

PRIMARY IMMUNODEFICIENCY DISEASES



Health Insurance and Access to Care

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

TYPE OF HEALTH INSURANCE

99%

of respondents reported having health insurance in 2016

89%

of U.S. population had health insurance in 2016



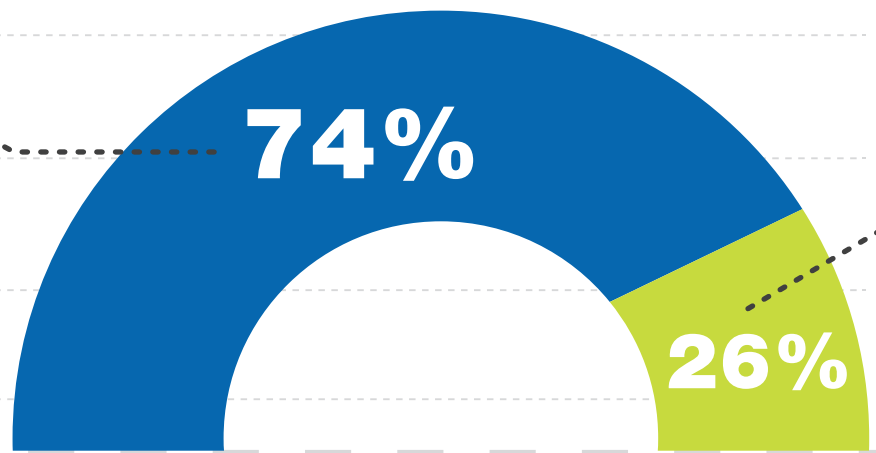
PRIVATE

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



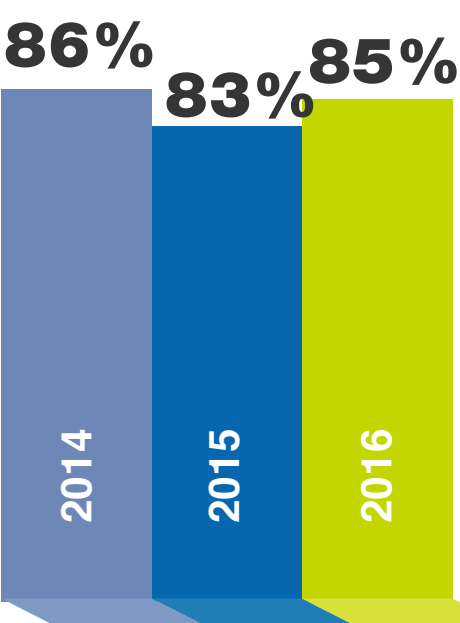
PUBLIC

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



Employer sponsored group plan	72%	Medicare Plan	49%
Individual policy plan (for individuals or family)	8%	Medicare eligibility due to disability	23%
Medicare Advantage Plan	6%	Medicaid	17%
Medicare Supplemental Plan	4%	TRICARE	8%
Exchange/Marketplace (State)	4%	State Children's Health Insurance Plan	2%
COBRA	2%	Veterans Policy	1%
Exchange/Marketplace (Federal)	2%		

SATISFACTION WITH INSURANCE



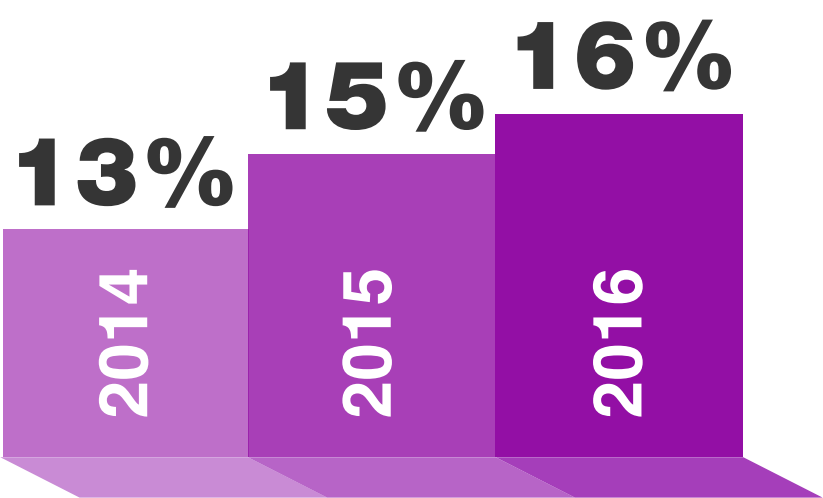
- The majority of respondents were satisfied with their insurance plans.



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

WHEN HEALTH PLANS INTERRUPT TREATMENT

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



39%

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



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



21%

of respondents (2014, 2015 and 2016) reported that as a result of their health plan's cost-sharing rules, the person with PI had problems affording visits to healthcare providers.



WHAT DOES IT MEAN?

Those surveyed by IDF for the most part are well insured and are satisfied with their health insurance coverage. However, a significant minority of respondents experienced challenges, which negatively impact their health. Such challenges included reduced access to care and treatment.



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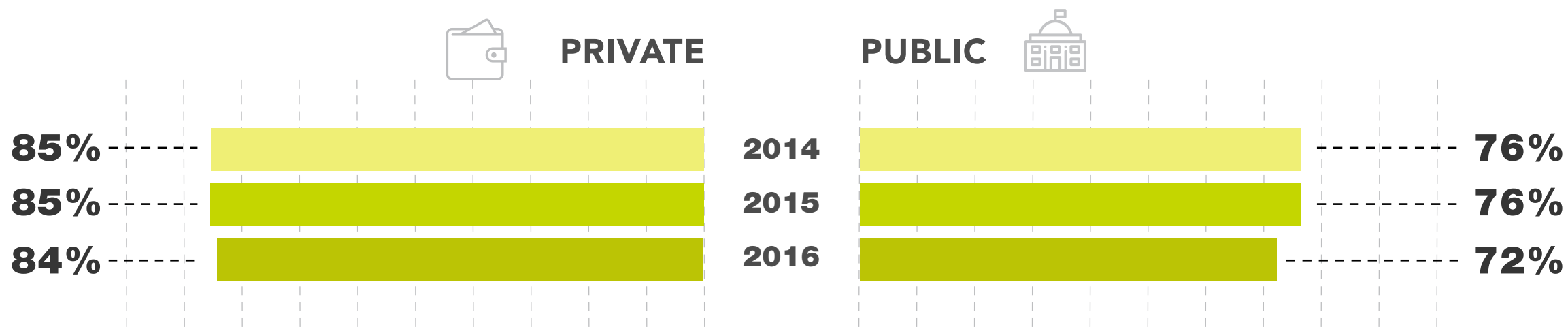
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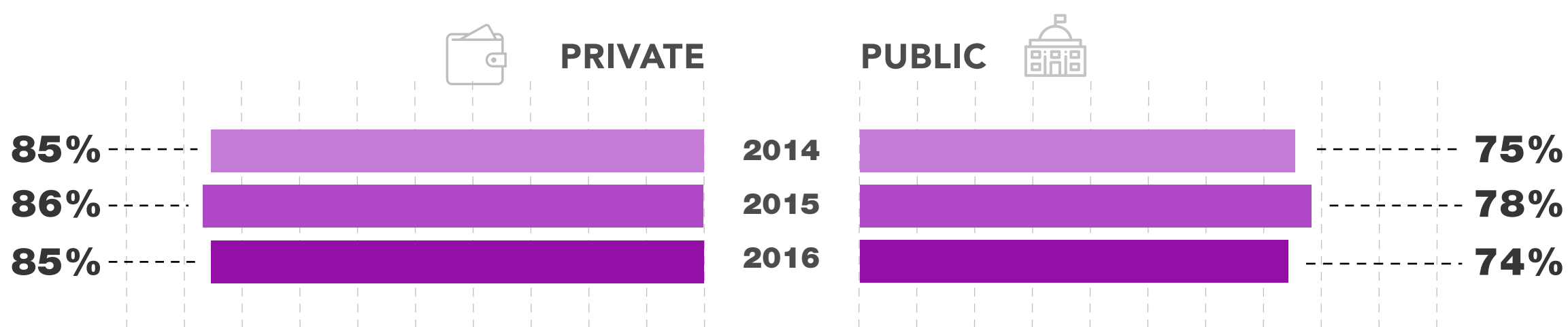
Quality of Care

How do those with primary immunodeficiency diseases (PI) rate the quality of the care they're receiving? The Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and caregivers found that generally, respondents are confident in their ability to receive appropriate medical care. Respondents with private insurance tend to be more confident than those with public insurance.

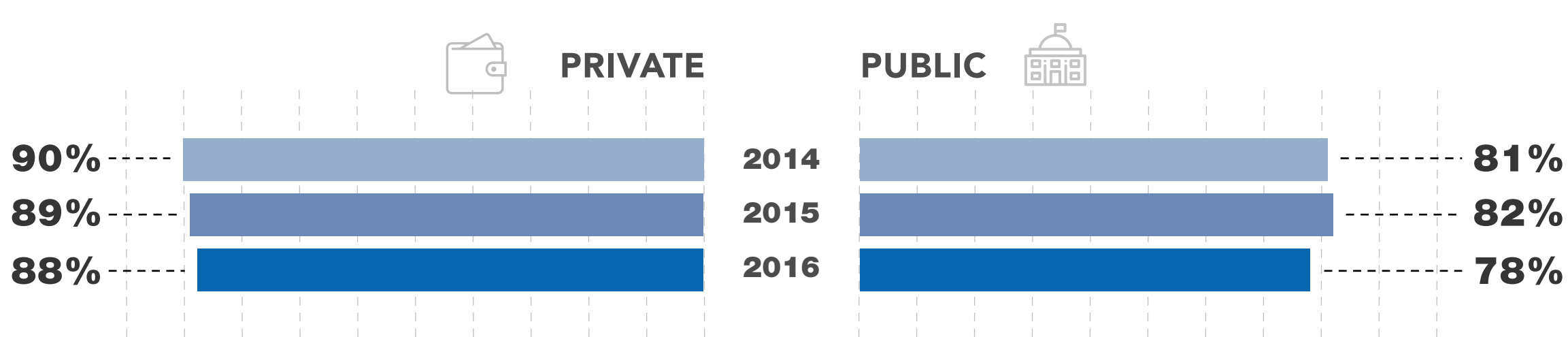
CONFIDENCE IN RECEIVING THE MOST EFFECTIVE DRUGS



CONFIDENCE IN RECEIVING THE BEST MEDICAL TECHNOLOGY



CONFIDENCE IN RECEIVING HIGH QUALITY AND SAFE MEDICAL CARE



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DEFINITIONS



PRIVATE

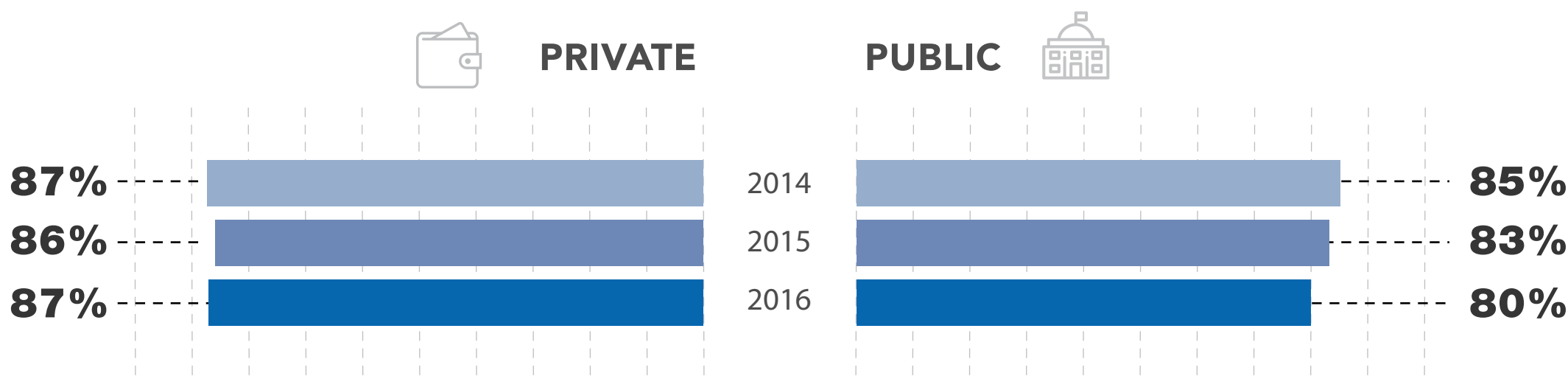
Any health insurance policy purchased by an employer or an individual from a private insurance company regardless of any public funding.



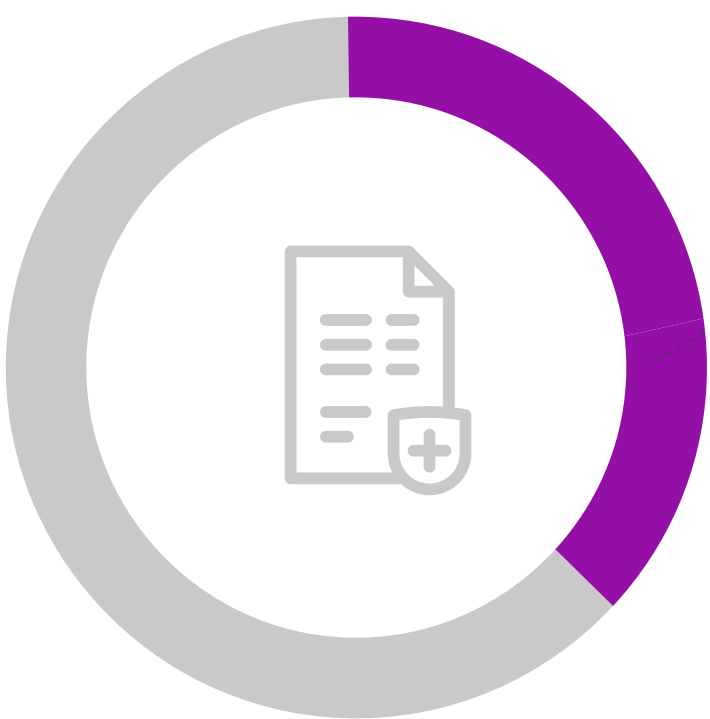
PUBLIC

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

SATISFACTION WITH QUALITY OF CARE



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



39%

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

WHAT DOES IT MEAN?



Despite many persons with PI having high confidence in their insurance coverage and quality of healthcare, significant challenges remain.

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PRIMARY IMMUNODEFICIENCY DISEASES



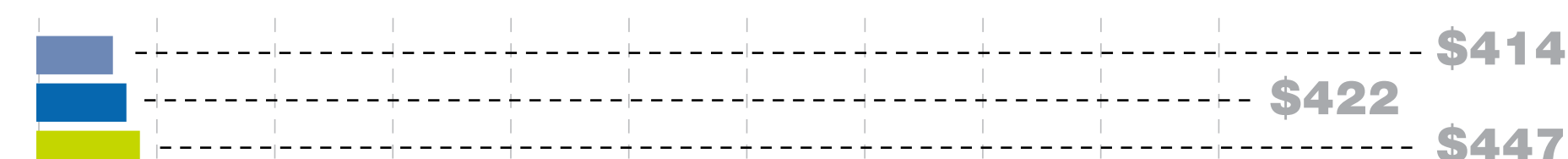
Affordability of Care

From access to specialists, life-long therapies or drugs, the financial burden on persons with primary immunodeficiency diseases (PI) can be extreme. The Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and caregivers looked into current costs of care.

