see definition) are two common ways to coordinate care.

**Catastrophic Plan**: A healthcare plan that only covers certain types of expensive care, like hospitalizations. May also include plans that have a high deductible, so that your plan begins to pay only after you’ve first paid up to a certain amount for covered services. You must be under 30 years old to purchase a catastrophic plan through a Marketplace/Exchange.

**Center for Consumer Information and Insurance Oversight (CCIIO)**: Located within the Centers for Medicare & Medicaid Services (part of the Department of Health & Human Services), the Center is the federal agency tasked with implementing many provisions of the Affordable Care Act related to private health insurance.

**Centers for Disease Control and Prevention (CDC)**: The federal agency responsible for protecting health and promoting quality of life through the prevention and control of disease, injury, and disability.

**Centers for Medicare and Medicaid Services (CMS)**: The federal agency that administers the Medicare, Medicaid, and Children’s Health Insurance Programs, and implements many provisions of the Affordable Care Act related to private health insurance Marketplaces/Exchanges.

**Certified Application Counselor (CAC)**: An individual (affiliated with a designated organization) who is trained to help consumers, small businesses, and their employees as they search for and enroll in health insurance options through the Marketplace/Exchanges created by the ACA. CAC services are free to consumers. (See Fact Sheet).

**Children’s Health Insurance Program (CHIP)**: Insurance program jointly funded by state and federal government that provides health insurance to low-income children. In some states, it covers pregnant women in families who earn too much income to qualify for Medicaid but cannot afford to purchase private health insurance coverage.

**Claim**: A request for payment that you or your healthcare provider submits to your health insurer after you receive covered items or services.

**Consolidated Omnibus Budget Reconciliation Act (COBRA)**: 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 (rather than a set dollar amount) of medical expenses after the deductible amount, if any, was paid.

**Community Health Centers (CHC)**: Public and private, nonprofit organizations providing comprehensive, culturally competent, quality primary and related health care services to medically underserved communities and vulnerable populations. The centers are managed and governed by a community board, which is primarily comprised of patients and community members. There are several different types of CHCs: Federally Qualified Health Centers; non-grant supported health centers; and outpatient health programs/facilities operated by tribal organizations.
Consumer Assistance Program (CAP): State programs available to assist consumers with problems or questions concerning health care coverage. Consumers with questions can usually access the programs through phone or e-mail. See https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/.

Consumer Operated Oriented Plan (CO-OP): A non-profit health insurance organization for which its insured people are also the owners. Cooperatives can be formed at a national, state, or local level and can include doctors, hospitals, and businesses as member-owners. Co-ops will offer insurance through the Marketplace/Exchange.

Coordination of Benefits (COB): A way to figure out who pays first when two or more health insurance plans are responsible for paying the same medical claim.

Copayment: 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. This share is commonly referred to as out-of-pocket (OOP) costs. Cost sharing includes deductibles, coinsurance and copayments, or similar charges, but it doesn’t include premiums, balance billing amounts for non-network providers, or the cost of non-covered services. Cost sharing in Medicaid and CHIP also includes premiums.

Cost-Sharing Reduction (CSR): A discount that lowers the amount you have to pay out-of-pocket for deductibles, coinsurance, and copayments. You can get this reduction if you get health insurance through the Marketplace/Exchange, your income is below a certain level, and you choose a Silver Health Plan (See “Metal Tiers” and “Silver Health Plan”). If you’re a member of a federally recognized tribe, you may qualify for additional cost-sharing benefits.

Creditable Coverage: Health insurance coverage under any of the following: a group health plan; individual health insurance; student health insurance; Medicare; Medicaid; CHAMPUS and TRICARE; Veterans Administration (VA) coverage; the Federal Employees Health Benefits Program; Indian Health Service; the Peace Corps; Public Health Plan (any plan established or maintained by a state, the U.S. government, a foreign country); Children’s Health Insurance Program (CHIP) or a state health insurance high-risk pool. If you have prior creditable coverage, it will reduce the length of a pre-existing condition exclusion period under new job-based coverage. Depending on state law, this may also apply to other types of coverage, such as state high-risk pools, in your state.

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.

Department of Health and Human Services (HHS): The federal agency charged with protecting the health of all Americans. Its agencies include the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA).

Dependent: A child or other individual for whom a parent, relative, or other person may claim a personal exemption tax deduction. Under the Affordable Care Act, individuals may be able to claim a premium tax credit to help cover the cost of coverage for themselves and their dependents.
Dependent Coverage: Insurance coverage for family members of the policyholder, such as spouse, children or partners.

Disability: A limit in action, restriction or impairment that can be physical and/or mental. Different state, federal or private programs may have different disability standards. A legal definition of disability can be found at: http://www.ada.gov/pubs/ada.htm.

Donut Hole, Medicare Prescription Drug: Most plans with Medicare prescription drug coverage (Part D) have a coverage gap, called a donut hole. This means that after you and your drug plan have spent a certain amount of money for covered drugs, you have to pay all costs out-of-pocket for your prescriptions up to a yearly limit. Once you have spent up to the yearly limit, your coverage gap ends and your drug plan helps pay for covered drugs again. The donut hole is being phased out and will be closed entirely by the ACA in 2020.

Drug List: Also referred to as a formulary, it is a list of prescription drugs covered by a prescription drug plan or another insurance plan offering prescription drug benefits.

Durable Medical Equipment (DME): Equipment and supplies ordered by a health care provider for everyday or extended use. Typically DME may be considered a separate category under a health insurance plan. Coverage for DME may include: oxygen equipment, wheelchairs, crutches or blood testing strips for diabetics.

Early Periodic Screening, Diagnostic & Treatment Services (EPSDT): The comprehensive set of benefits covered for children in Medicaid.

Electronic Medical Record (EMR): A digital version of a paper chart that contains all of a patient’s medical history from one practice.

Eligible Immigration Status: An immigration status that’s considered eligible for getting health coverage through the Marketplace/Exchange. The rules concerning eligible immigration status may be different in each insurance affordability program.

Emergency Room Services: Evaluation and treatment of an illness, injury, or condition that needs immediate medical attention in an emergency room.

Employer Mandate: The Affordable Care Act requires certain employers with at least 50 full-time employees (or equivalents) to offer health insurance coverage to their full-time employees (and their dependents) that meets certain minimum standards set by the Affordable Care Act or to make a tax payment.

Employer-Sponsored Insurance (ESI): Sometimes called group health insurance, this is health insurance provided by an employer, who typically covers a portion of the costs. Plan options include HMOs, PPOs, and EPOs, among others.

Employee Retirement Income Security Act of 1974 (ERISA): A federal law that establishes standards for some employer-sponsored health insurance, particularly for self-insured employer-sponsored plans (See Employer Sponsored Insurance and Self-Insured Plan). ERISA plans can only be regulated by federal law; state health insurance laws don’t apply to them. In the context of the ACA, ERISA plans are exempt from some of the private health insurance reforms (See Fact Sheet).

Essential Community Providers (ECP): The ACA designates certain providers as Essential Community Providers, those that are included in section 340B(a)(4) of the Public Health Service Act. Plans offered through the Marketplace/Exchanges are required to include some ECPs in their networks.
Essential Health Benefits (EHB): A set of healthcare service categories that must be covered by certain plans starting in 2014. The Affordable Care Act defines essential health benefits to “include at least the following general categories and the items and services covered within the categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.”

EHB services are defined differently in each state, based on what is covered by a typical plan that existed in the state in 2011. Private health insurance policies must cover these benefits in order to be certified and offered in Marketplaces/Exchanges. Medicaid plans must cover a comprehensive bundle of services by 2014 as well.

Non-grandfathered health plans are no longer able to impose a lifetime dollar limit on spending for these services. All plans, except grandfathered individual health insurance policies, were required to begin phasing out annual dollar spending limits for these services starting with plan/policy years that began on or after September 23, 2010. For the majority of health insurance plans, annual dollar limits on essential health benefits will be completely phased out by 2014. (See Fact Sheet).

Exclusions: Items or services that aren’t covered under a contract for insurance and which an insurance company won’t pay.