COST OF CARE (ALL INSURANCE TYPES)

■ 2014 ■ 2015 ■ 2016

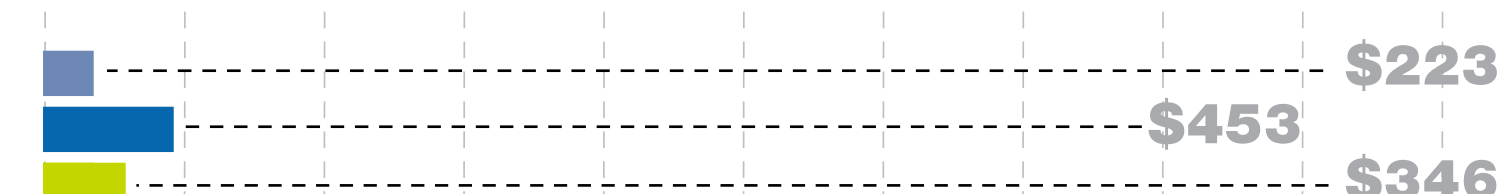
MONTHLY PREMIUMS



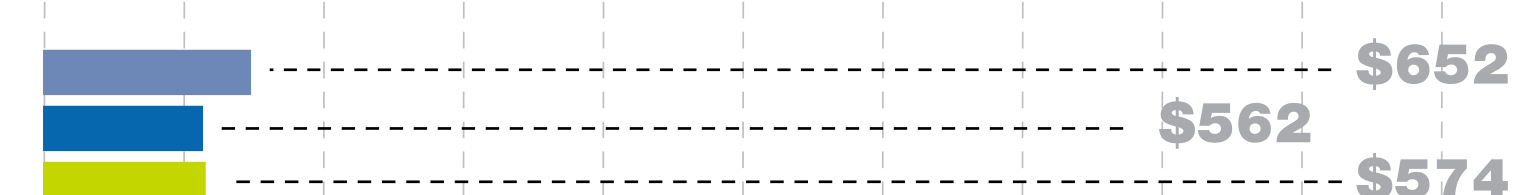
MAX OUT-OF-POCKET EXPENSE



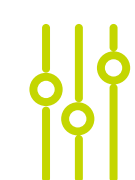
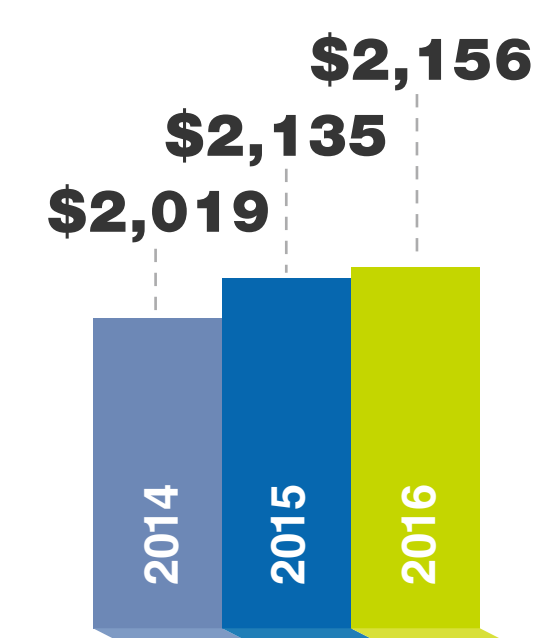
MONTHLY CO-PAY FOR IG THERAPY



MONTHLY COINSURANCE FOR IG THERAPY



ANNUAL DEDUCTIBLE



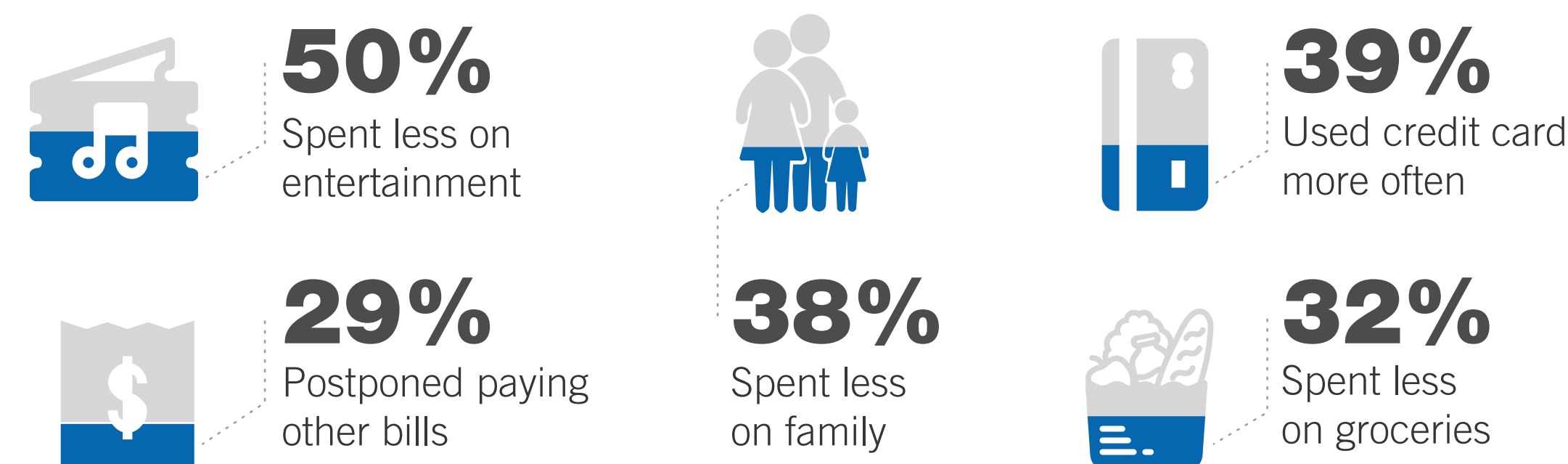
The results of 2014, 2015 and 2016 Health Insurance Surveys are based on respondents connected with IDF and may represent those with better than average coverage and experience.

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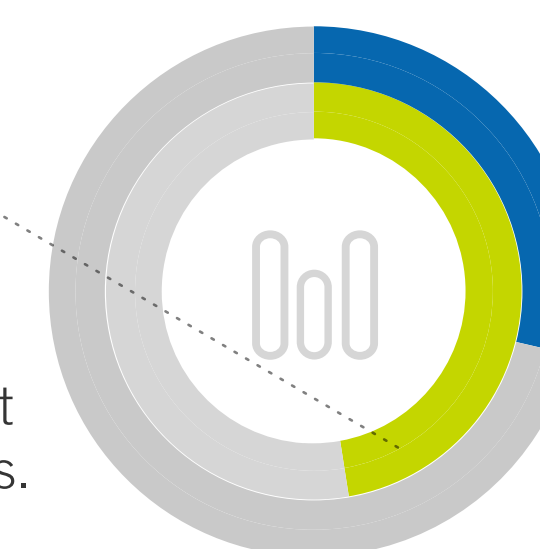


IN 2016, RESPONDENTS REPORTED DOING THE FOLLOWING IN ORDER TO PAY FOR HEALTHCARE COSTS



2016 FINANCIAL BURDEN OF CARE

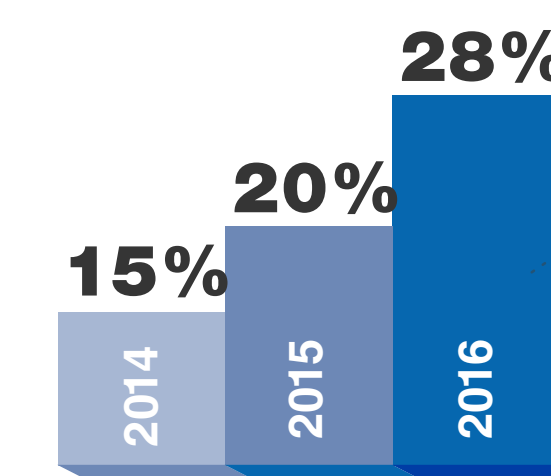
48% of people who reported skipping at least one treatment, did so due to cost or health care plan problems.



Annual medical expenses that require patients to spend more than **10%** of their family's total income are considered high burden^{1,2}

47% of families spent over 10% of their income on healthcare expenses

28% of respondents reported currently receiving financial assistance (for co-pay, co-insurance or health insurance premium expenses).



WHAT DOES IT MEAN?



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

¹Cunningham, Peter, Carolyn Miller and Alwyn Cassil, Living on the Edge: Health Care Expenses Strain Family Budgets. HSC Research Brief No 10. Washington DC: Center for Studying Health System Change, 2008. Accessed September 6, 2016. <http://www.hschange.org/CONTENT/1034/1034.pdf>

²Abramowitz, Joelle and Brett O'Hara, "The financial burden of medical spending: estimates and implications for evaluating the impact of ACA reforms." Medical Care Research and Review, 72, no. 2 (2015). 187-199. doi: 10.1177/1077558714563173.)

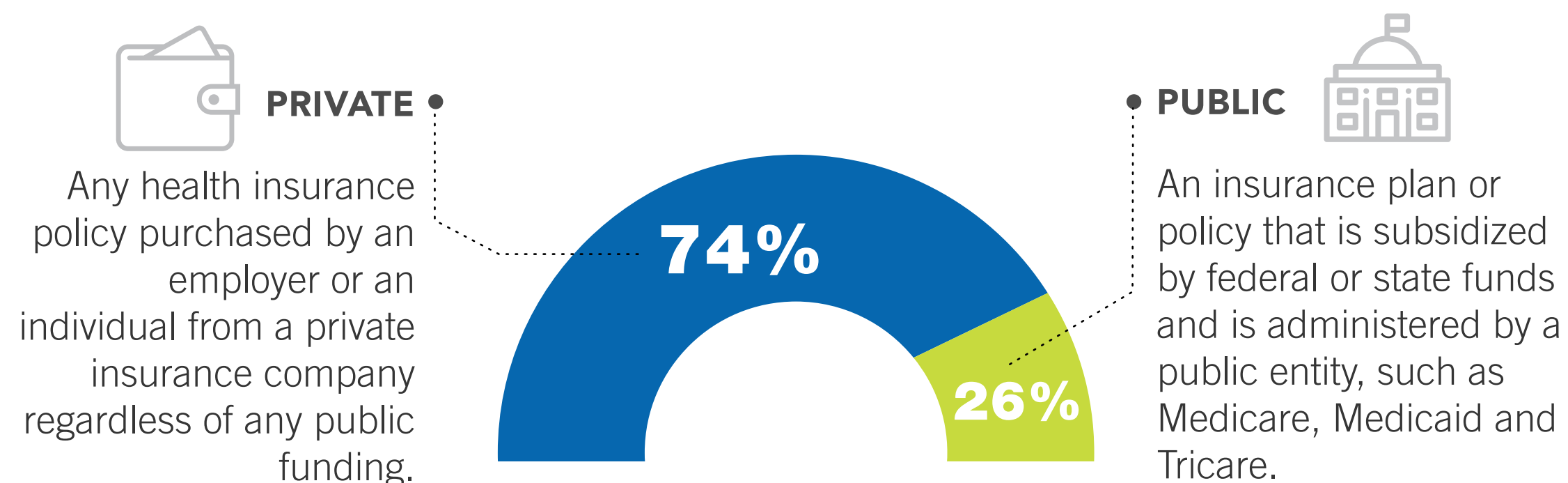
PRIMARY IMMUNODEFICIENCY DISEASES



Public Policy Impacts

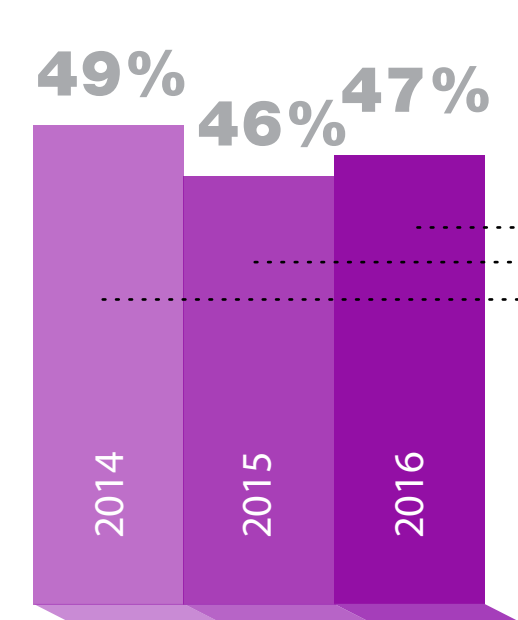
As the Immune Deficiency Foundation (IDF) Health Insurance Surveys of persons with PI and their caregivers show, many people are either taking actions or being forced to take actions that are detrimental to their health, as a direct result of health insurance policies, health insurance costs and the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

TYPE OF HEALTH INSURANCE



FINANCIAL BURDEN OF CARE

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



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

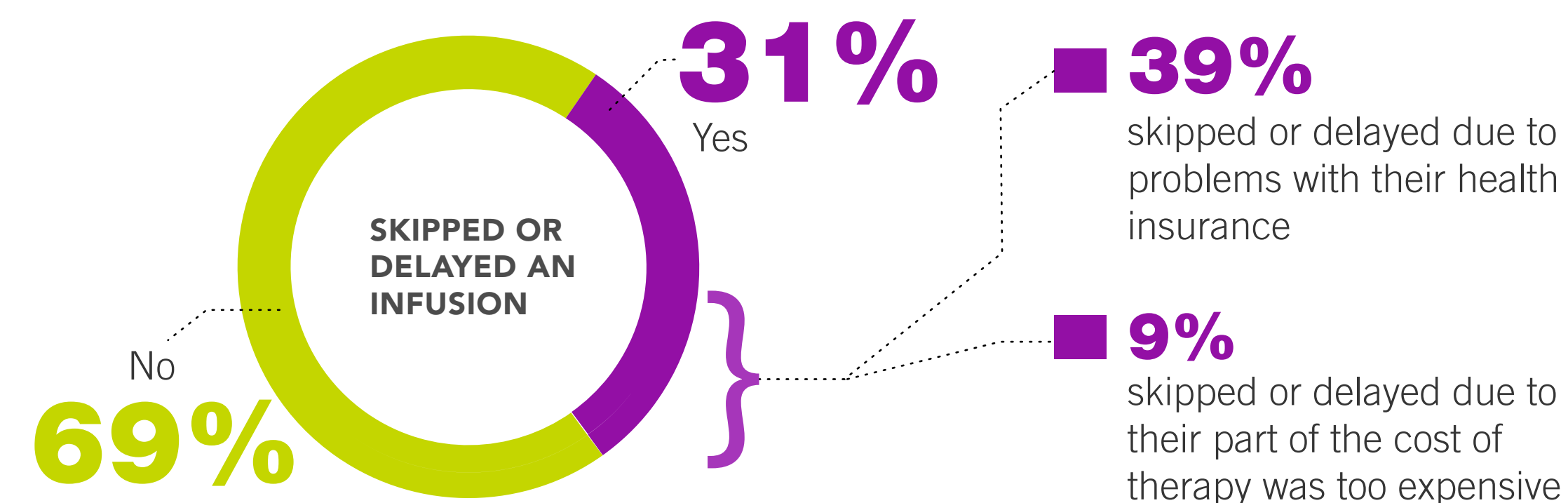
¹Cunningham, Peter, Carolyn Miller and Alwyn Cassil, Living on the Edge: Health Care Expenses Strain Family Budgets. HSC Research Brief No 10. Washington DC: Center for Studying Health System Change, 2008. Accessed September 6, 2016. <http://www.hschange.org/CONTENT/1034/1034.pdf>

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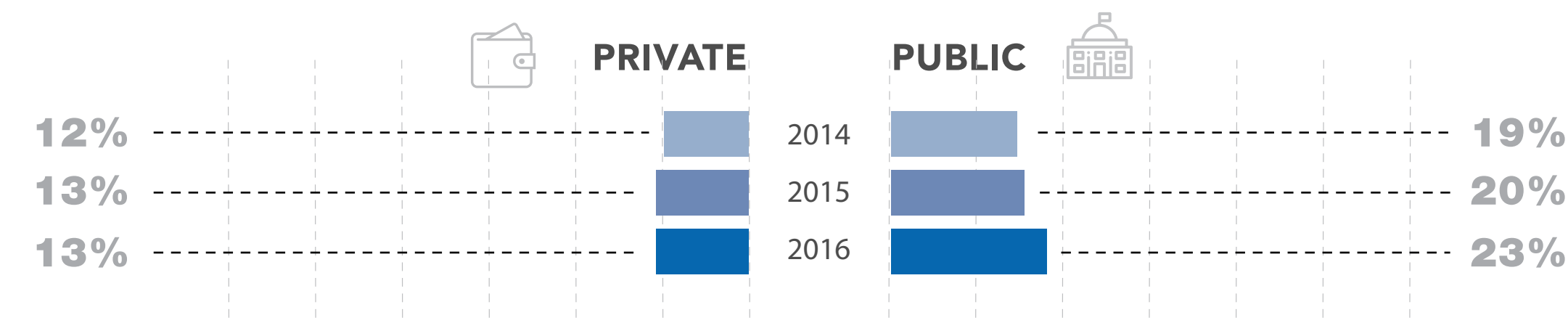
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SKIPPED OR DELAYED INFUSIONS IN 2016

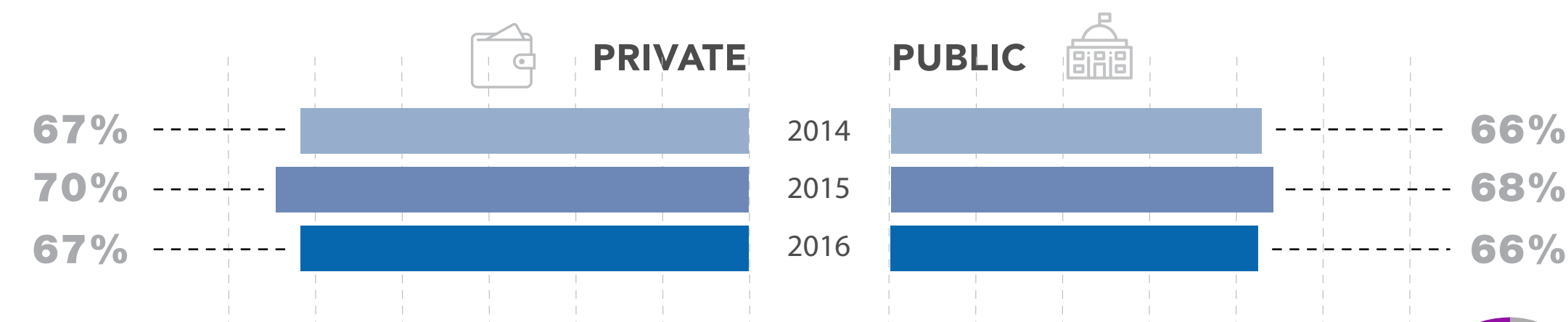


HAD A PROBLEM SEEING A SPECIALIST DUE TO HEALTH PLAN RULES

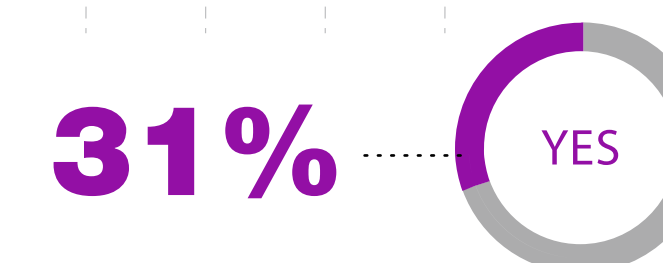
Having a problem seeing a specialist due to health plan rules:



Confidence in ability to afford the needed care:



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



WHAT DOES IT MEAN?



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

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2014, 2015 and 2016 IDF National Health Insurance Surveys



Tracking Health Care Reform's Impact on Persons with PI with Primary immunodeficiency

Introduction

- The Patient Protection and Affordable Care Act (ACA) became law in March 2010. The goal of the law is to make healthcare more affordable and accessible for millions of Americans who either do not have access to or cannot afford health insurance.
- However, the decentralized nature of the healthcare marketplaces makes it difficult to project what types of issues or challenges persons with PI may face in obtaining their IgG therapy.
- In order to capture the impact ACA may have on those with PI, as well as to describe in general the health insurance experiences of those impacted by PI, IDF conducted a series of web-based surveys of persons with PI in our database in 2014, 2015 and 2016: IDF National Health Insurance Surveys.



2014, 2015 and 2016 Survey Overview

Methodology

- The IDF Survey Research Team and other IDF Staff developed the IDF National Health Insurance Survey questionnaires. Each of the three individual surveys contained about 53 main questions, with an average completion time of approximately 25 minutes.
- The 2014, 2015 and 2016 IDF National Health Insurance Surveys were designed to measure how the ACA impacted public and private health insured persons with PI. Survey questions focused on:
 - Out of pocket costs, cost sharing, premium costs
 - Annual limits
 - Essential health benefits
 - Access to preferred therapy- product, site of care and mode of infusion
 - Ability to access specialists

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



2014, 2015 and 2016 Survey Overview

Field Period and Completed Surveys

- IDF 2014 National Health Insurance Survey
 - In field: November 14, 2014 – December 4, 2014
 - 9,133 e-mail invitations delivered
 - 1,417 surveys completed
- IDF 2015 National Health Insurance Survey
 - In field: December 4, 2015 – December 31, 2015
 - 10,532 e-mail invitations delivered
 - 1,504 surveys completed
- IDF 2016 National Patient Survey
 - In field: November 30, 2016 – January 15, 2017
 - 11,198 e-mail invitations delivered
 - 1,414 surveys completed

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



Topics

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

Type of Insurance Coverage and Access to Care

Health Insurance by Type

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

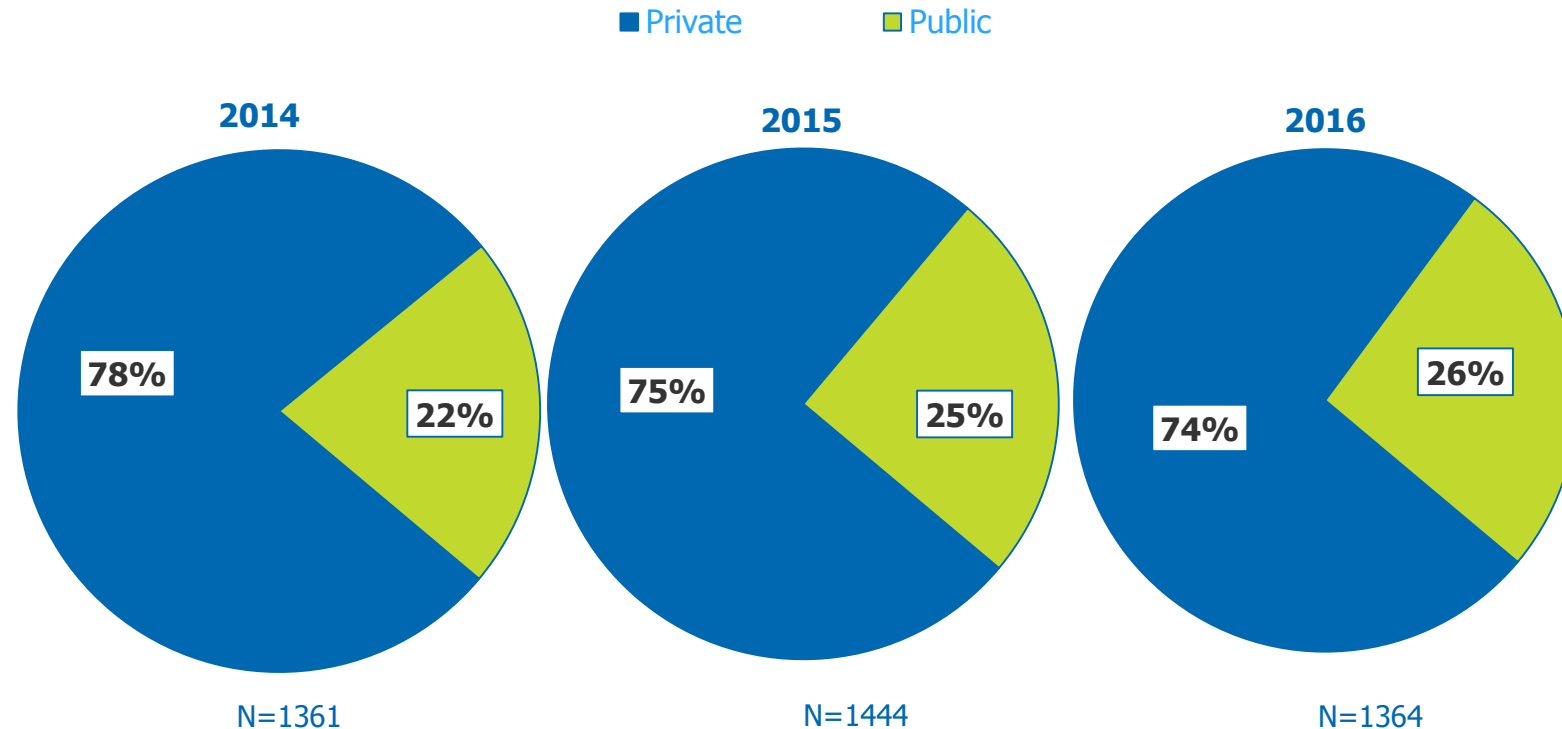
In 2014, 2015 and 2016 over 98% of persons with PI with PI were insured

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



Private or Public Pay Health Insurance

"Private Pay"	"Public Pay"
Employer sponsored	Medicare
COBRA	Medicare-disability
Individual policy	Medicaid
Medicare Supplemental	SCHIP
Medicare Advantage	TRICARE
State Marketplace	Veterans Policy
Federal Marketplace	

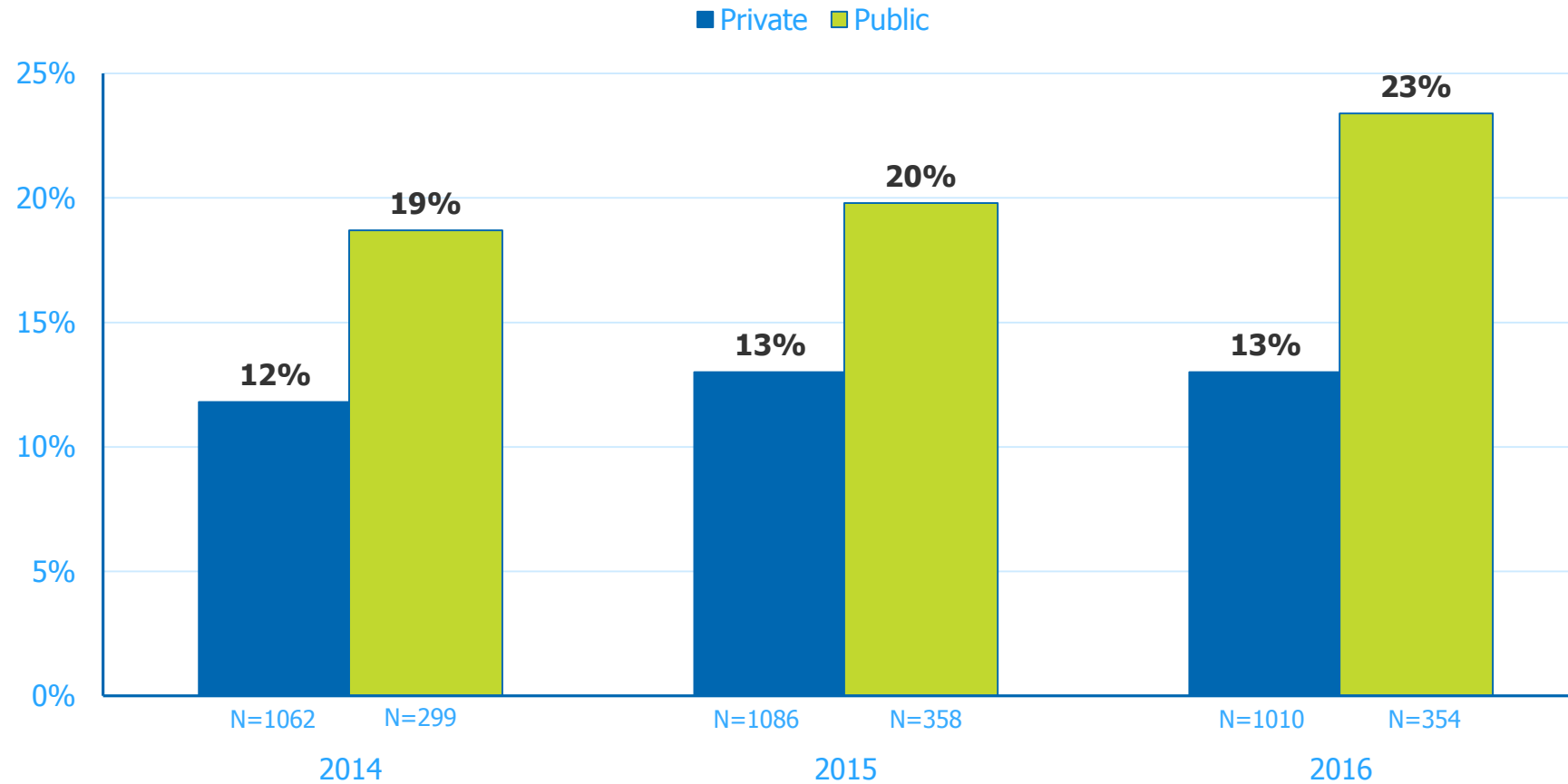


Q7b. What is this person's main type of health insurance?

Base: All Insured Persons with PI, *Other Insurance* and *Not Sure/Don't Know Insurance* not included



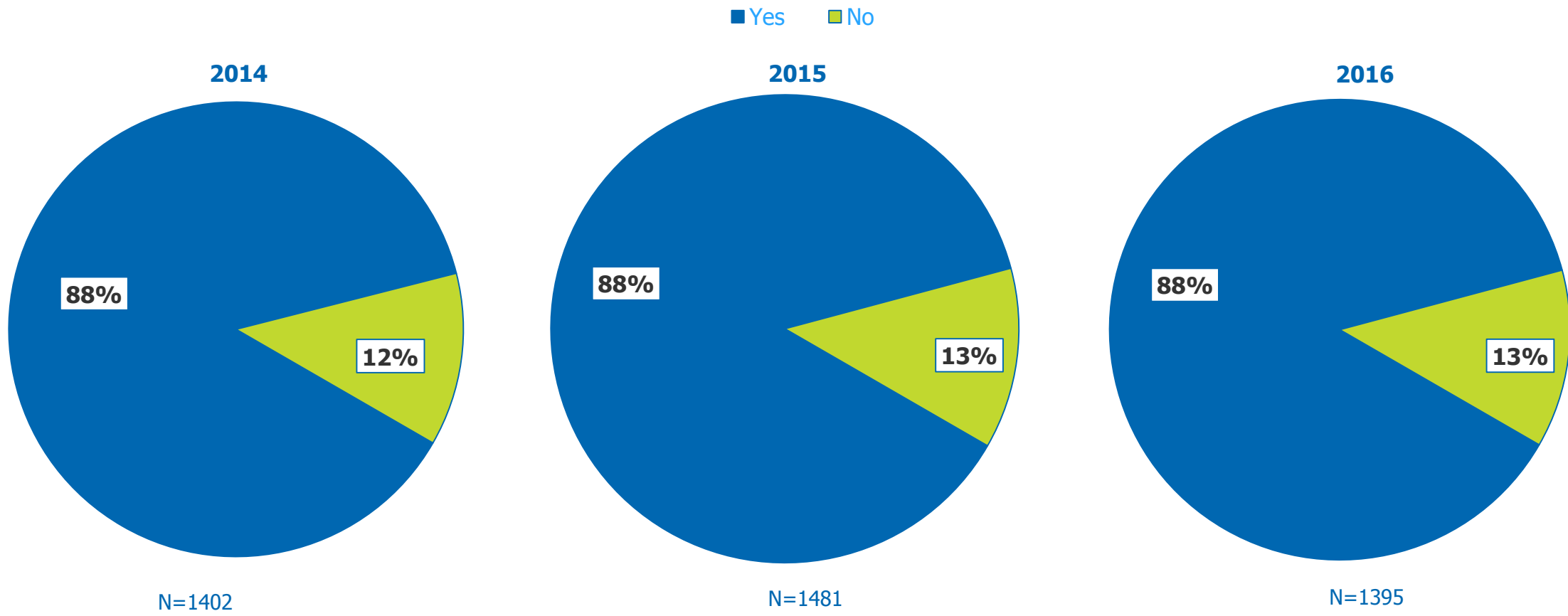
Had Problems Seeing Any Healthcare Specialists Due to Health Plan Rules



Q17a. Since January 2014/2015/2016 as a result of your health plan's rules, has the person with PI had any problems seeing any healthcare specialists?
Base: All Private or Public Insured Persons with PI



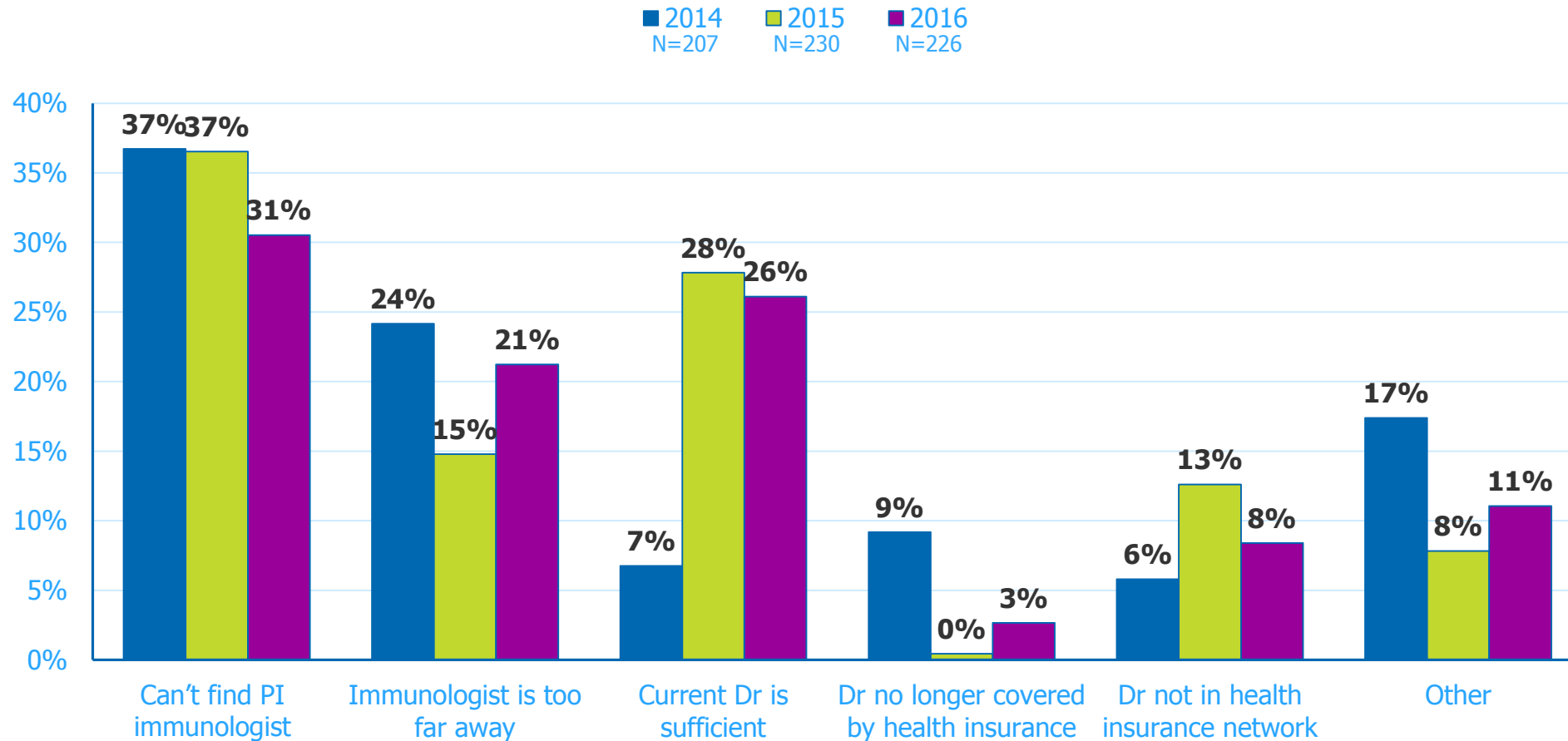
Does the person have access to a PI Specialist