Exclusive Provider Organization (EPO) Plan: A managed care plan in which services are covered only if you go to doctors, specialists or hospitals in the plan’s network (except in an emergency).

Explanation of Benefits (EOB): A form sent by an insurance company to an insured that includes such items as a summary of the claims processed for an insured since their last claim, a summary of what the insurer paid for the claim and what the insured’s responsibility may be, and a summary of the person’s year-to-date costs in the plan.

External Review: A review of a plan’s decision to deny coverage for or payment of a service by an independent third-party not related to the plan. If the plan denies an appeal, an external review can be requested. In urgent situations, an external review may be requested even if the internal appeals process isn’t yet completed. External review is available when the plan denies treatment based on medical necessity, appropriateness, health care setting, level of care, or effectiveness of a covered benefit; when the plan determines that the care is experimental and/or investigational; or for rescissions of coverage. An external review either upholds the plan’s decision or overturns all or some of the plan’s decision. The plan must accept this decision.

Federally-Facilitated Marketplace/Federally-Facilitated Exchange (FFM/FFE): One of the three types of Marketplace/Exchange options for states under the Affordable Care Act. States opting for an FFM/FFE will have a Marketplace/Exchange that is run by the federal government.

Federal Poverty Level (FPL): A measure of income level issued annually by the Department of Health and Human Services. FPL is used to determine eligibility for certain programs and benefits. For more information on FPL please visit: http://aspe.hhs.gov/poverty/index.cfm. Many public health insurance programs set eligibility based on a percentage of the FPL.

Federally Qualified Health Centers (FQHC): Federally-funded nonprofit health centers or clinics that serve medically underserved areas and populations. Federally qualified health centers provide primary care services regardless of your ability to pay. Services are provided on a sliding scale fee.
**Fee for Service (FFS):** A reimbursement plan in which doctors and other healthcare providers are paid for each service performed, such as for tests and office visits.

**Flexible Benefits Plan:** Also known as a Cafeteria Plan or IRS 125 Plan, these plans offer employees a choice between various benefits including cash, life insurance, health insurance, vacations, retirement plans and child care. Although a common core of benefits may be required, you can choose how your remaining benefit dollars are to be allocated for each type of benefit from the total amount promised by the employer. Sometimes you can contribute more for additional coverage.

**Flexible Spending Account (FSA):** Accounts offered and administered by employers that allow employees to set aside pre-tax dollars out of their paycheck to pay for the employee’s share of insurance premiums or medical expenses not covered by the employer’s health plan. The employer may also make contributions to a FSA. Typically, benefits or cash must be used within the given benefit year or the employee loses the money. Flexible spending accounts can also be provided to cover childcare expenses, but those accounts must be established separately from medical FSAs.

**Formulary:** Sometimes referred to as a “drug list,” it is a list of drugs your insurance plan covers and may include how much you pay for each drug. If the plan categorizes drugs into different groups with different co-pays, also known as tiers, then the formulary may list drugs by these tiers. Formularies may include both generic drugs and brand-name drugs.

**Fully Insured Job-based Plan:** A plan in which the employer contracts with another organization to assume financial responsibility for the enrollees’ medical claims and for all incurred administrative costs.

**Gold Health Plan:** A plan in the health insurance Marketplaces/Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 80%. (See Actuarial Value).

**Grandfathered Health Plan:** As defined in the Affordable Care Act, a group health plan that was created—or an individual health insurance policy that was purchased—on or before March 23, 2010. Grandfathered plans are exempt from many changes required under the Affordable Care Act.

Plans or policies may lose their grandfathered status if they make certain significant changes that reduce benefits or increase costs to consumers. A health plan must disclose in its plan materials if it is a grandfathered plan. It must also advise consumers how to contact the U.S. Department of Labor or HHS with questions. (See New Plan).

**Grievance:** A complaint an insured communicates to his or her health insurer or plan.

**Guaranteed Issue:** A requirement that health plans must permit you to enroll regardless of health status, age, gender or other factors that might predict the use of health services. Except in some states, guaranteed issue doesn’t limit how much you can be charged if you enroll.

**Guaranteed Renewal:** A requirement that your health insurance issuer must offer to renew your policy as long as you continue to pay premiums. Except in some states, guaranteed renewal doesn’t limit how much you can be charged if you renew your coverage.
**Habilitative/Habilitation Services**: Health care services that help you keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings. Habilitative services are one of the 10 essential health benefits (EHBs).

**Health Care Reform (HCR)**: Also known as the Patient Protection and Affordable Care Act (PPACA), the Affordable Care Act (ACA) and Obamacare, it is the comprehensive healthcare reform law enacted in March 2010. The law was enacted in two parts: PPACA was signed into law on March 23, 2010. It was amended by the Health Care and Education Reconciliation Act on March 30, 2010. Health Care Reform refers to the final, amended version of the law.

**Health Insurance Exchange (HIE)**: Also known as a Health Insurance Marketplace, these are new transparent and competitive health insurance Marketplaces/Exchanges where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state will have a Marketplace/Exchange in 2014 and beyond.

**Health Insurance Marketplace (HIM)**: Also known as a Health Insurance Exchange (HIE), these are new transparent and competitive health insurance Marketplaces/Exchanges where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state will have a Marketplace/Exchange in 2014 and beyond.

**Health Insurance Portability and Accountability Act (HIPAA)**: HIPAA is a 1996 law that eliminated discrimination by health insurers for those with pre-existing medical conditions. It also sets important privacy and security standards for health care entities so that consumers’ health information is protected.

**Health Maintenance Organization (HMO)**: An insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO. Generally won’t cover out-of-network care except in an emergency, and may require you to live or work in its service area to be eligible for coverage.

**Health Resources and Services Administration (HRSA)**: An agency of the U.S. Department of Health and Human Services that works to improve access to health care services for people.

**Health Savings Account (HSA)**: A medical savings account available to taxpayers who are enrolled in a High-Deductible Health Plan. The funds contributed to the account aren’t subject to federal income tax at the time of deposit. Funds must be used to pay for qualified medical expenses. Unlike a Flexible Spending Account (FSA), funds roll over year to year if you don’t spend them.

**Health Status**: Refers to your medical conditions (both physical and mental health), claims experience, receipt of healthcare, medical history, genetic information, evidence of insurability and disability.

**High-Deductible Health Plan (HDHP)**: A plan that features higher deductibles than traditional insurance plans. HDHPs can be combined with a health savings account or a health reimbursement arrangement to allow you to pay for qualified out-of-pocket medical expenses on a pre-tax basis.

**High-Risk Pool (HRP) Plan (State)**: High-risk pool plans offer health insurance coverage that is subsidized by a state government. Not all states offer high-risk pools, and those that do have distinct rules in terms of cost, eligibility and benefits. Many high-risk pools will be phased out following the implementation of plans in the Marketplaces/Exchanges.
Home and Community-based Services (HCBS): Services and support provided by most state Medicaid programs in your home or community that gives help with such daily tasks as bathing or dressing. Covered when provided by care workers or, if your state permits it, by your family.

Home Healthcare: Healthcare services and supplies in your home that a doctor prescribes.

Hospital Readmission: A return by a patient to the hospital following discharge for the same or related care within 30, 60 or 90 days. Hospital readmissions are often used in part to measure the quality of hospital care.

Individual Health Insurance Policy: Policies for people who aren’t connected to job-based coverage. Individual health insurance policies are regulated under state and federal 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.).

Individual Mandate: Also known as “individual responsibility,” under the Affordable Care Act. Starting in 2014, you must be enrolled in a health insurance plan that meets basic minimum standards. If you aren’t, you may be required to pay a penalty. Exempt from this are people with very low income for whom coverage is unaffordable, or for other reasons, including religious beliefs.

In-Network Coinsurance: The percent (for example, 20%) you pay of the allowed amount for covered health care services to providers who contract with your health insurance or plan. In-network coinsurance usually costs you less than out-of-network coinsurance.

In-Network Copayment: A fixed amount (for example, $15) you pay for covered health care services to providers who contract with your health insurance or plan. In-network copayments usually are less than out-of-network copayments.

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.

In-Person Assisters (IPA): Individual or organizations that are trained to provide help to consumers, small businesses, and their employees as they look for health coverage options through the Marketplace/Exchanges. IPAs help consumers complete eligibility and enrollment forms and are required to be unbiased. Their services are free to consumers. (See Fact Sheet).

Lifetime Limit: A cap on the total lifetime benefits your insurance policy will cover (also known as a lifetime cap). Before passage of the ACA, many insurers set a lifetime dollar limit on benefits (like $1 million) and would not pay for covered services once the limit was hit. As of September 2010, non-grandfathered health plans can no longer set lifetime dollar limits on the Essential Health Benefits (EHBs). Plans can continue to limit specific benefits by number (for example, covering only a certain number of visits). (See Fact Sheet).

Long-Term Care (LTC): Medical and nonmedical services provided to people who are unable to perform basic activities of daily living such as dressing or bathing. Long-term supports and services can be provided at home, in the community, in assisted living or in nursing homes. Individuals may need long-term supports and services at any age. Medicare and most health insurance plans don’t pay for long-term care.
Managed Care Plan: A plan that generally provides comprehensive health services to its members, and offers financial incentives for patients to use the providers who belong to the plan. Examples include: health maintenance organizations (HMOs), preferred provider organizations (PPOs), exclusive provider organizations (EPOs) and point of service plans (POSs).

Managed Care Provisions: Features within health plans that provide insurers with a way to manage the cost, use and quality of healthcare services received by group members. Examples of managed care provisions include:

- **Preadmission certification** - Authorization for hospital admission given by a healthcare provider to a group member prior to hospitalization. Failure to obtain a preadmission certification in nonemergencies reduces or eliminates the healthcare provider’s obligation to pay for services rendered.

- **Utilization review** - The process of reviewing the appropriateness and quality of care provided to patients. Utilization review may take place before, during or after the services are rendered.

- **Preadmission testing** - Requirement designed to encourage patients to obtain necessary diagnostic services on an outpatient basis prior to nonemergency hospital admission. The testing is designed to reduce the length of a hospital stay.

- **Nonemergency weekend admission restriction** - A requirement that imposes limits on reimbursement to patients for nonemergency weekend hospital admissions.

- **Second surgical opinion** - A cost-management strategy that encourages or requires patients to obtain the opinion of another doctor after a physician has recommended that a nonemergency or elective surgery be performed. Programs may be voluntary or mandatory in that reimbursement is reduced or denied if the participant does not obtain the second opinion. Plans usually require that such opinions be obtained from board-certified specialists with no personal or financial interest in the outcome.

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 from state to state, and may have a different name in your state.

Medical Loss Ratio (MLR): A financial tool that measures the percentage of premium dollars taken in by a health insurer that are spent on customers’ medical claims and quality improvement activities as compared with money spent on overhead expenses, including salaries, administrative costs and agent commissions. The Affordable Care Act sets minimum medical loss ratios for different markets, as do some state laws. If your plan does not meet an applicable MLR, then you or your employer could receive a refund.

Medically Necessary: Services or supplies that are needed for the diagnosis or treatment of your health condition and meet accepted standards of medical practice.

Medical Underwriting: A process used by insurance companies that uses your health status when you’re applying for health insurance coverage to determine whether to offer you coverage, at what price and with what exclusions or limits.
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-State Renal Disease (ESRD)/Medicare is composed of four parts:

- **Medicare Part A**: Hospital insurance that helps cover inpatient care in hospitals, skilled nursing facilities, hospice and home care. Most beneficiaries are enrolled in Part A automatically.
- **Medicare Part B**: Medical coverage that helps to cover medically necessary services like doctors' services, outpatient care, home health services and other medical services. Part B also covers some preventive services, and physician-administered drugs like immunoglobulin replacement therapy for patients with most kinds of primary immunodeficiency diseases. Most beneficiaries are enrolled in Part B automatically.
- **Medicare Part C/Medicare Advantage (MA)**: A type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A and Part B benefits. There are many types of Medicare Advantage Plans (MAP) include HMOs, PPOS, Private Fee-for-Service Plans, Special Needs Plans and Medicare Medical Savings Account Plans. If you're enrolled in an MA plan, Medicare services are covered through the plan and aren't paid for under Parts A and B. Most Medicare Advantage Plans offer prescription drug coverage.
- **Medicare Part D**: An optional program that provides prescription drug coverage. There are two ways to get Medicare prescription drug coverage: through a Medicare Prescription Drug Plan or a Medicare Advantage Plan that includes drug coverage. These plans are offered by insurance companies and other private companies approved by Medicare.

**Minimum Essential Coverage**: The type of coverage an individual needs to have to meet the individual responsibility requirement under the Affordable Care Act. This includes individual market policies, job-based coverage, Medicare, Medicaid, CHIP, TRICARE and certain other coverage.

**Minimum Value**: A health plan meets this standard if it’s designed to pay at least 60% of the total cost of medical services for a standard population. Starting in 2014, individuals offered employer-sponsored coverage that provides minimum value and that’s affordable won’t be eligible for a premium tax credit if they choose to purchase health insurance through the Marketplace/Exchange.

**Modified Adjusted Gross Income (MAGI)**: The figure used to determine eligibility for lower costs in the Marketplace/Exchange and for Medicaid and CHIP. Generally, modified adjusted gross income is your adjusted gross income plus any tax-exempt Social Security, interest, or foreign income you have.

**Navigator**: An individual or organization that’s trained to help consumers, small businesses, and their employees as they look for health coverage options through the Marketplace/Exchanges established pursuant to the Affordable Care Act. Navigators assist consumers with completing eligibility and enrollment forms. These individuals and organizations are required to be unbiased and their services are free to consumers (See Fact Sheet).

**New Plan**: As referenced in the Affordable Care Act, a health plan that is not grandfathered and therefore subject to the reforms in the Affordable Care Act. In the individual health insurance market, this is a plan that your family is purchasing for the first time. In the group health insurance market, this is a plan that your employer is offering for the first time. New employees and new family members may be added to existing grandfathered group plans – so a plan that is new to you and your family may still be a grandfathered plan.

In both the individual and group markets, a plan that loses its grandfathered status will be considered a new plan. This happens when it makes significant changes to the plan, such as reducing benefits or increasing cost-sharing for enrollees (See Grandfathered Plan).
Nondiscrimination: A requirement that job-based insurance not discriminate based on health status by denying or restricting health coverage, or charging more. Job-based plans can restrict coverage based on other factors such as part-time employment that aren’t related to health status.

Open Enrollment Period (OEP): The time period set up to allow you to choose from available plans, usually once a year.

Out-of-Network Coinsurance: The percentage (for example, 40%) you pay of the allowed amount for covered health care services to providers who don’t contract with your health insurance or plan. Out-of-network (OON) coinsurance usually costs you more than in-network coinsurance. The amount of coinsurance you pay may be more when you use an out-of-network provider.

Out-of-Network Copayment: A fixed amount (for example, $30) you pay for covered health care services from providers who don’t contract with your health insurance or plan. Out-of-network (OON) copayments usually are more than in-network copayments. The copayment you pay may be more when you use an out-of-network provider.

Out-of-Network Providers: A duly licensed or certified institution or health professional not under contract with your insurance provider.

Out-of-Pocket (OOP) Limit: The maximum amount you will be required to pay for covered services in a year, before the plan covers 100% of all costs. Generally, this includes the deductible, coinsurance, and copayments (varies from plan to plan), but not premiums. Plans can set different out-of-pocket limits for different services, and some plans do not have out-of-pocket limits.

Patient-Centered Outcomes Research Institute (PCORI): Institute authorized by the ACA to conduct comparative effectiveness research (CER).

Pharmacy Benefit Manager (PBM): Health plans and sponsors contract with Pharmacy Benefit Managers to handle the claims processing and administrative functions involved with prescription drug programs. In addition to processing and paying claims, PBMs develop and maintain a program drug formulary, contract with participating pharmacies and negotiate discounts and rebates with drug manufacturers.