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



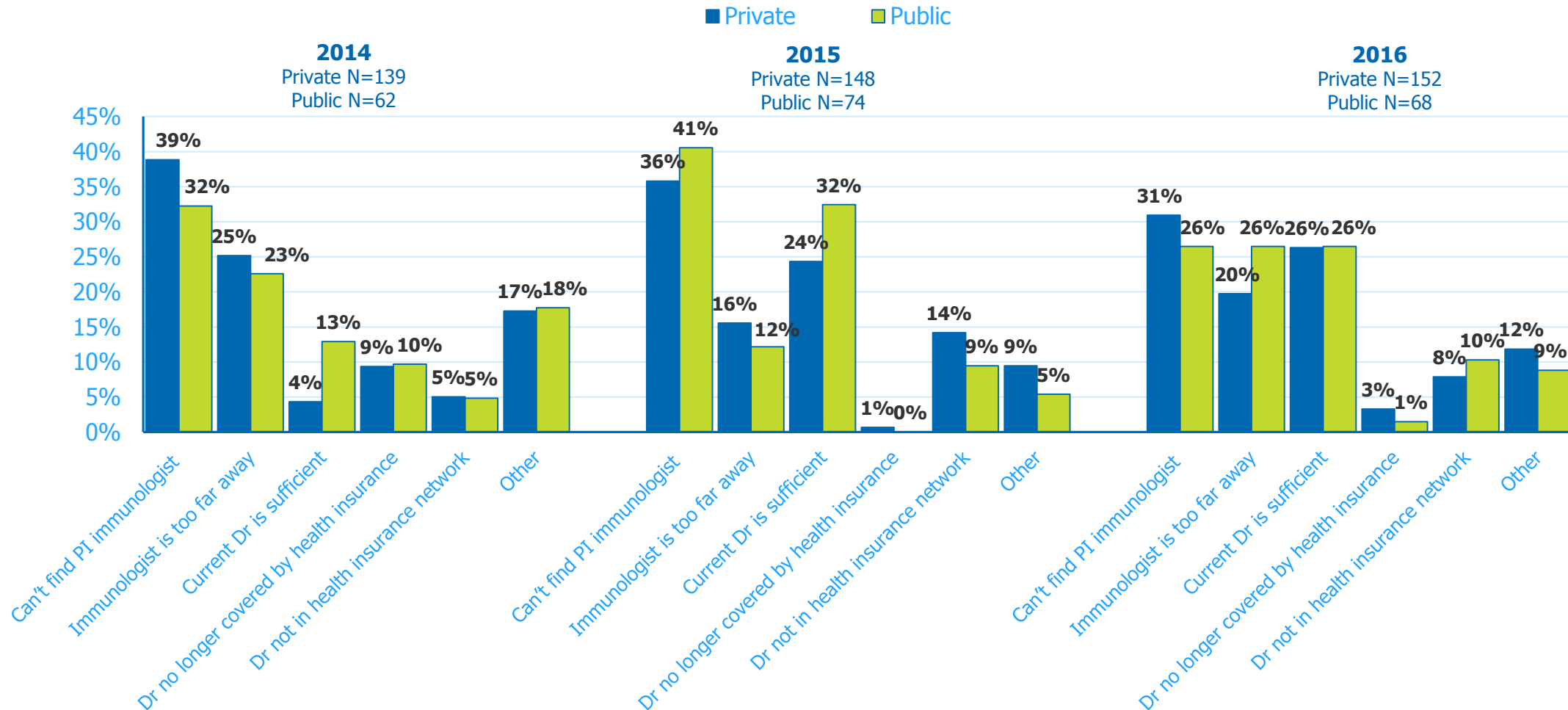
Why doesn't the person have access to a PI Specialist



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



Why doesn't the person have access to a PI Specialist Private vs. Public

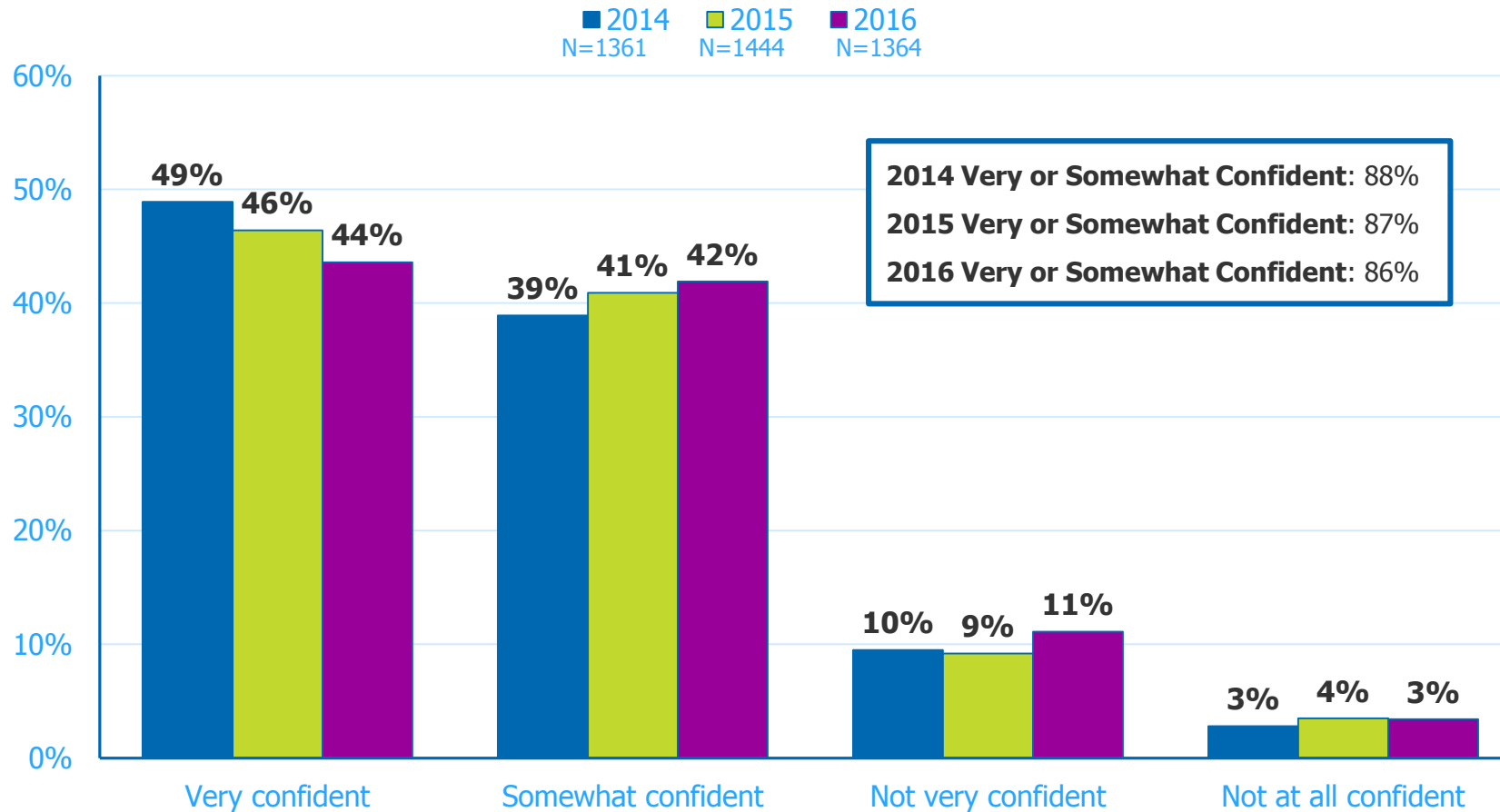


Q15b. Why doesn't this person have access to an immunologist who specializes in primary immunodeficiency?
Base: All Private or Public Insured Persons with PI who Did Not Have Access to a PI Specialist



Perception of Quality of Care

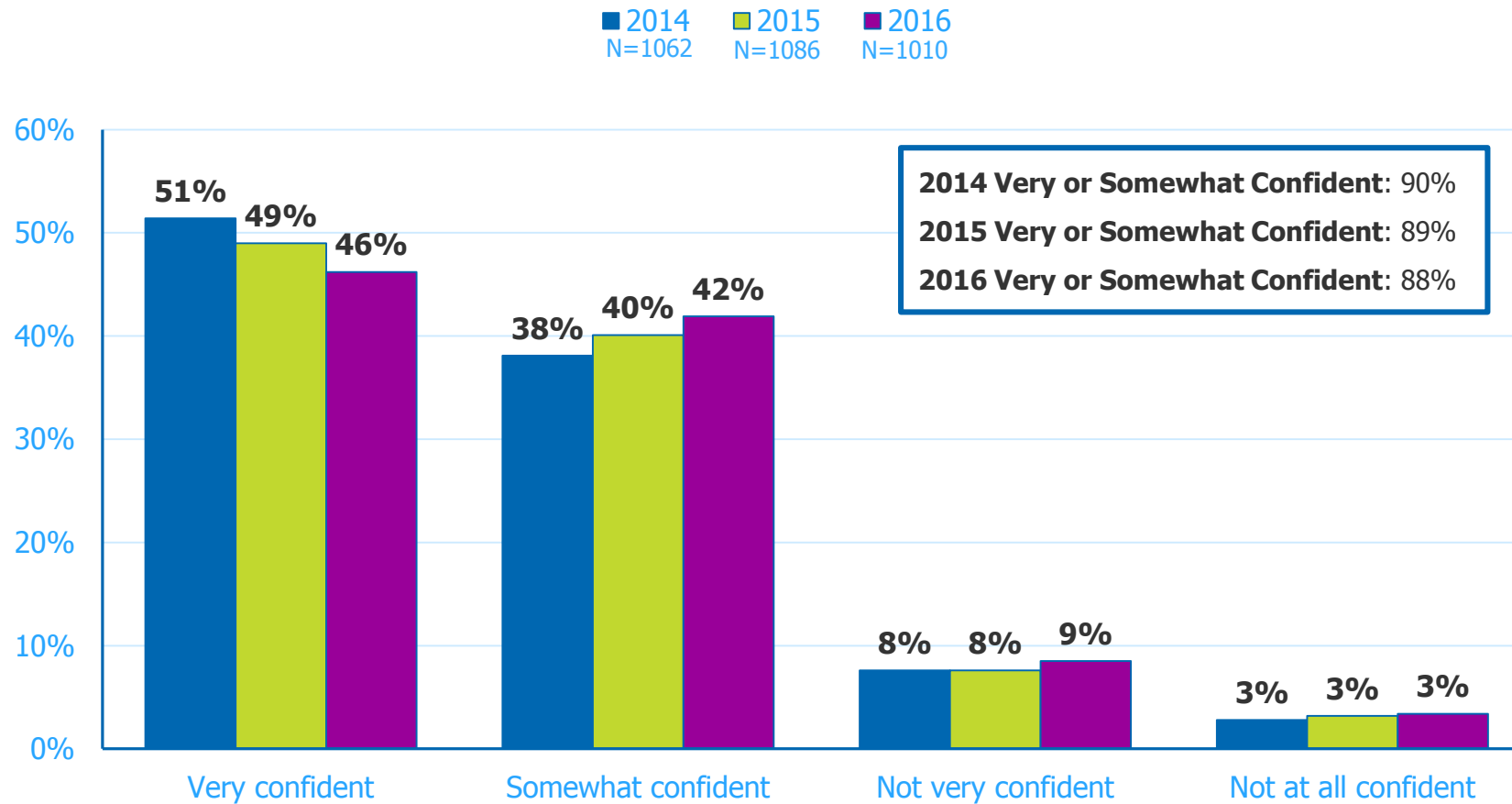
Overall: Receive High Quality and Safe Medical Care



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



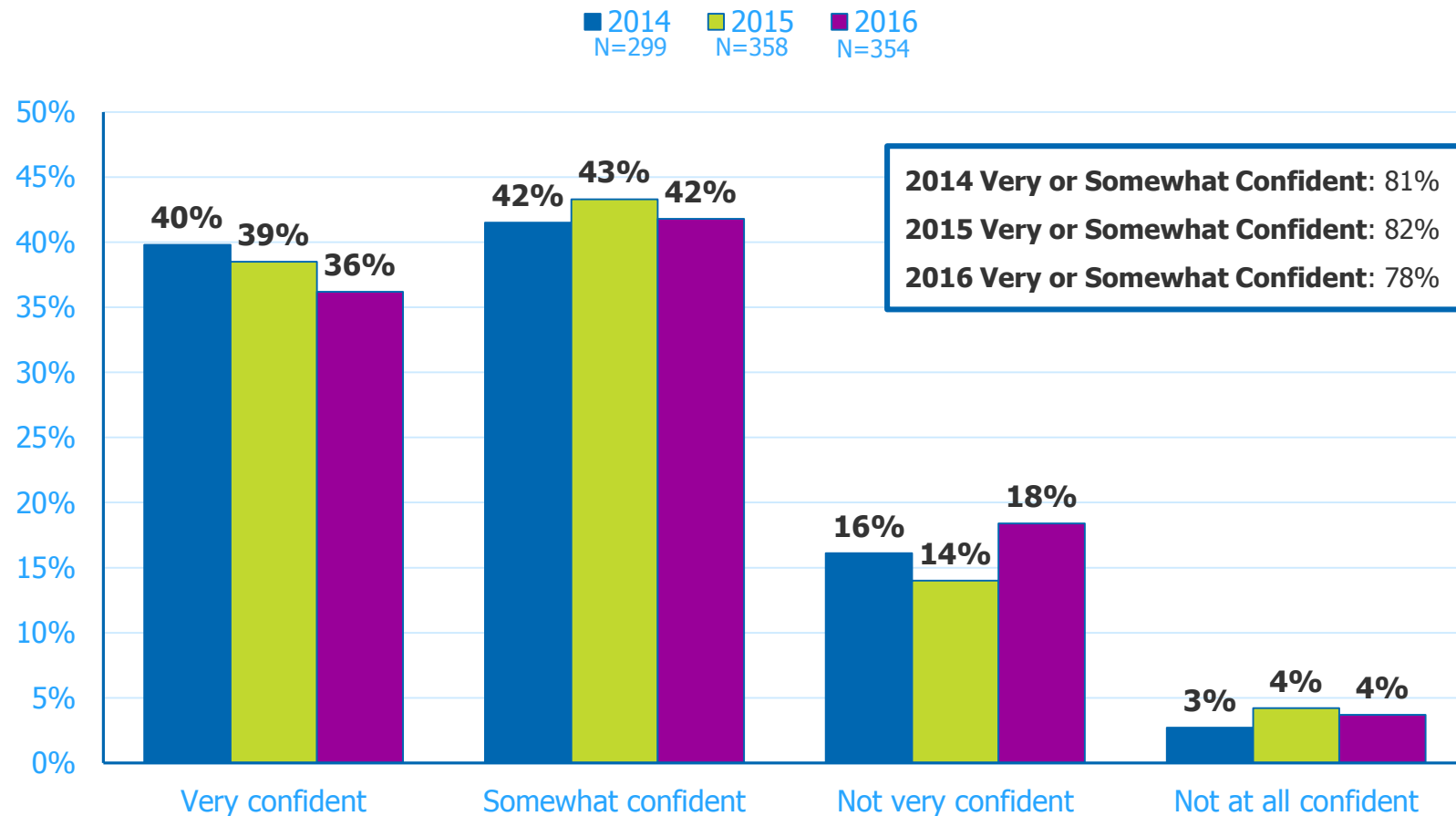
Private: Receive High Quality and Safe Medical Care



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



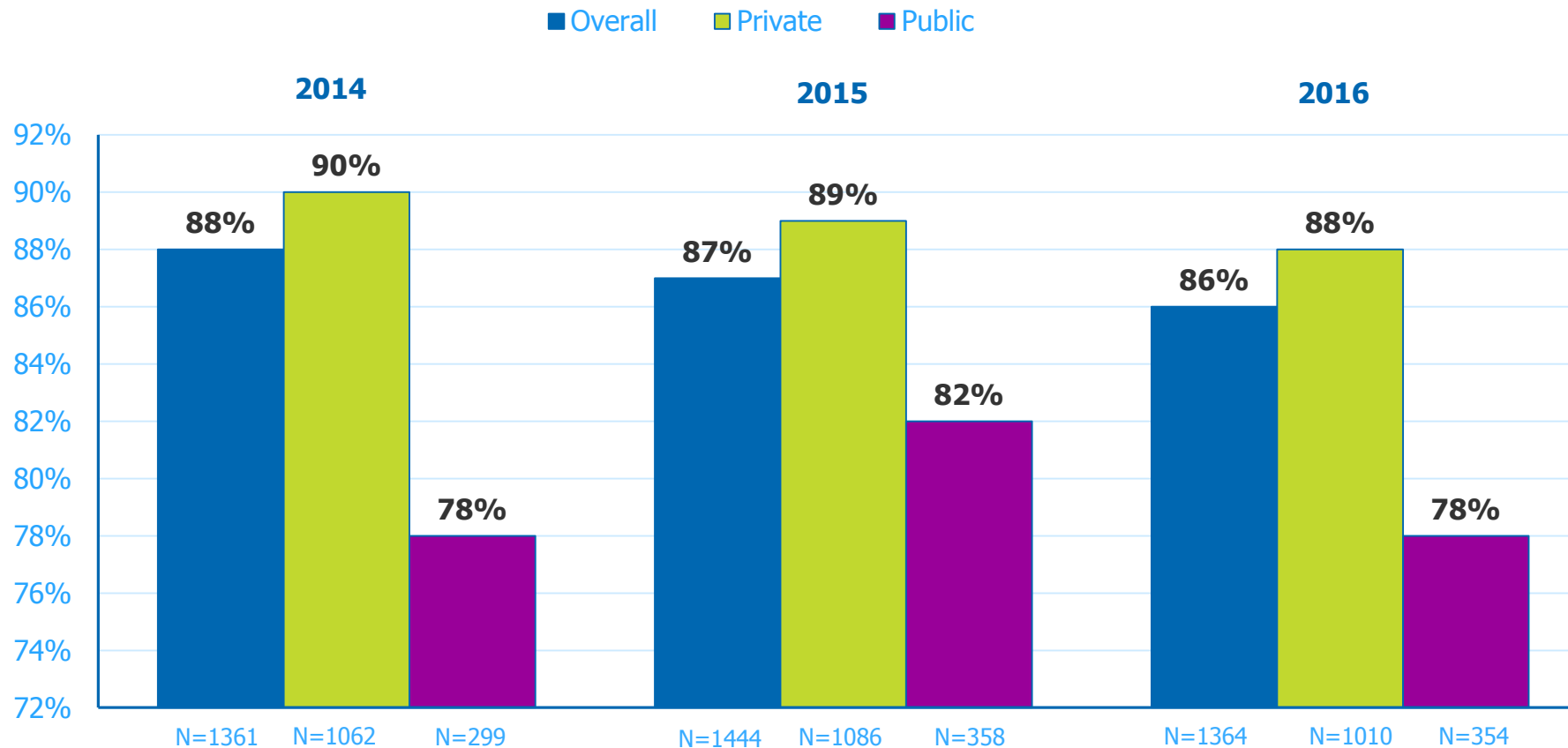
Public: Receive High Quality and Safe Medical Care