Plan Year: A 12-month period of benefits coverage under a health plan. This 12-month period might be different than the calendar year, depending on when your health plan renews.

Platinum Health Plan: A plan in the health insurance Marketplaces/Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 90%.

Policy Year: A 12-month period of benefits coverage under an individual health insurance plan. This 12-month period might be different than the calendar year.

Point-of-Service Plan (POS) Plan: A type of plan in which you pay less if you use doctors, hospitals and other healthcare providers that belong to the plan’s network. POS plans may also require you to get a referral from your primary care doctor in order to see a specialist.

Preauthorization: A decision by your health insurer or plan that a health care service, treatment plan, prescription drug or durable medical equipment is medically necessary. Sometimes called prior authorization, prior approval or precertification. Your health insurance or plan may require preauthorization for certain services before you receive them, except in an emergency. Preauthorization isn’t a promise your health insurance or plan will cover the cost.
Pre-Existing Condition: With certain limited exceptions, a pre-existing condition is any condition (physical, mental or a disability) for which medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period before you enrolled in a health insurance plan. Before passage of the ACA, insurers could either not offer health insurance to you if you had a pre-existing condition or could refuse to cover any services related to a pre-existing condition (known as a pre-existing condition exclusion). As of September 23, 2010 (for children) and as of January 1, 2014 (for adults), health insurance plans can’t refuse to cover you or charge you more just because you have a pre-existing health condition. Coverage for pre-existing conditions begins immediately.

Pre-Existing Condition Insurance Plan (PCIP): A health insurance program created by the ACA beginning in 2010 and scheduled to expire December 31, 2013, that provided coverage for individuals that were uninsured, had pre-existing conditions and were denied health coverage as a result. Every state had a PCIP program. In some states it was operated by the state, while in others it was operated by the federal government.

Preferred Provider Organization (PPO): A type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. You pay less if you use providers who belong to the plan’s network. You can use doctors, hospitals and providers outside of the network for an additional cost.

Premium: A monthly or annual 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.

Prescription Drug Coverage: Health insurance or plan that helps pay for prescription drugs and medications.

Preventive Services: Routine healthcare that includes screenings, checkups, and patient counseling to prevent illnesses, disease or other health problems.

Primary Care: Health services that cover a range of prevention, wellness and treatment options for common illnesses. Primary care providers (PCP) include doctors, nurses, nurse practitioners and physician assistants. They often maintain long-term relationships with you, and advise and treat you on a range of health-related issues. They may also coordinate your care with specialists.

Qualified Health Plan (QHP): Under the Affordable Care Act, starting in 2014, an insurance plan that is certified by a Marketplace/Exchange, provides essential health benefits, follows established limits on cost-sharing (like deductibles, copayments, and out-of-pocket maximum amounts) and meets other requirements. A qualified health plan will have a certification by each Marketplace/Exchange in which it is sold.

Qualifying Event: Any event or occurrence such as death, termination of employment, divorce or a terminal illness that changes an employee’s eligibility status and permits an acceleration or continuation of benefits or coverage under a group health plan. The term is most frequently used in reference to COBRA eligibility.

Rate Review: A process that allows state insurance departments to review rate increases before insurance companies can apply them to you.

Referral: A written order from your primary care doctor for you to see a specialist or get certain medical services. In many Health Maintenance Organizations (HMOs), you need to get a referral before you can get medical care from anyone except your primary care doctor. If you don’t get a referral first, the plan may not pay for the services.
Rehabilitative/Rehabilitation Services: Health care services that help you keep, get back, or improve skills and functioning for daily living that have been lost or impaired because you were sick, hurt, or disabled. These services may include physical and occupational therapy, speech-language pathology, and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.

Rescission: The retroactive cancellation of a health insurance policy. Insurance companies will sometimes retroactively cancel your entire policy if you made a mistake on your initial application when you buy an individual market insurance policy. Under the Affordable Care Act, rescission is illegal except in cases of fraud or intentional misrepresentation of material fact as prohibited by the terms of the plan or coverage.

Rider (Exclusionary Rider): An amendment to an insurance policy. Some riders add coverage while other riders exclude coverage (known as exclusionary rider). Example: You buy a maternity rider to add coverage for pregnancy to your policy. An exclusionary rider is an amendment permitted in individual policies that permanently excludes coverage for a health condition, body part or body system (such as a certain disease state or disability). Beginning January 1, 2014, no exclusionary riders will be permitted in any health insurance plan.

Risk Adjustment: A statistical process that takes into account the underlying health status and health spending of the enrollees in an insurance plan when looking at their healthcare outcomes or healthcare costs.

Self-Insured Plan: Type of plan usually present in larger companies where the employer itself collects premiums from enrollees and takes on the responsibility of paying employees’ and dependents’ medical claims. These employers can contract for insurance services such as enrollment, claims processing, and provider networks with a third party administrator, or they can be self-administered.

Silver Health Plan: A plan in the health insurance Marketplaces/Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 70%.

Skilled Nursing Facility (SNF) Care: Skilled nursing care and rehabilitation services provided on a continuous, daily basis, in a skilled nursing facility. Example: Physical therapy or intravenous injections that can only be given by a registered nurse or doctor.

Small Business Health Options Program (SHOP): The Marketplace/Exchange available to small businesses under the Affordable Care Act. Small businesses buying plans in the SHOP select the plan and decide how much they pay toward employee premiums. Participating small businesses may qualify for a small business health tax credit worth up to 50% of their premium costs.

Social Security Disability Income (SSDI): Income payable by the federal government to individuals who are determined to be totally disabled.

Special Enrollment Period (SEP): A time outside of the open enrollment period during which you and your family have a right to sign up for job-based health coverage. Job-based plans must provide a special enrollment period of 30 days following certain life events that involve a change in family status (such as marriage or birth of a child) or loss of other job-based health coverage.

Special Healthcare Need: The healthcare and related needs of children who have chronic physical, developmental, behavioral or emotional conditions. Such needs are of a type or amount beyond that required by children generally.
Specialty Pharmacy Provider (SPP): A pharmacy that is designated to provide specialized medication for complex, genetic, rare, and chronic health conditions. Specialty pharmacy providers may provide home health or nursing services.

State Based Marketplace/State Based Exchange (SBM/SBE): One of the three types of Marketplace/Exchange options for states under the Affordable Care Act. States opting for an SBM/SBE will manage their own Marketplace/Exchange in accordance with applicable federal laws.

State Continuation Coverage: A state-based requirement similar to COBRA that applies to group health insurance policies of employers with fewer than 20 employees. In some states, state continuation coverage rules also apply to larger group insurance policies and add to COBRA protections. Example: In some states, if you’re leaving a job-based plan, you must be allowed to continue your coverage until you reach the age of Medicare eligibility.

State Partnership Marketplace/State Partnership Exchange (SPM/SPE): One of the three types of Marketplace/Exchange options for states under the Affordable Care Act. States opting for an SPM/SPE will have a Marketplace/Exchange that is run by the federal and state government jointly.

Summary of Benefits and Coverage (SBC): The ACA requires plans to offer this easy-to-read summary that lets you make apples-to-apples comparisons of costs and coverage between health plans. You’ll get the “Summary of Benefits and Coverage” (SBC) when you shop for coverage on your own or through your job, renew or change coverage, or request an SBC from the health insurance company.

Supplemental Security Income (SSI): A monthly benefit paid by Social Security to people with limited income and resources who are disabled, blind, or 65 or older. SSI benefits are different than Social Security retirement or disability benefits.

Third Party Administrator (TPA): An individual or firm hired by an employer to handle claims processing, pay providers and manage other functions related to the operation of health insurance. The TPA is not the policyholder or the insurer. The TPA may often be a company you associate with health insurance, such as Aetna or Blue Cross, but in this role it is not the actual insurer but simply managing the plan on behalf of the employer.

TRICARE: A healthcare program for active-duty and retired uniformed services members and their families.

Uncompensated Care: Healthcare or services provided by hospitals or healthcare providers that don’t get reimbursed. Often uncompensated care arises when people don’t have insurance and cannot afford to pay the cost of care.

Urgent Care: Care for an illness, injury or condition serious enough that a reasonable person would seek care right away, but not so severe as to require emergency room care.

Usual, Customary and Reasonable (UCR) Charges: A healthcare provider’s usual fee for a service that does not exceed the customary fee in that geographic area, and is reasonable based on the circumstances. Instead of UCR charges, PPO plans often operate based on a negotiated (fixed) schedule of fees that recognize charges for covered services up to a negotiated fixed dollar amount. Conventional indemnity plans typically operate based on UCR charges.
**Veteran's Health Benefits**: Veterans may be eligible for a broad range of services, including health care benefits, through the Veteran’s Administration.

**Waiting Period (Job-Based coverage)**: The time that must pass before coverage can become effective for an employee or dependent, who is otherwise eligible for coverage under a job-based health plan. Applies to all new employees, and is not based on health status. This is different than a pre-existing condition exclusion period, which is applied to individual employees and is based on health status.

**Well-Baby/Well-Child Visits**: Routine doctor visits for comprehensive preventive health services that occur when a baby is young and annual visits until a child reaches age 21. Services include physical exam and measurements, vision and hearing screening, and oral health risk assessments.

**Wellness Programs**: A program intended to improve and promote health and fitness that’s usually offered through the work place, although insurance plans can offer them directly to their enrollees. The program allows your employer or plan to offer you premium discounts, cash rewards, gym memberships and other incentives to participate. *Examples*: programs to help you stop smoking, diabetes management programs, weight loss programs and preventive health screenings.

Sources:
- [www.healthcare.gov/glossary](http://www.healthcare.gov/glossary)
- [www.hrsa.gov](http://www.hrsa.gov)
- [www.healthit.gov](http://www.healthit.gov)
- [www.cms.gov](http://www.cms.gov)
- [www.hhs.gov](http://www.hhs.gov)
- [www.pcori.org/](http://www.pcori.org/)
- [www.va.gov](http://www.va.gov)
- [www.cdc.gov](http://www.cdc.gov)
- [www.dol.gov](http://www.dol.gov)
- [www.healthinsurance.org](http://www.healthinsurance.org)
Making Benefits Easier to Understand: Summary of Benefits and Coverage (SBC) and Uniform Glossary

Under the Affordable Care Act (ACA), all health insurance companies and employers offering coverage will have to use the same standard form to summarize the benefits and coverage offered under the plan. With each insurance company and employer using the same form, consumers can more clearly compare plans and choose one, and can better understand the benefits and costs they have under the plan in which they are enrolled.

The new, standard summaries will include information on important elements of the coverage, such as the deductible, co-pays, services not covered by the plan, and whether enrollees need a referral to see a specialist—all presented in a way that makes it easier for consumers to make an apples-to-apples comparison of their coverage options. The Summary of Benefits and Coverage (SBC) must also include “coverage examples” of two common medical conditions (managing diabetes and having a baby), offered in a format modeled after the “Nutrition Facts” label consumers use now to make informed decisions about food choices. All health insurance companies and employer plans must also provide consumers with a uniform glossary of terms commonly used in health insurance coverage, such as “deductible,” “non-preferred provider,” and “co-insurance.”

Some additional points to keep in mind:

• If an employer offers some benefits under a separate policy, such as prescription drug coverage or mental health services, they can provide multiple forms, which may be confusing. Starting in late 2013, employers will have to combine all information on one form.

• The SBC requirement applies to all plans, whether you buy it on your own or get it from an employer.

• Health plans must automatically provide the standard summary to a person who completes an application for coverage or to any person who requests a summary (within seven days). Employers must provide the summary when coverage renews (30 days prior to renewal) and upon request (within seven business days). Employers must also provide an updated summary if there is a substantial change in coverage during the plan year.


To see the uniform glossary of terms, go to: http://www.cms.gov/CCIIO/Resources/Files/Downloads/uniform-glossary-final.pdf.
What If I Am Denied Coverage?
Appeals and Grievances

Dealing with insurance companies can be a complicated and frustrating endeavor and even more so when dealing with a chronic illness, such as a primary immunodeficiency disease. Should your insurance plan deny coverage of a medically necessary treatment, you could be left in an anxious situation not knowing how you will get your next dosage. Fortunately, there are options available to you that will allow you to appeal your insurance company’s decision. In addition to filing an appeal, you may also wish to speak with an insurance case manager, should your plan provide one, as a resource regarding your grievance.

Guarantees of the Affordable Care Act
The Affordable Care Act (ACA) includes new rules that spell out how your plan must handle your appeal (usually called an “internal appeal”). If your plan still denies payment after considering your appeal, the ACA permits you to have an independent review organization decide whether to uphold or overturn the plan’s decision. This final check is often referred to as an “external appeal.”

When your plan denies a claim, it is required they notify you of the reason the claim was denied, your right to file an internal appeal, your right to request an external review if your internal appeal was unsuccessful, and the availability of a Consumer Assistance Program (CAP) that can help you file an appeal or request a review (if your state has such a program).

How to File an Appeal
When you request an internal appeal, your insurance company may ask your provider for more information in order to make a decision about the claim. They should inform you of the deadline to send additional information and if a deadline is not given, call your insurer at the number on the back of your ID card. Remember, you should receive the denial in writing. Be proactive and call your insurance company.

Also, keep notes on every conversation you may have with your insurance company.

When you request an internal appeal, your plan must give you its decision within:

- 72 hours after receiving your request when you are appealing the denial of a claim for urgent care. If your appeal concerns urgent care, you may be able to have the internal appeal and external review take place at the same time.
- 30 days for denials of non-urgent care you have not yet received.
- 60 days for denials of services you have already received.

Steps in the Appeal Process
1. You have the right to appeal this decision in writing to the appropriate department. You can find the address to submit appeals in the denial letter, your coverage documents or by contacting your insurer using the member services telephone number on your ID card. Write a clear and simple letter providing:
   a) Pertinent clinical information regarding your health history and treatment history as well as your medical records documenting past drug trials and health history. Your prescribing physician should have these
   b) History of any adverse reactions or side effects, you have had to similar treatments
   c) If your insurer requires the prescribing physician to complete a drug authorization form, you should make sure this has been done; and,
   d) If you received a letter of denial for the treatment, ensure that the information provided directly addresses the reasons for the denial.
e) If the dispute is over the medical necessity of your treatment, your physician’s support in the form of a letter including studies supporting the benefit of the treatment in question is invaluable. Request that your physician write a letter of medical necessity. A service is medically necessary if it meets any one of the three standards below:

• The service or benefit will, or is reasonably expected to, prevent the onset of an illness condition, or disability.

• The service or benefit will, or is reasonably expected to, reduce or ameliorate the physical, mental or developmental effects of an illness, condition or disability.

• The service or benefit will assist the individual to achieve or maintain maximum functional capacity in performing daily activities taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age.

The letter should assert that the prescribed treatment is medically necessary and:

• Any product on the formulary would not be as effective and/or would be harmful to you.

• All other product or dosage alternatives on the plan’s formulary have been ineffective or caused harm, or based on sound clinical evidence and knowledge of the patient, are likely to be ineffective or cause harm.

f) Contact your insurer after submitting your request to make sure they have received it.

2. Your physician can also request a peer-to-peer review to discuss the specific reason why this type of treatment is needed for you if the initial appeal is unsuccessful.

3. If after internal appeal the plan still denies your request for payment or services, you can ask for an Independent External Review. This will be a reconsideration of your original claim by professionals with no connection to your insurance plan. Your plan must include information on your denial notice about how to request this review, do not assume this happens automatically. If the independent reviewers think your plan should cover your claim, your health plan must cover it.

How much these new ACA rules will change your current appeal rights depends on the state you live in and the type of plan you have. Some group plans may require more than one level of internal appeal before you are allowed to submit a request for an external review. However, all levels of the internal appeals process must be completed within the timeframes above.

These new rules apply only to new plans (purchased or created after 3/23/2010). Grandfathered plans do not have to comply with the new rules. However, over time all plans will lose that status and have to comply.
I Have Coverage, What Does the ACA Mean to Me? Individual Mandate

Requirement to Buy Coverage under the Affordable Care Act Beginning in 2014

Start here.