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



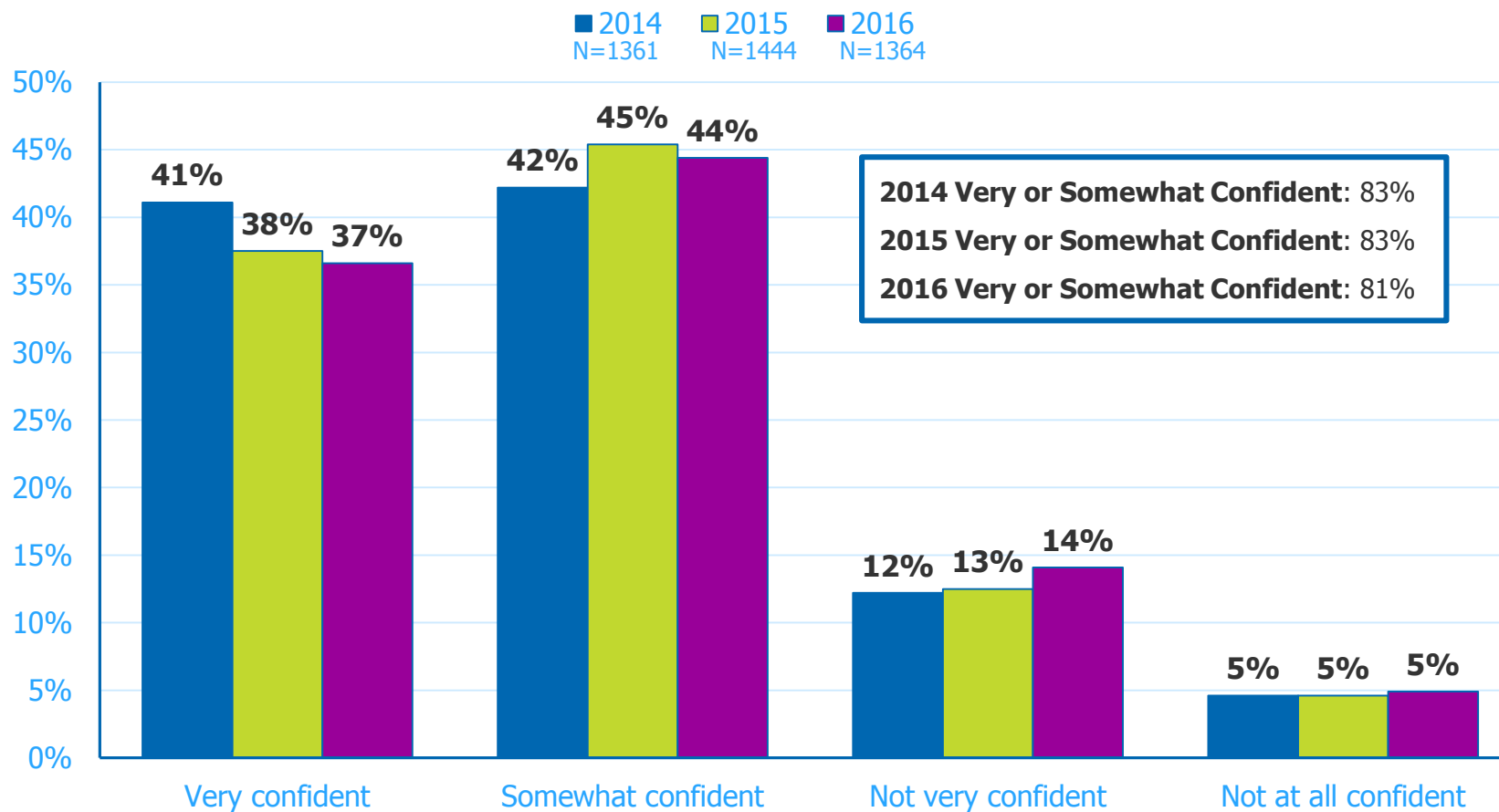
Very to Somewhat Confident Receive High Quality and Safe Medical Care



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



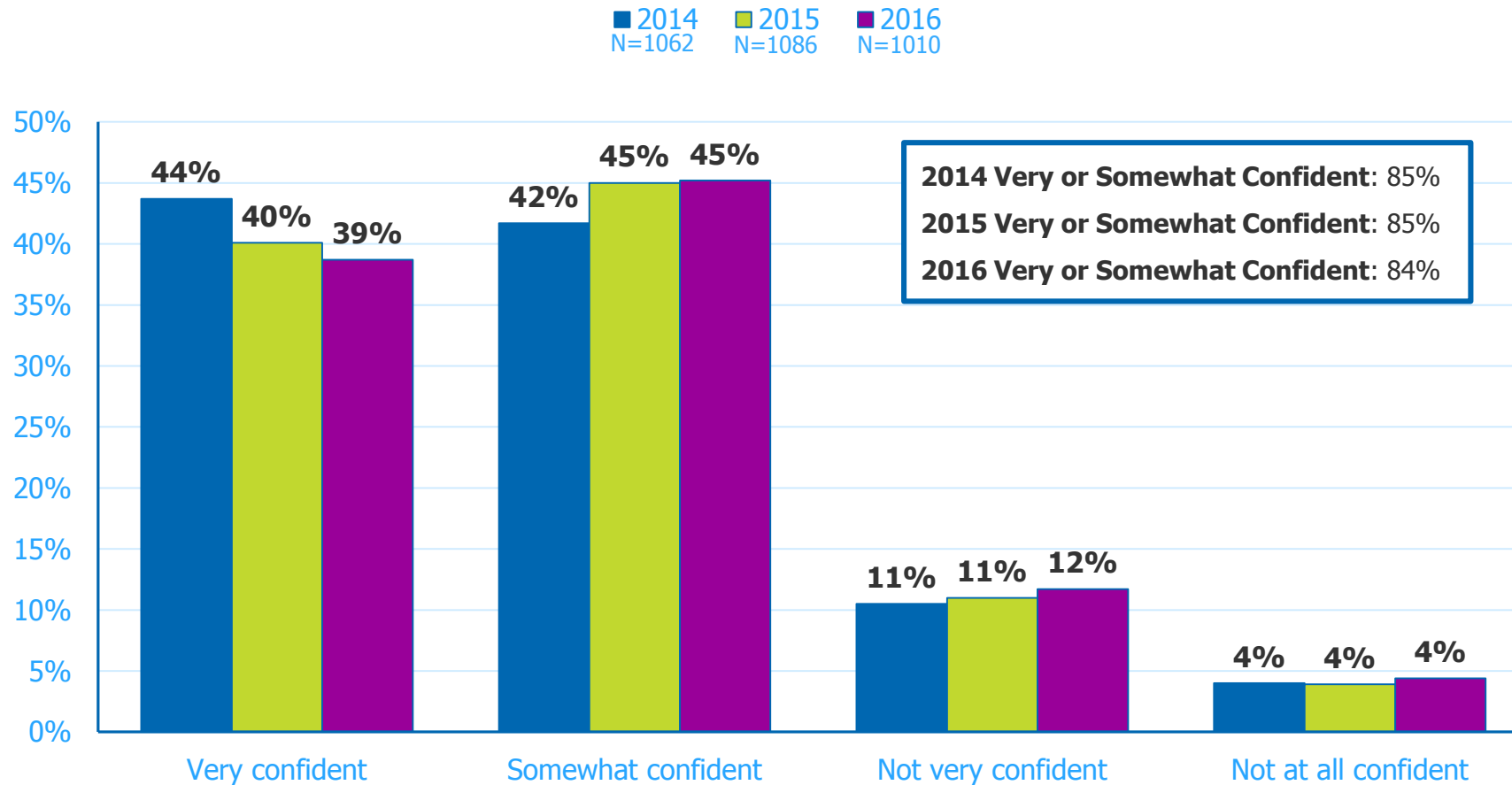
Overall: Receive the Most Effective Drugs



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



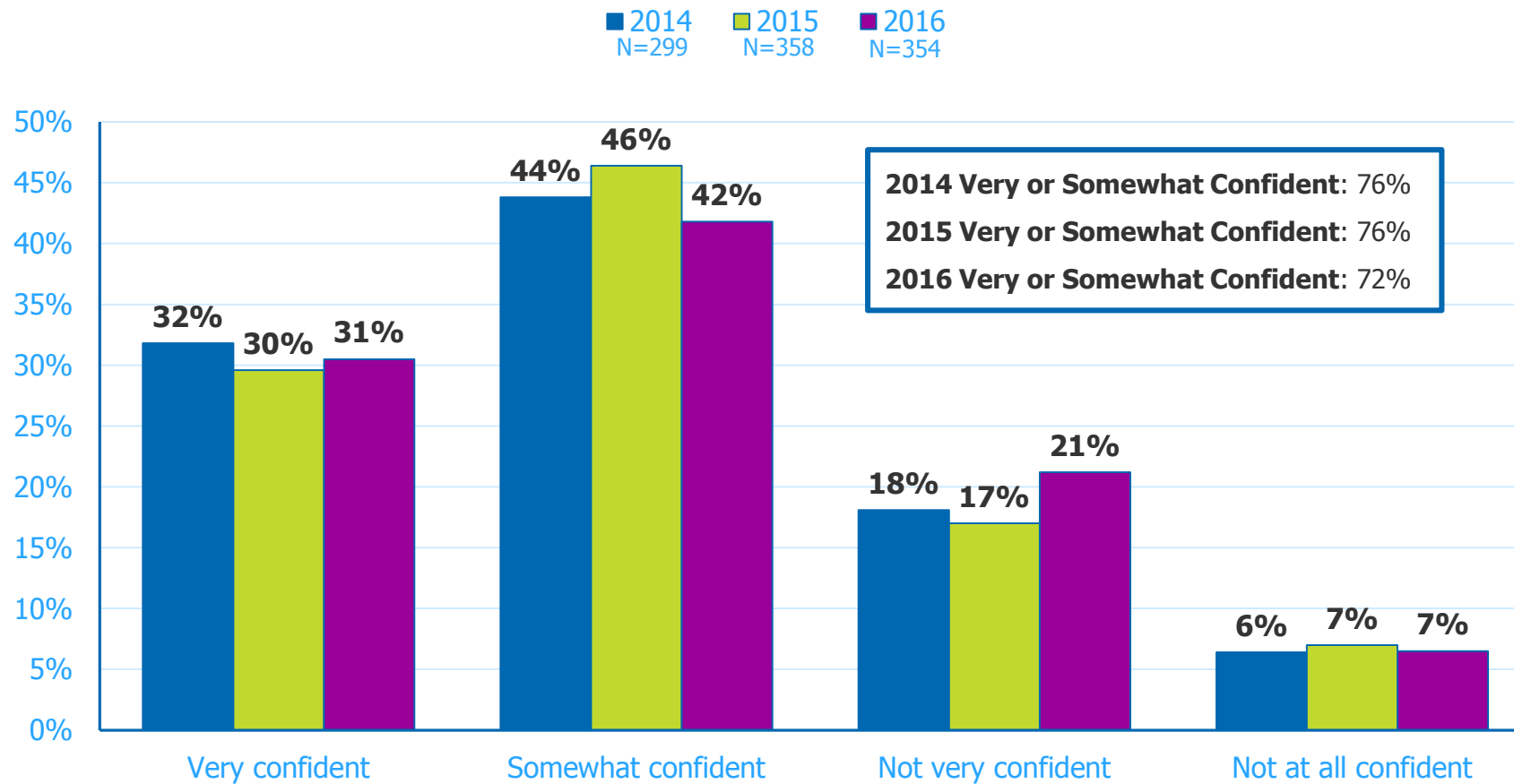
Private: Receive the Most Effective Drugs



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



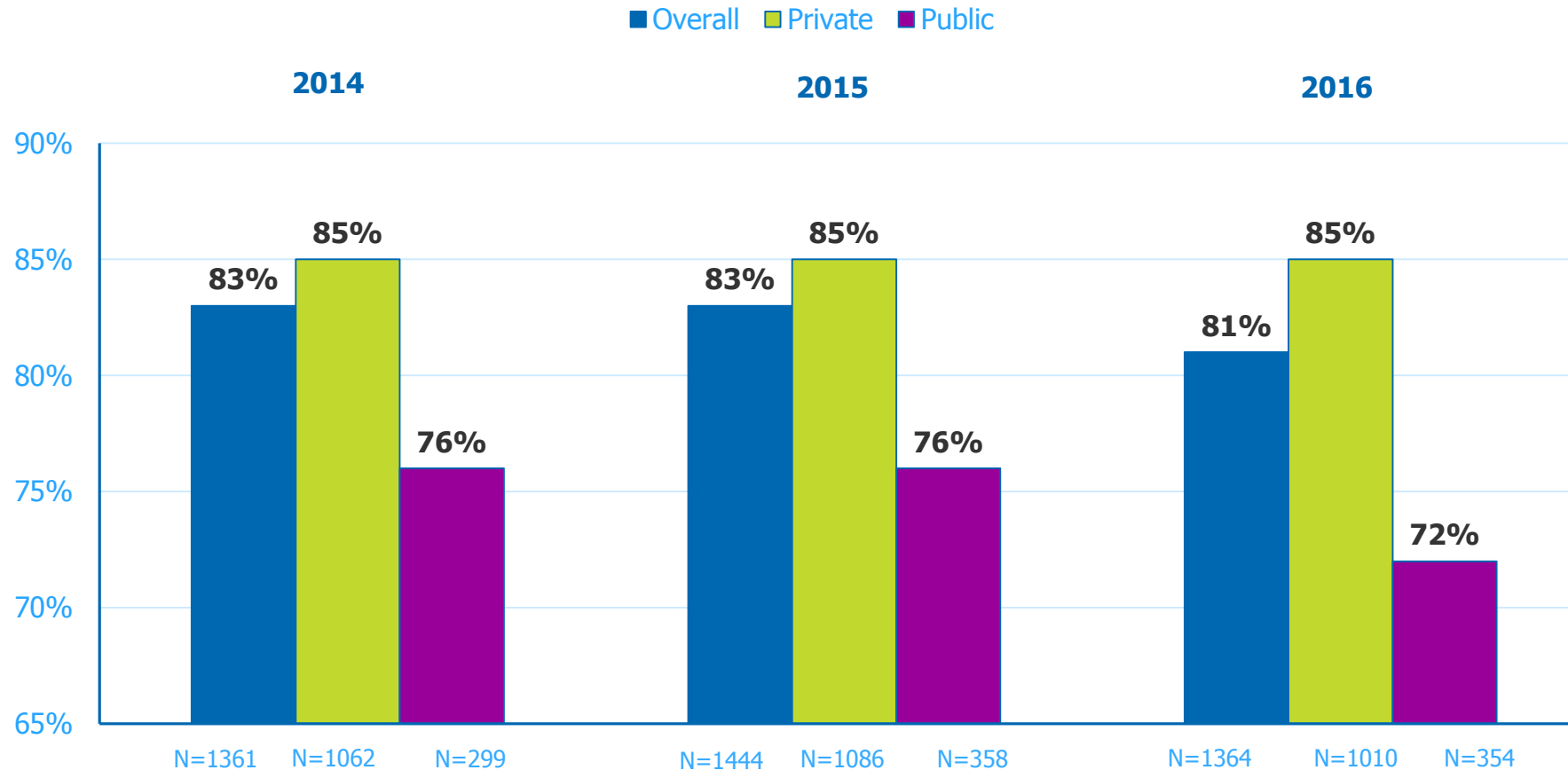
Public: Receive the Most Effective Drugs



Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...
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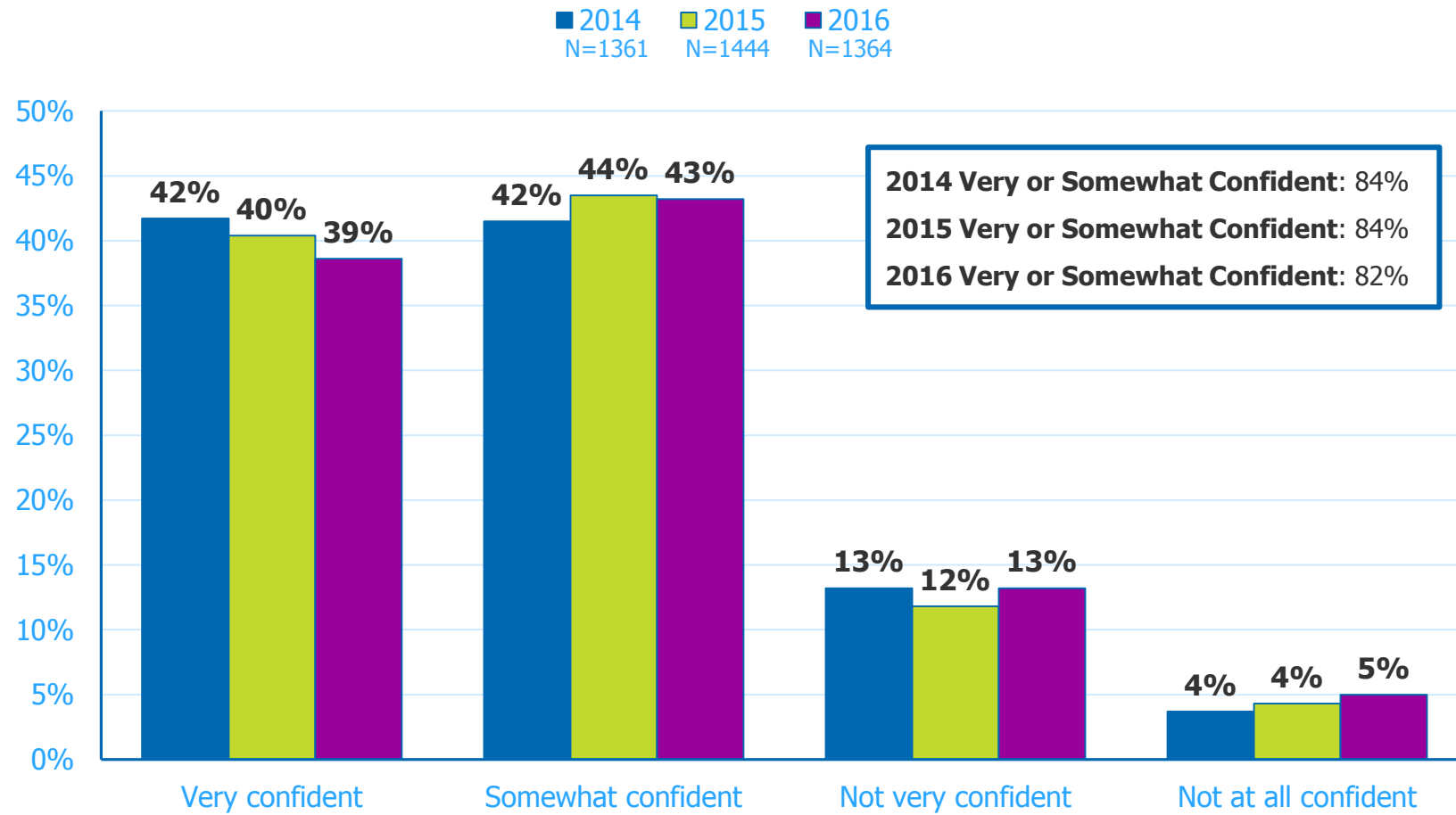
Very to Somewhat Confident Receive Most Effective Drugs



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



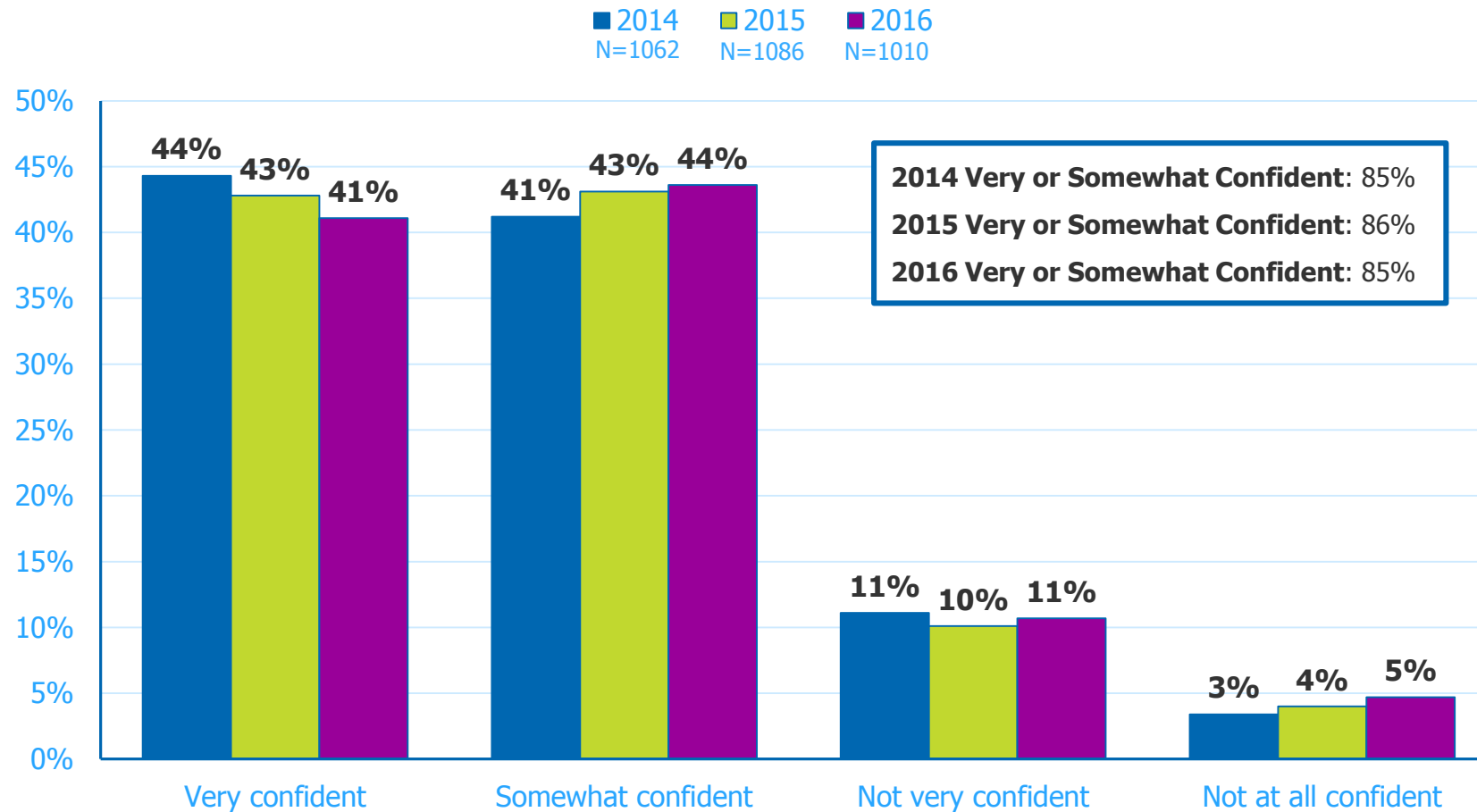
Overall: Receive the Best Medical Technology



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



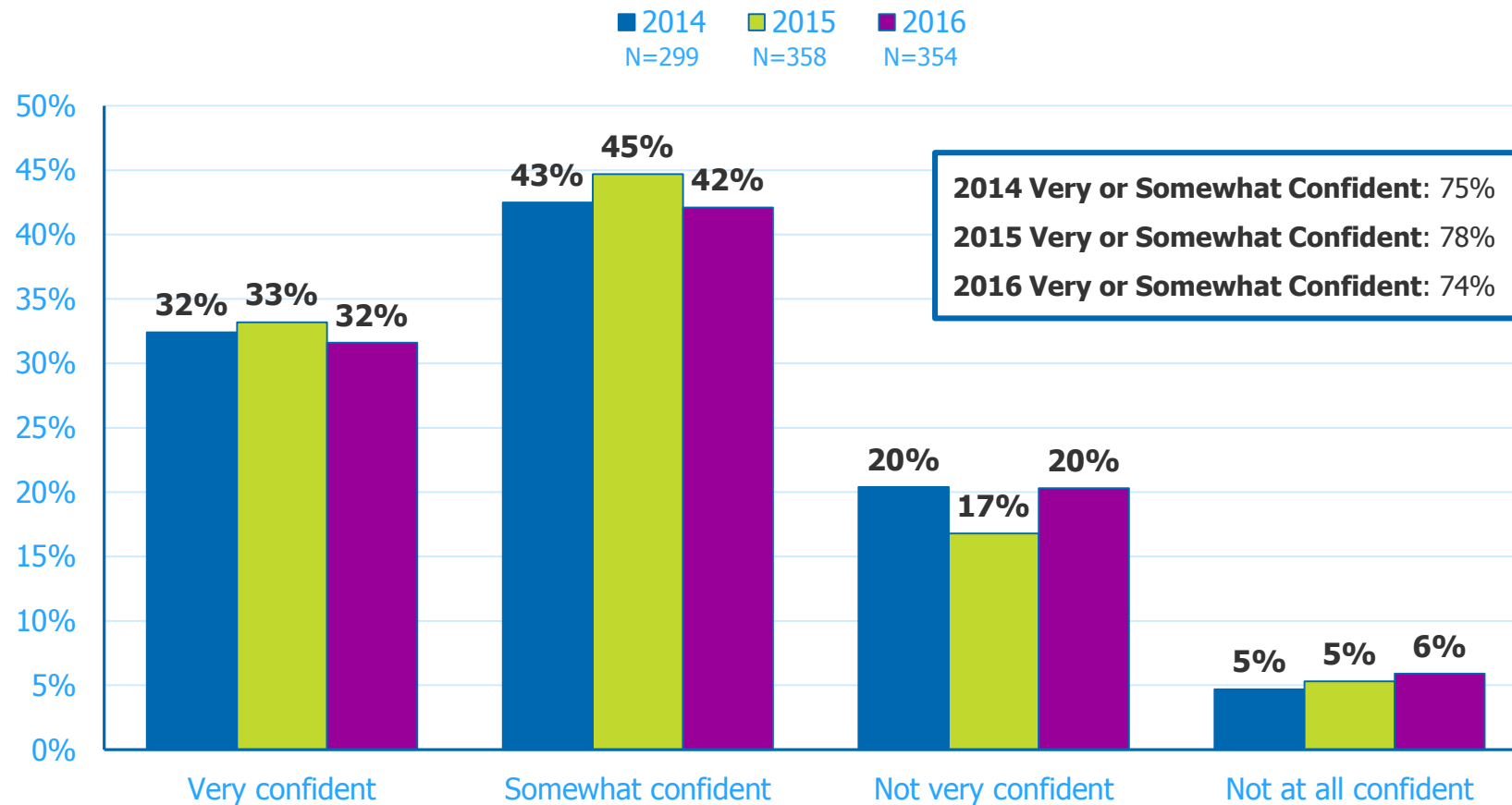
Private: Receive the Best Medical Technology



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



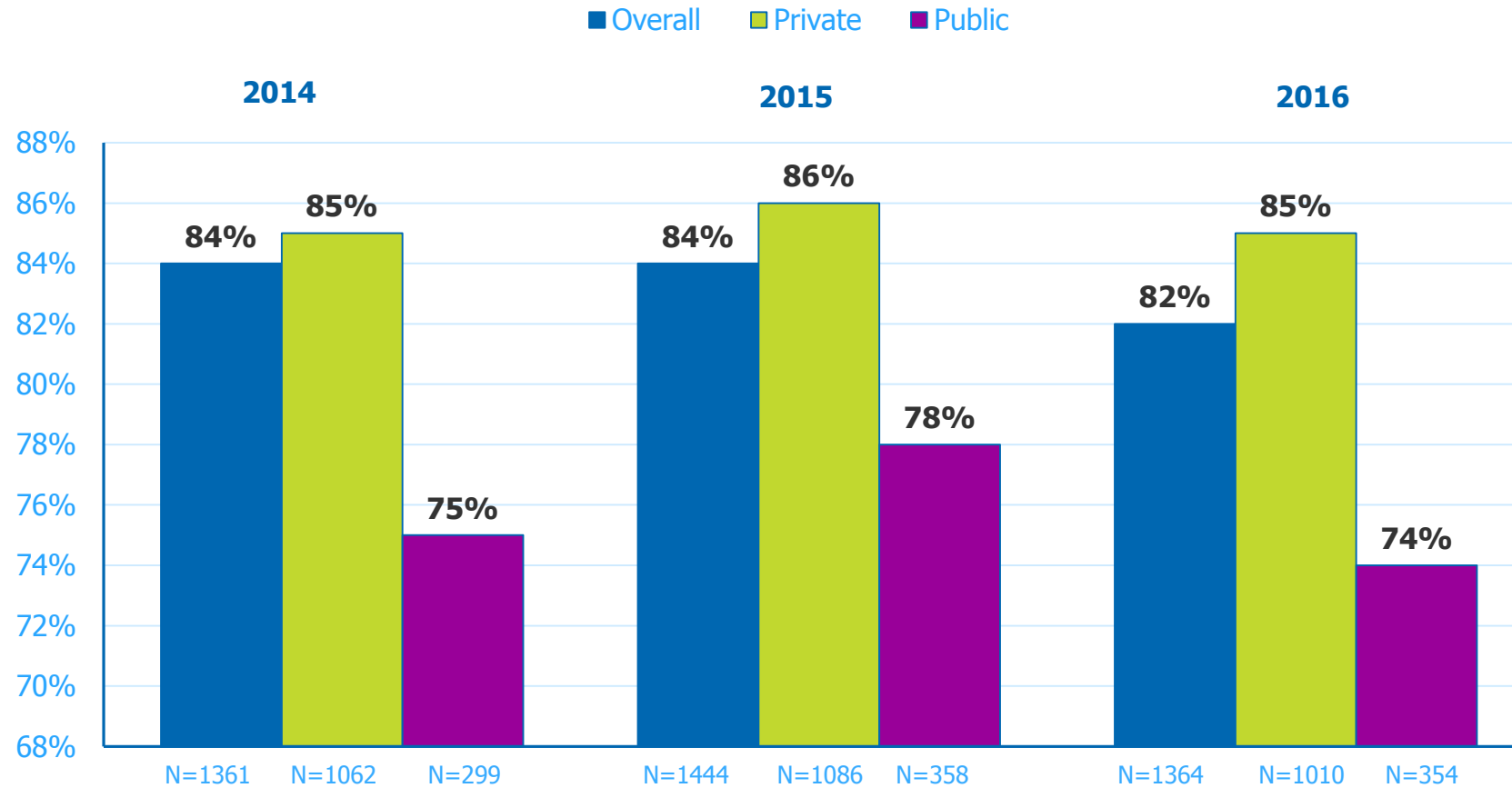
Public: Receive the Best Medical Technology



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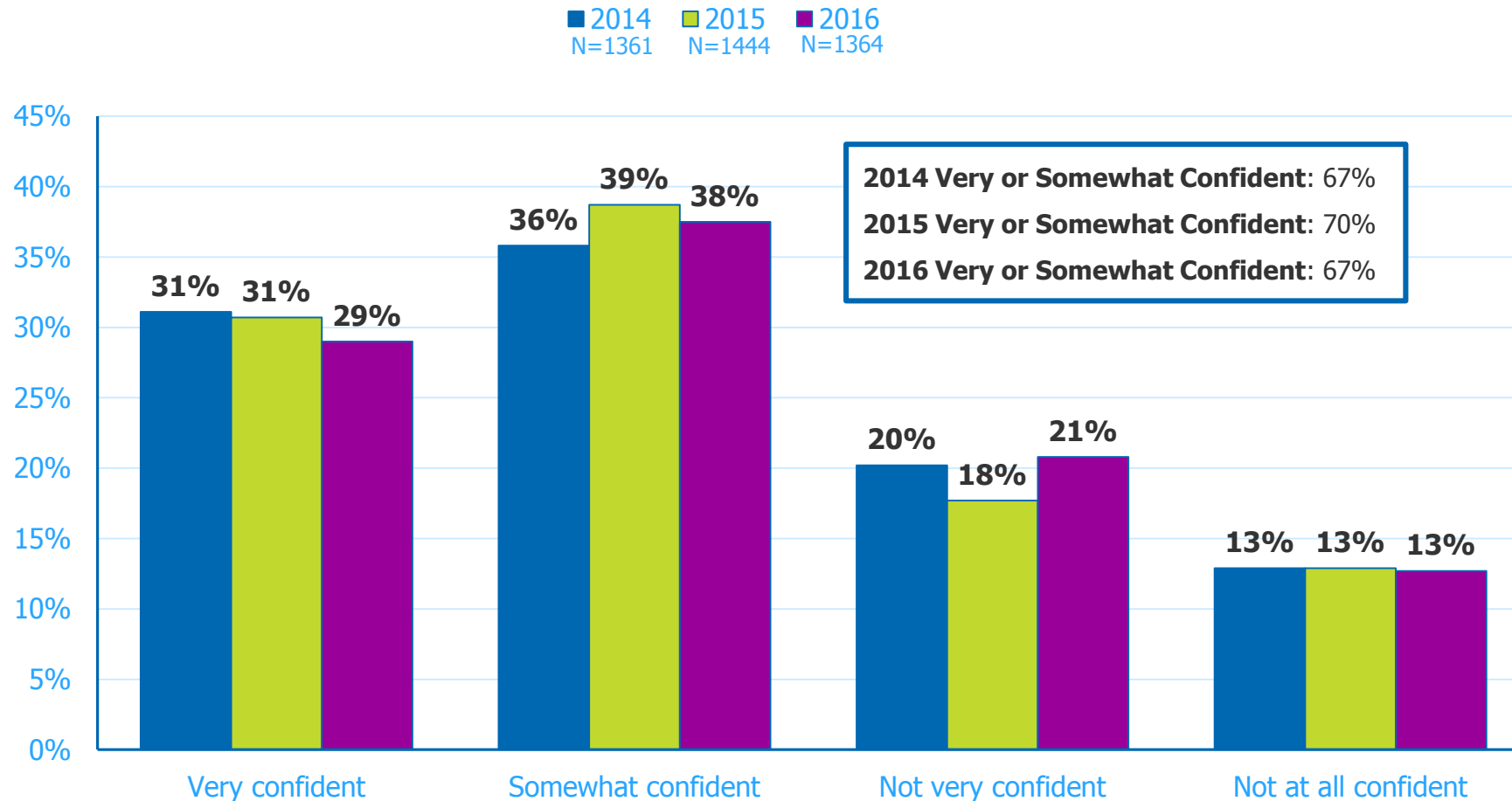
Very to Somewhat Confident Receive Best Medical Technology