Do any of the following apply?
- You are part of a religion opposed to acceptance of benefits from a health insurance policy.
- You are an undocumented immigrant.
- You are incarcerated.
- You are a member of an Indian tribe.
- Your family income is below the threshold requiring you to file a tax return ($9,350 for an individual, $18,700 for a family in 2010."
- You have to pay more than 8% of your income for health insurance, after taking into account any employer contributions or tax credits.

There is no penalty for being without health insurance.

There is a penalty for being without health insurance.

Were you insured for the whole year through a combination of any of the following sources?
- Medicare
- Medicaid or the Children’s Health Insurance Program (CHIP)
- TRICARE (for service members, retirees, and their families).
- The veteran’s health program.
- A plan offered by an employer.
- Insurance bought on your own that is at least at the Bronze level.
- A grandfathered health plan in existence before the health reform law was enacted.

The requirement to have health insurance is satisfied and no penalty is assessed.

Yes

No

2014
Penalty is $95 per adult and $47.50 per child (up to $285 for a family) or 1.0% of family income, whichever is greater.

2015
Penalty is $325 per adult and $162.50 per child (up to $975 for a family) or 2.0% of family income, whichever is greater.

2016 and Beyond
Penalty is $695 per adult and $347.50 per child (up to $2,085 for a family) or 2.5% of family income, whichever is greater.

The penalty is pro-rated by the number of months without coverage, though there is no penalty for a single gap in coverage of less than 3 months in a year. The penalty cannot be greater than the national average premium for Bronze level coverage in an Exchange. After 2016, penalty amounts are increased annually by the cost of living.

Key Facts:
- Premiums for health insurance bought through Exchanges would vary by age. The Congressional Budget Office estimates that the national average annual premium in an Exchange in 2016 would be $4,500-5,000 for an individual and $12,000-12,500 for a family for Bronze coverage (the lowest of the four tiers of coverage that will be available).
- In 2010 employees paid $899 on average towards the cost of individual coverage in an employer plan and $3,997 for a family of four.
- A Kaiser Family Foundation subsidy calculator illustrating premiums and tax credits for people in different circumstances is available at http://healthreform.kff.org/subsidycalculator.aspx

IDF Health Insurance Toolkit for Patients with Primary Immunodeficiency Diseases and Their Families
### Does My Current Plan Meet ACA Requirements?

#### Standards for Health Insurance Plans by Plan Type

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Individual plans and new non-plans</th>
<th>Small-group plans</th>
<th>Grandfathered plans</th>
<th>Non-grandfathered employer-sponsored plans</th>
<th>Self-insured employer-sponsored plans</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No lifetime or annual limits:</strong> Plans are now prohibited from limiting the lifetime dollar value of benefits. Annual limits are currently restricted to between $1.25 million and $2 million and are banned completely beginning Jan. 1, 2014. Some plans have been granted waivers to the annual limit requirements through 2013.</td>
<td>○</td>
<td>○</td>
<td>○ (ban doesn’t apply to grandfathered individual plans)</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Dependents under age 26:</strong> Plans must allow adult children under age 26 to enroll in a parent’s plan effective now. Through 2013, a grandfathered employer sponsored plan is permitted to limit coverage of adult children to those that are ineligible for another employer-sponsored plan.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Plan administrative costs:</strong> Plans must now provide rebates to consumers if the percentage of premiums spent on medical services and quality improvement activities falls below 85 percent for large group plans or 80 percent for small group and individual plans (or higher standard set by state, if applicable).</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Preventive care:</strong> Plans must now offer first dollar coverage (no cost sharing or deductible) for certain preventive services.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Internal appeals and external review:</strong> Plans are required to provide a fair internal appeal and independent external review process for adverse coverage determinations.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Patient protections:</strong> Plans are now prohibited from requiring a referral to see an OB-GYN and from requiring prior authorization or higher cost sharing for out-of-network emergency services.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td><strong>Out-of-pocket maximums:</strong> Plans must limit out-of-pocket costs to $6,400 for single coverage and $12,800 for family coverage effective in 2014.</td>
<td>○</td>
<td>○</td>
<td>○ (postponed to 2015)</td>
<td>○ (postponed to 2015)</td>
<td>○</td>
</tr>
<tr>
<td><strong>Pricing:</strong> Medical underwriting is prohibited and rating variation is only allowed based on age (3:1 ratio), tobacco (1.5:1.0), family composition and geography effective in 2014.</td>
<td>○</td>
<td>○</td>
<td>○ Small group only</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Deductibles:</strong> Plans must limit deductibles to $2,000 for single coverage and $4,000 for family coverage in 2014. Plans may exceed limit if they cannot reasonably reach the specified actuarial value.</td>
<td>○</td>
<td>○</td>
<td>○ Small group only</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Essential health benefits:</strong> Plans must cover preventive and primary care, emergency, hospital, physician, outpatient, maternity and newborn care, pediatric (including dental and vision), medical/surgical care, prescription drugs, lab, and mental health and substance abuse, effective in 2014. States set benchmarks within each category. Except for catastrophic plans, cost sharing must be limited to provide a minimum actuarial value of 60% and designed to offer one of four “metal” levels of coverage tied to specific actuarial values.</td>
<td>○</td>
<td>○</td>
<td>○ Small group only</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Where Do I Go for Help With Insurance Questions and/or Problems?

The IDF Patient Insurance Center provides information regarding insurance issues, as well as other possible sources of assistance, for you and your family. IDF also has a Patient Advocate who provides individualized assistance for patients and families who face insurance problems including denials for therapy, procedures related to PI, reimbursement complications and help getting insurance. Our Patient Advocate can also help you locate a specialist, connect with peer support and more. You can find information about these resources at http://primaryimmune.org/services/patient-insurance-center.

Many states offer direct help with problems or questions about health insurance, through either Consumer Assistance Programs, the Department of Insurance or the Department of Labor (if you are in a self-insured plan). To find out if your state has a Consumer Assistance Program, you can visit www.healthcare.gov. In addition, the Marketplace will offer several kinds of assistance to help you apply for coverage and choose a plan that meets your needs, visit https://www.healthcare.gov/contact-us/ to find the following resources:

- Online questions and answers
- Online chat
- Toll-Free call center, available 24/7: 800-318-2596 (TTY 855-889-4325)

Local help will also be available through insurance agents and brokers as well as government agencies such as State Medicaid and Children’s Health Insurance Program (CHIP) offices. All states will have additional organizations/people trained and certified to help you understand your health coverage options and to help you enroll in a plan. Depending on which state you live in and who is providing the service, these organizations may be known as Navigators, In-Person Assisters or Certified Application Counselors. A list of the services available by these organizations can be found in the chart below. To find help in your area visit https://LocalHelp.HealthCare.gov or view the Consumer Resources section (page 26) of this toolkit.
What Is the Health Insurance Marketplace?
Marketplace Primer

A New Marketplace for Individuals and Small Businesses

Marketplaces/Exchanges are essentially organized insurance Marketplaces, which are intended to provide individuals and small business owners with a “one-stop-shop” to compare and purchase health insurance. They will use the power of a large insurance risk pool to generate competition among health plans based on quality and cost. Marketplaces will also have “no wrong door” enrollment in which individuals and families apply for coverage and the Marketplace will determine the program they are eligible for and enroll them, whether it is in Medicaid, CHIP or subsidized Marketplace plans. These new marketplaces will be “open for business” by January 1, 2014 and will serve as the gateway for an estimated 29 million people to access coverage by 2019.

The ACA creates two types of Marketplaces:

1. The American Health Benefit Marketplaces for individuals; and
2. Small Business Health Options Program (SHOP) Marketplaces for small business owners.

While the federal law sets minimum standards and delegates certain responsibilities to the states.

Minimum Standards for Health Insurance Marketplaces

Help consumers compare plans and enroll in coverage: The state Marketplaces must allow consumers and small business owners to compare and purchase insurance plans in person, through the mail, phone, or a web portal. The portal will also have comparative information about participating insurers, including covered benefits, premium rates, cost-sharing, provider networks, and financial information such as the “medical loss ratio,” or the amount plans spend to pay claims relative to overhead costs. Consumers will be able to use an electronic calculator to determine their actual cost of coverage that takes into account any premium subsidy they are eligible to receive. The Marketplaces are also required to maintain a toll-free consumer assistance hotline and make all information available in a culturally and linguistically appropriate manner.

Marketplaces will facilitate enrollment in plans by offering annual open enrollment periods, and provide a standardized form that all exchange participants may use to enroll. The law also provides grants to consumer assistance programs (CAP) and requires Marketplaces to fund “Navigators,” organizations that can help inform consumers about the availability of qualified coverage and financial assistance, and help enroll eligible individuals in the coverage that's right for their needs.

In addition to Navigators, in-person assisters (IPAs) and certified application counselors (CACs) may be available to assist consumers.

1The terms Marketplace and Exchanges have the same definition and are often used interchangeably. Originally termed Exchanges, the federal government renamed these “one-stop-shops” Marketplaces.

2Funding, training and availability for the various consumer assistance programs varies and availability is based on the type of Marketplace (state, federal or partnership).
Certify participating plans: The ACA envisions that Marketplaces will be more than just clearinghouses that connect consumers with health plans. Rather, Marketplaces may offer only “qualified” health plans (QHPs) that meet minimum requirements related to marketing and network adequacy, and offer at least a minimum essential health benefits (EHB) package. The comprehensiveness of coverage in each plan will be standardized into four “tiers”: bronze, silver, gold and platinum, with bronze plans being the least generous and platinum being the most. All participating plans must offer at least one silver and one gold option.

They must also “decertify” any health plans that use marketing techniques or benefit designs that discourage sicker individuals from enrolling. The law also encourages Marketplaces to contain premium increases, by allowing them to exclude health plans that have a history of unreasonable premium increases.

Administer subsidies and help individuals and employers meet their coverage requirements: Marketplaces will be responsible for determining who is eligible for premium tax credits (available to those with income up to four times the poverty level), and cost sharing subsidies certifying individuals who are exempt from the individual mandate, and sharing that information with the Internal Revenue Service. They will also need to verify whether employees are eligible for premium subsidies through the Marketplace based on whether they have access to “affordable, adequate” employer-sponsored coverage.

Coordinate with state Medicaid and CHIP programs: Many individuals and families may attempt to get coverage through their state Marketplace, but may be eligible for Medicaid or CHIP. In some families, children will be eligible for Medicaid or CHIP, but their parents will be eligible for premium tax credits to purchase private insurance. One of the most challenging and important aspects of the ACA is the requirement that states create a “no wrong door” policy for individuals and families seeking coverage. States must establish procedures for screening applicants no matter where they initially seek coverage (whether through the Marketplace, Medicaid or CHIP), and enrolling them in the appropriate program, without making applicants go through additional, burdensome steps to find out which program they are eligible for.

It is also vital that state Marketplaces coordinate with Medicaid and CHIP programs because, as their income fluctuates, many people will move back and forth between subsidized commercial coverage in the Marketplaces and eligibility for public programs. The ACA makes changes intended to create a seamless eligibility and enrollment system:

- A new income standard, the Modified Adjusted Gross Income (MAGI), will be used when determining eligibility for the exchange subsidies, CHIP, and most populations under Medicaid.

- States must use a single, streamlined application form developed or approved by the Department of Health and Human Services (HHS) to enroll people in exchange subsidies, Medicaid, CHIP. States must also coordinate benefits for families who have some members enrolled in Medicaid and CHIP, and others that receive premium subsidies for commercial insurance.

---

3In 2012, 400 percent of the federal poverty level is $45,000 for an individual and $92,000 for a family of four. The poverty level is adjusted annually to reflect inflation and vary by family size.
· Establish electronic interfaces that will enable the exchange of information between programs.

· Marketplaces and Medicaid agencies must operate linked web portals through which families can obtain information on their eligibility for the different programs and enroll in coverage. States must accept an electronic signature for all programs, and use data matching to federal databases whenever possible to establish, verify, and update eligibility.

**Hold health plans accountable:** The ACA sets out new requirements for transparency and plan disclosure that will give consumers unprecedented access to information about benefits, cost sharing, and plans’ business practices, as well as enhance regulators’ ability to identify and crack down on “bad behavior.” For example, plans must provide a standardized summary of benefits to consumers that uses uniform definitions of insurance and medical terms, breaks down and describes cost-sharing charges, and details exceptions and limitations on coverage, all in culturally and linguistically appropriate and easily understandable language.

Plans must also provide information to consumers on the availability of in and out-of-network providers. Further, plans must provide a “coverage facts label” that illustrates examples of an enrollee’s likely cost-sharing under two common scenarios: delivering a baby or managing diabetes.

For plans to be certified to participate in the Marketplaces, the new law requires them to disclose information on certain business practices, such as claims payment policies and practices, financial disclosures, enrollment and disenrollment, the number of claims denied, rating practices, cost-sharing and payments for out-of-network coverage, enrollee rights and other information as required by HHS.

**Improve health plan quality and value:** To encourage quality improvement, plans must report to HHS and their enrollees on what programs they are implementing to improve health outcomes, reduce hospital readmissions, implement patient safety and error reduction programs, promote prevention and wellness, and reduce health disparities. HHS will post these reports on www.healthcare.gov.

**Marketplaces Vary by State**

It is important to understand that while state Marketplaces must meet certain standards and perform key functions, there is considerable flexibility for states in designing and operating their Marketplaces. States can operate their own Marketplaces alone or in partnership with HHS, or can default to complete federal operation of the Marketplace. Depending on who is operating the Marketplace, key policies, procedures and governance issues may differ. To date, states have made a variety of decisions concerning the governance of their Marketplaces. To learn more about your state’s Marketplace, visit www.healthcare.gov.
What Level of Coverage is Available through the Marketplace?

Standardized Health Plans: Four Levels of Coverage

Beginning in 2014, all new health plans sold to individuals and small businesses will need to meet new requirements for standardization in the scope and value of health insurance coverage. Researchers have found that too many plan choices can confuse consumers and give more power to insurers to use benefit design to attract and enroll healthier people and avoid individuals with high cost health conditions. Standardization of plan levels of coverage will help individuals and businesses make apples-to-apples comparisons among insurance plan options and help guard against insurance company efforts to use benefit design to cherry pick the healthiest people.

Under the Affordable Care Act (ACA) health plans will be required to provide four levels of coverage, sometimes referred to as metal tiers: Bronze, Silver, Gold and Platinum.

All plans offered within the individual and small group markets, both inside and outside of the Health Insurance Marketplace must offer the same comprehensive package of items and services, known as essential health benefits (See Glossary: Essential Health Benefits).

While the scope of benefits will be the same among the plans, the share of the costs the plan will pay for those benefits will vary across the four levels of coverage. Bronze plans will be the least generous, with higher out-of-pocket costs for covered benefits, and platinum plans will be the most generous, with less cost-sharing.

However, no plan will be allowed to impose total out-of-pocket costs – deductibles, copayments or other forms of cost sharing – greater than those imposed by high deductible plans (for 2014, the limit will be $6,350 for an individual and $12,700 for a family). However, it is important to note that the out-of-pocket limit applies to care obtained in-network for essential health benefits. Spending for out-of-network care and services that are outside the essential health benefits will not count toward the out-of-pocket limit.

How will the levels of coverage differ?
The division of health plan versus patient costs is shown below for each category of health insurance plan. This does not necessarily mean that for each individual medical service the patient pays a given co-insurance percentage, but rather the percentage refers to the amount of overall medical and drug costs the patient will be responsible for through deductibles, co-payments and co-insurance.