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



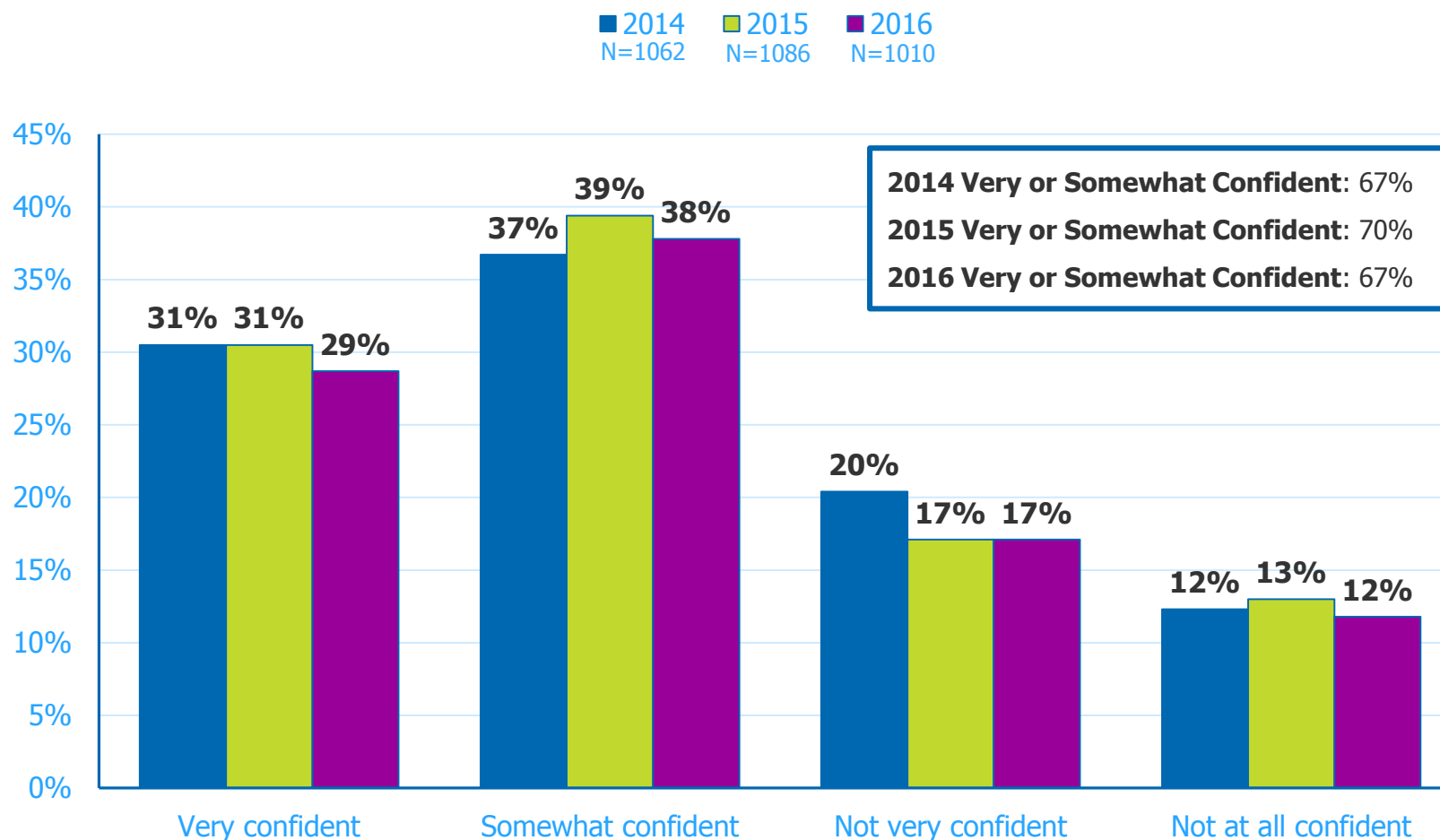
Overall: Be Able to Afford the Care Needed



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



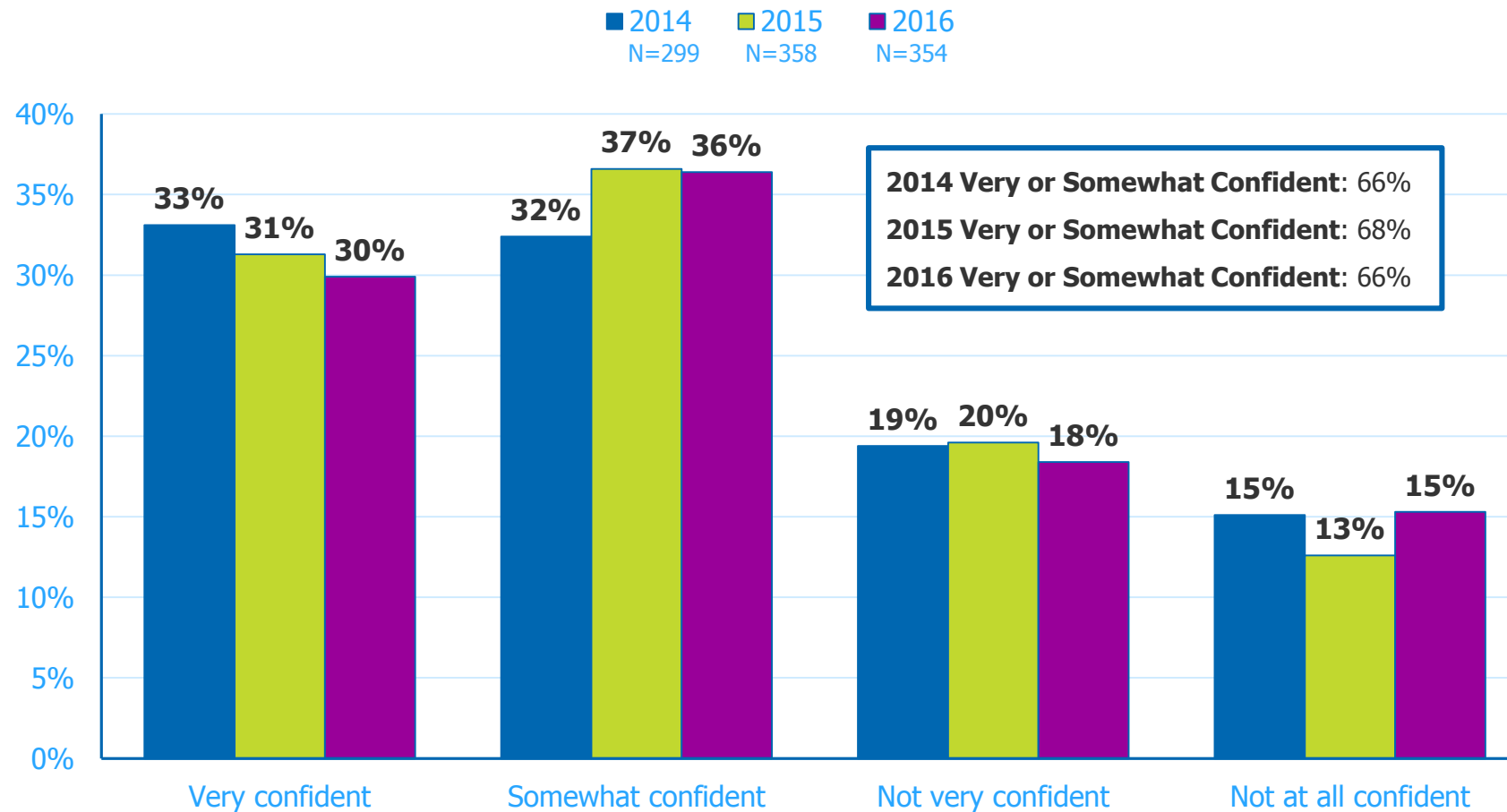
Private: Be Able to Afford the Care Needed



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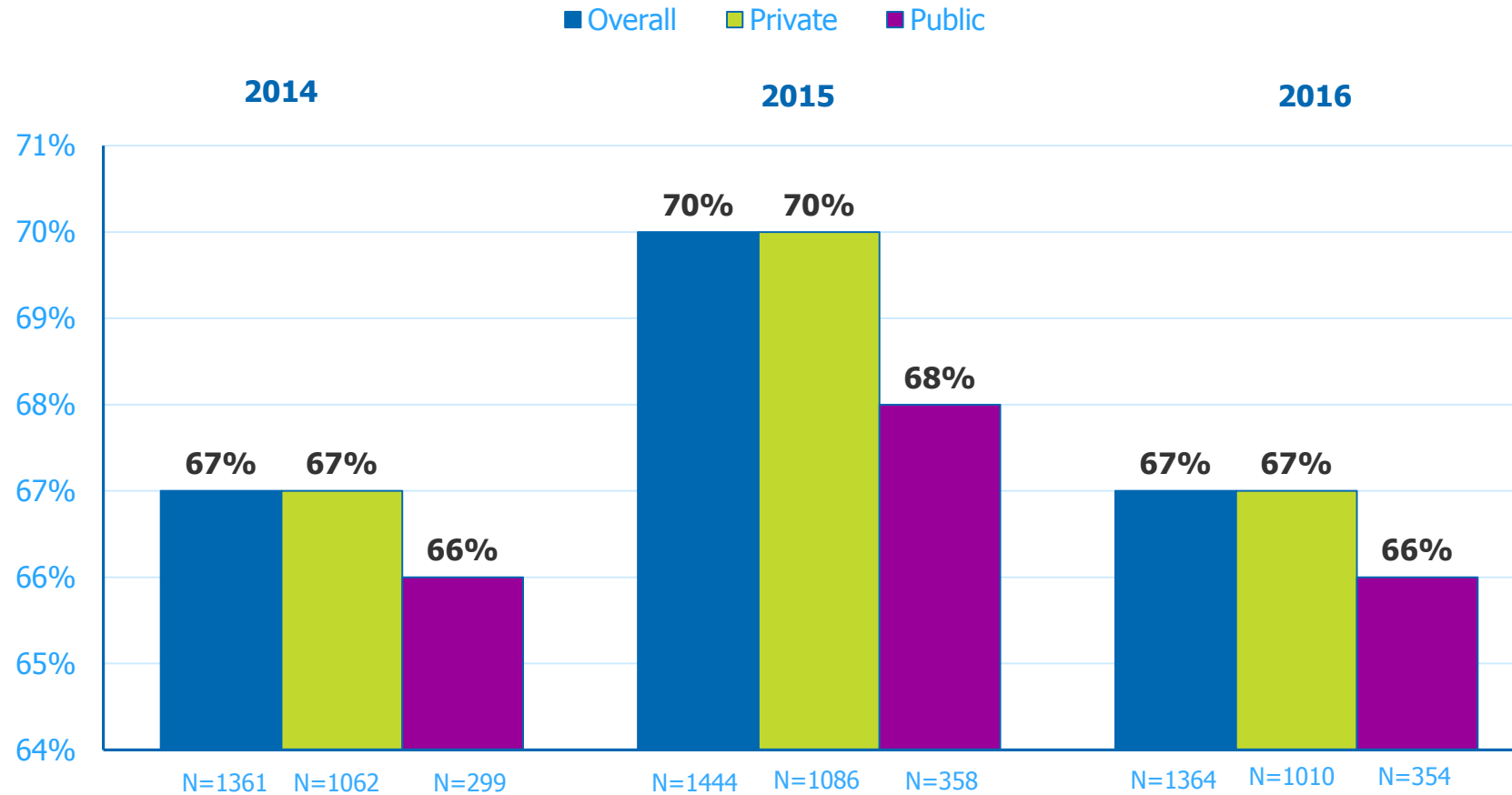
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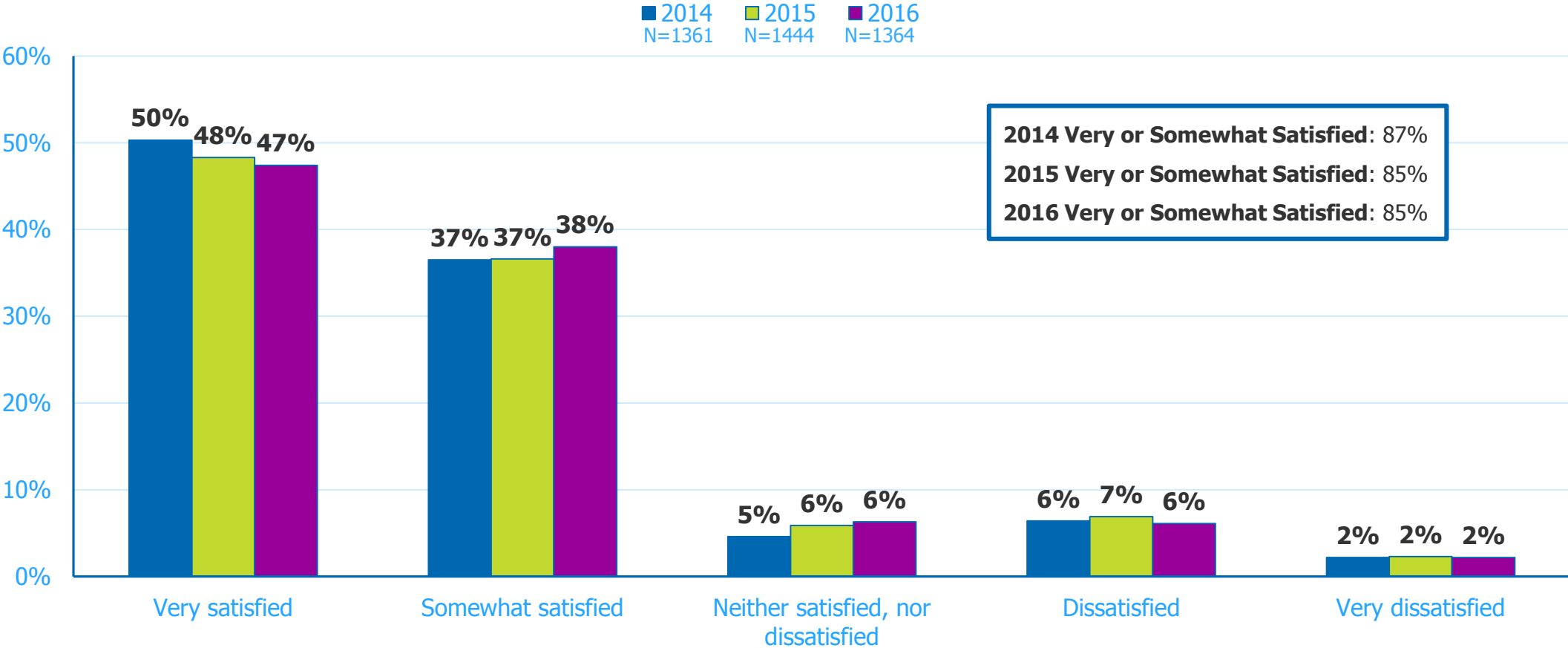
Very to Somewhat Confident Afford the Care Needed