**Bronze Plan (60-40)**
- Characterized with less expensive premiums
- While the premium may be low, OOP costs are high
- Plan will pay for 60% of the medical and drug benefits and the buyer will pay 40% through deductibles, flat co-pays and/or co-insurance
- Individuals must determine whether this cost structure will work for them – especially if they have a rare and chronic disease requiring on-going and long term treatment
**Silver Plan (70-30)**
- One step up from the Bronze Plan
- Higher premiums than the Bronze Plan and more benefits
- Plan will pay for 70% of the medical and drug benefits and the buyer will pay 30% through deductibles, flat co-pays and/or co-insurance
- Individuals must determine whether this cost structure will work for them – especially if they have a rare and chronic disease requiring on-going and long term treatment

**Gold Plan (80-20)**
- Closer to the “average” plan that is currently offered by employers
- Premiums are higher than the Silver Plan and the medical and drug benefits are more generous
- Plan will pay for 80% of the medical and drug benefits and the buyer will pay 20% through deductibles, flat co-pays and/or co-insurance

**Platinum Plan (90-10)**
- Most generous of all plan offerings
- Premiums are higher than the Gold Plan and medical and drug benefits are more comprehensive
- Plan will pay for 90% of the medical and drug benefits and the buyer will pay 10% through deductibles, flat co-pays and/or co-insurance
- Many platinum plans will have an OOP limit that is lower than Bronze, Silver, and Gold plans. If you anticipate high OOP costs, it is likely that overall health costs, which include premiums and OOP spending, may be lower in such a platinum plan.

There will likely be a variety of plans available that fall under each of the above categories. State and the federal government determine which insurance products qualify to be sold through the Marketplace. All companies participating in the Marketplace must offer at least one silver-level plan and one gold-level plan. The number of choices available for each individual depends both on the state and federal government and on the insurance companies.

In addition to these four levels of coverage, young adults under the age of 30 and individuals exempted from the individual mandate because there is no available affordable coverage will be able to purchase “catastrophic” plans that cover essential benefits but have high deductibles.

Keep in mind that, in general, the lower the premium is the higher the OOP costs will be when a patient needs care. It is necessary for patients to calculate the costs for their current Ig treatment, number of trips to doctors’ offices, emergency room visits, treatments for other conditions and any other costs including drug costs. Once calculated, one needs to investigate how each plan will pay or not pay for those services and Ig products that a patient will need. If one’s expected OOP costs are greater than the premium for any particular plan, that plan is probably not the right plan. **It may very well turn out that a Gold or Platinum plan which have higher premiums may be the better buy when OOP costs and premium subsidies are taken into account – especially for those families who have rare and chronic diseases and need on-going and expensive treatments.**
What If I Can’t Afford Coverage?
Subsidies to Buy Coverage in the Health Insurance Marketplace

Premium tax credits are adjusted to take into account premium differences because of age, family size and geography. However, premium tax credits will not take into account a premium surcharge for tobacco use. Tobacco users must pay that surcharge out of pocket, without the help of premium tax credits.

Cost Sharing Subsidies
Individuals and families with income below 250% of poverty may also qualify for help paying out-of-pocket costs for services covered by their plan. This financial help, which is only available with a silver level plan, comes in two forms: a lower out-of-pocket limit and a higher actuarial value.

First, the cost-sharing subsidy will lower the out-of-pocket limit for eligible individuals to a fraction of what would apply otherwise. Second, the cost-sharing subsidy will effectively increase the actuarial value of the Silver level plan in which an individual enrolls, since the individual will pay less of the costs. Where the standard value of a Silver plan is 70% of total average costs for covered services, individuals eligible for the cost-sharing reduction will get a Silver plan that covers 73%, 87% or 94% of total average costs for covered services, depending on income. The subsidy goes directly to the insurer to reduce an enrollee’s out-of-pocket costs at the time the covered service is received.

Cost-Sharing Subsidies for Consumers Enrolled in a Silver Level Plan Based on Income

<table>
<thead>
<tr>
<th>Income</th>
<th>Actuarial Value</th>
<th>Oct-of-Pocket Limit</th>
</tr>
</thead>
<tbody>
<tr>
<td>100 – 150% FPL</td>
<td>94%</td>
<td>$2,250 individual; $4,500 family</td>
</tr>
<tr>
<td>150 – 200% FPL</td>
<td>87%</td>
<td>$2,250 individual; $4,500 family</td>
</tr>
<tr>
<td>200 – 250% FPL</td>
<td>73%</td>
<td>$5,250 individual; $10,500 family</td>
</tr>
</tbody>
</table>

1 In 2013, 400 percent of the federal poverty level is $46,000 for an individual and $94,000 for a family of four. The poverty level is adjusted annually to reflect inflation and vary by family size. “Minimum Essential Coverage” includes most types of coverage, including Medicare, Medicaid, and employer-sponsored coverage that is considered affordable and adequate.

2 The ACA requires insurers to offer four standardized levels of coverage: Bronze, Silver, Gold and Platinum. The four plan levels will vary based on the share of covered services paid by the plan. They range from the least generous level (Bronze, with an actuarial value of 60%) to the most generous level (Platinum, with an actuarial value of 90%).

3 The out-of-pocket limit for plans offered on Marketplaces in 2014 will be $6,350 for an individual plan and $12,700 for a family plan.
Consumer Resources

The Centers for Medicare & Medicaid Services Center for Consumer Information and Insurance Oversight (CCIIO), part of the Department of Health and Human Services (DHHS), provides national leadership in setting and enforcing standards for health insurance that promote fair and reasonable practices to ensure that affordable, quality health coverage is available to all Americans. The center also provides consumers with comprehensive information on coverage options currently available so they may make informed choices on the best health insurance for their family. Visit CCIIO at: http://cciio.cms.gov.

Families USA is a national nonprofit, nonpartisan organization dedicated to achieving high-quality, affordable healthcare for all Americans. For more than 30 years, it has been a highly effective consumer advocate organization at the national, state and community levels. In addition to providing user-friendly consumer resources, it offers extensive tools for state and local advocates, including state budget, healthcare-related legislation and implementation efforts. For access to the complete list of resources visit: http://www.familiesusa.org.

Immune Deficiency Foundation offers a variety of resources including our Patient Insurance Center and electronic personal health record, which can help patients keep track of all of their medical information. You can see all of our resources at http://primaryimmune.org.

Healthcare.gov is the website managed by the U.S. Department of Health and Human Services that educates Americans about the Affordable Care Act (ACA). The website has a tool to find individual state’s Consumer Assistance Programs, which states have established them, and other helpful sources for health insurance. Visit: http://www.healthcare.gov.

Kaiser Family Foundation website provides access to reports, surveys, issue briefs, charts, slides and fact sheets about health policy-related issues such as the number of uninsured, Medicare, Medicaid, healthcare costs, and health reform. Through the main site one can access the Health Reform Source, a site devoted entirely to health reform implementation, including explanations of the health reform law, public policy issues and easy access to relevant data, studies and developments. The main Website is: http://www.kff.org.


For states with a State-Based Marketplace, a list of Navigators must be obtained from the state’s Marketplace website. The following are links to State-Based Marketplace websites:

- California – Covered California – www.coveredca.com
- D.C. – DC Health Link – www.dchealthlink.com
- Idaho – Your Health Idaho – www.yourhealthidaho.org
- Minnesota – MN Sure – www.mn.gov/hix
- Nevada – Nevada Health Link – www.nevadahealthlink.com
Consumer Resources

- Oregon – Cover Oregon – www.coveroregon.com
- Rhode Island – Health Source Rhode Island – www.healthsourceri.com

**Patient Services Incorporated (PSI)** evaluates an individual’s financial, medical and insurance situation to determine who is eligible for premium or co-payment assistance including COBRA. It provides help for many illnesses and offer many types of financial assistance. For more information, call: 800-366-7741 or visit: www.patientservicesinc.org.

**State Specific Resources**: Every state has a bureau/agency that may be contacted for assistance. The name of the agency may differ from state to state. *Examples are*: Department of Insurance; Insurance Commission’s Office; Office of Insurance Regulation, etc.

Many manufacturer or therapy providers have a division or third party group that is designed to assist you with insurance questions/concerns. Please check with your provider.

For more information and the most updated version of the toolkit, please visit http://primaryimmune.org/services/patient-insurance-center