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



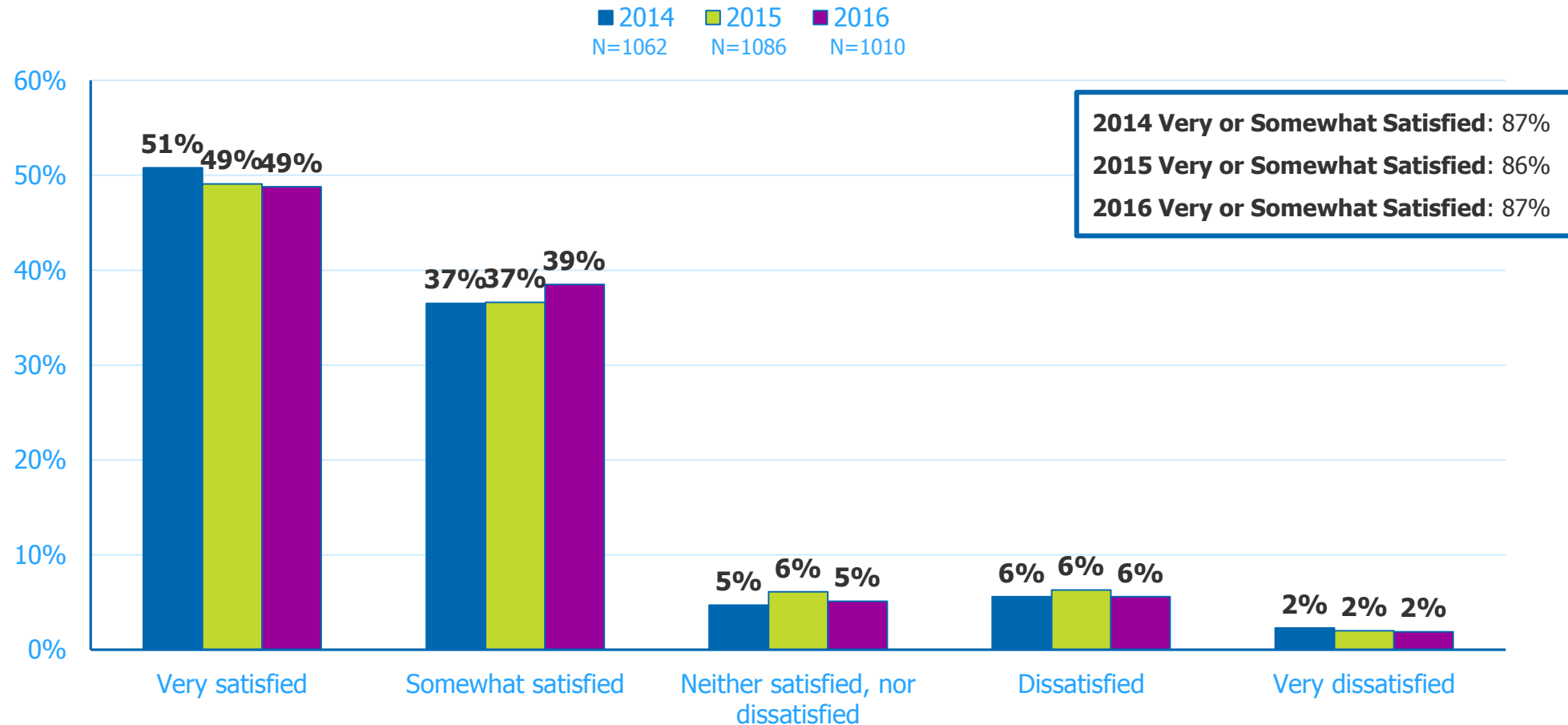
Overall: Satisfaction with Quality of Healthcare Received



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



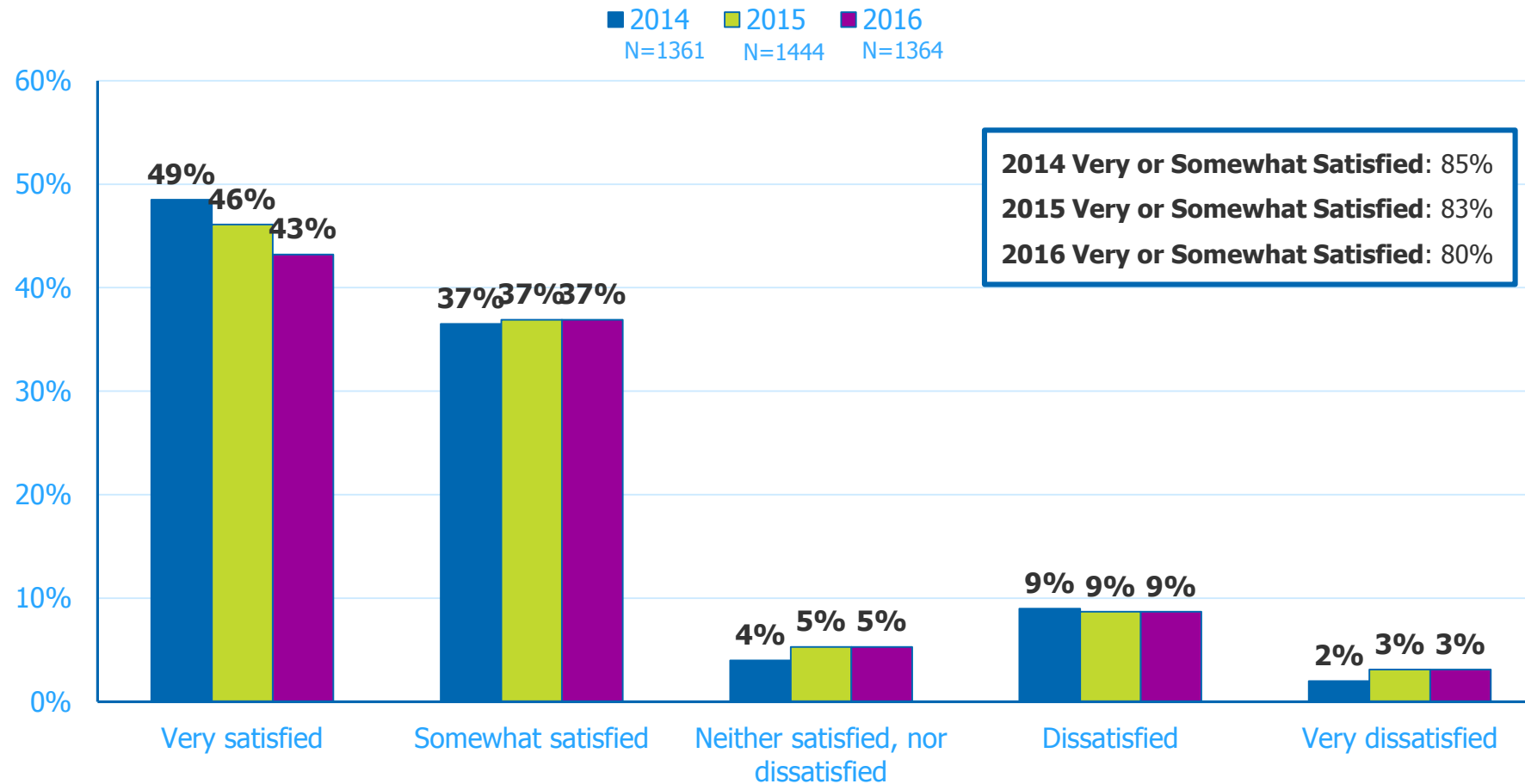
Private: Satisfaction with Quality of Healthcare Received



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



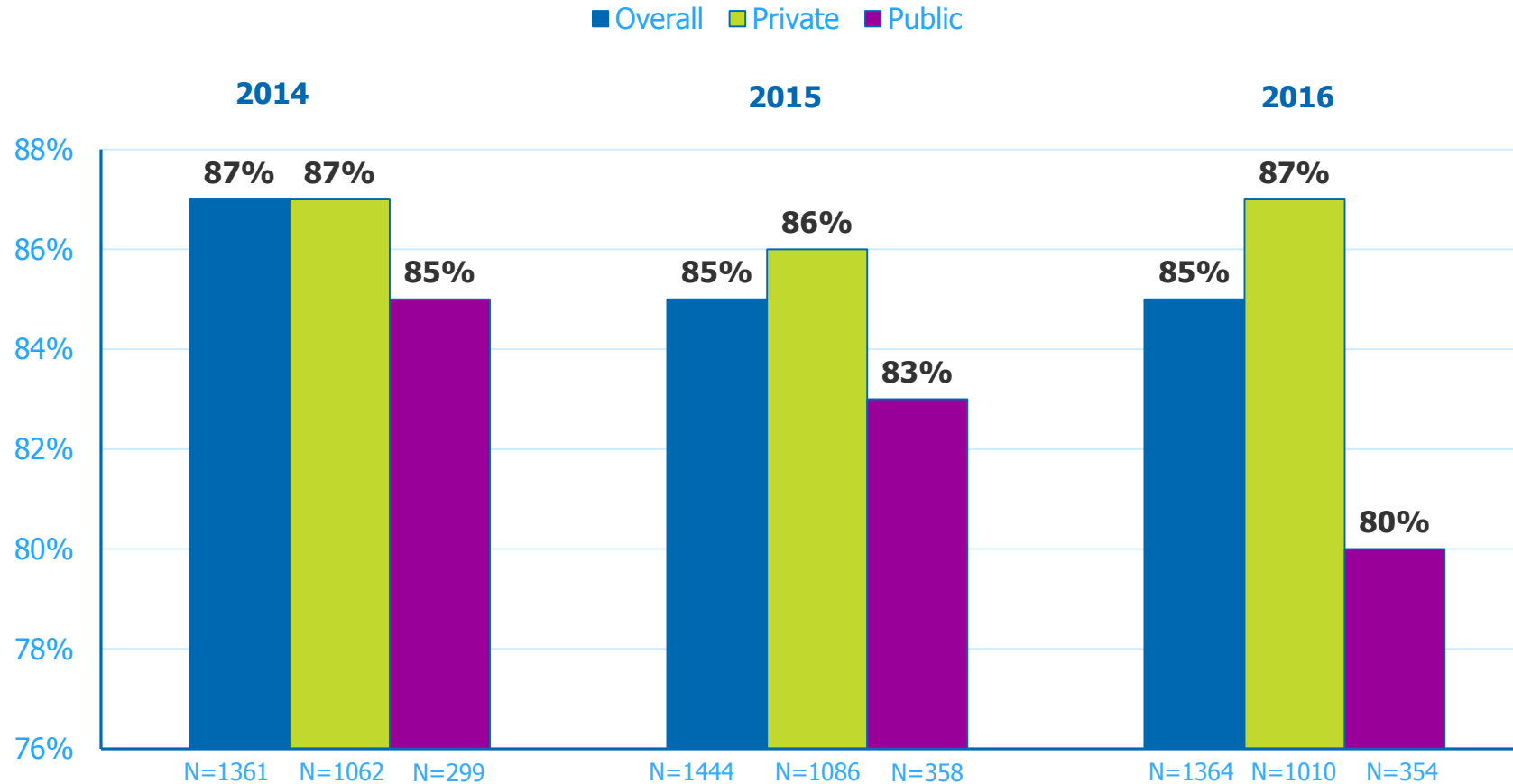
Public: Satisfaction with Quality of Healthcare Received



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



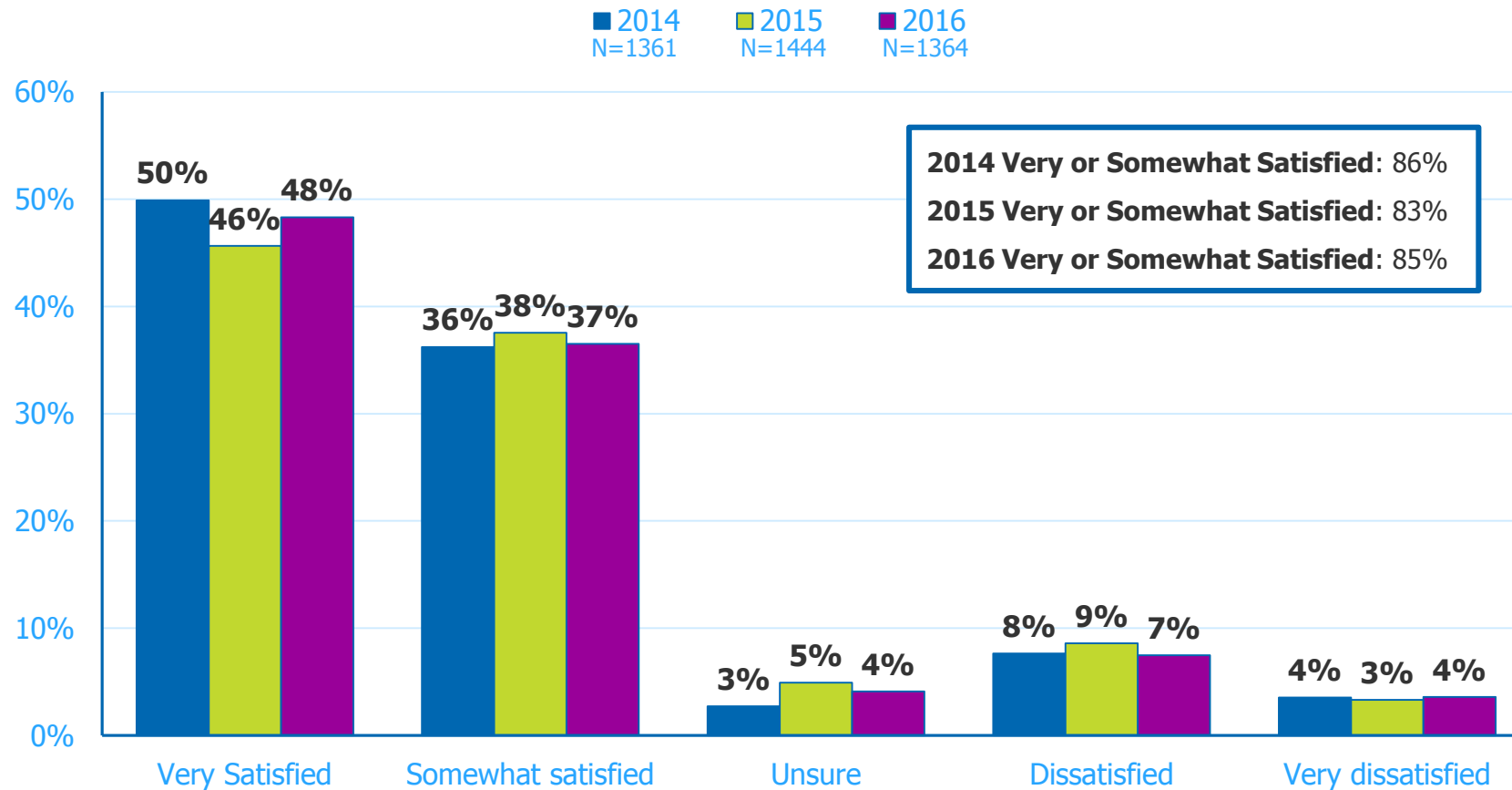
Very to Somewhat Satisfied with Quality of Healthcare Received



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



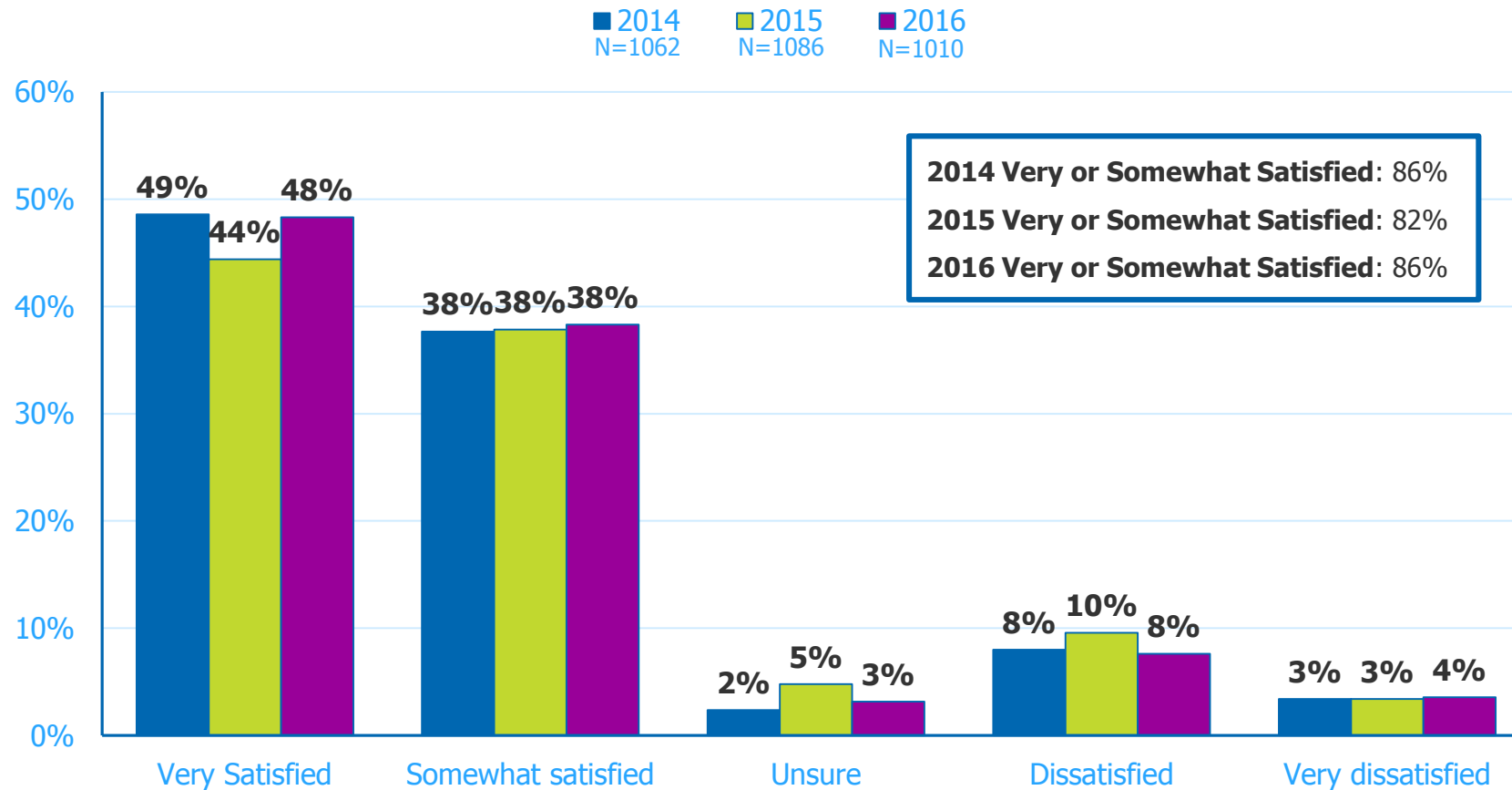
Overall Satisfaction with Health Insurance



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



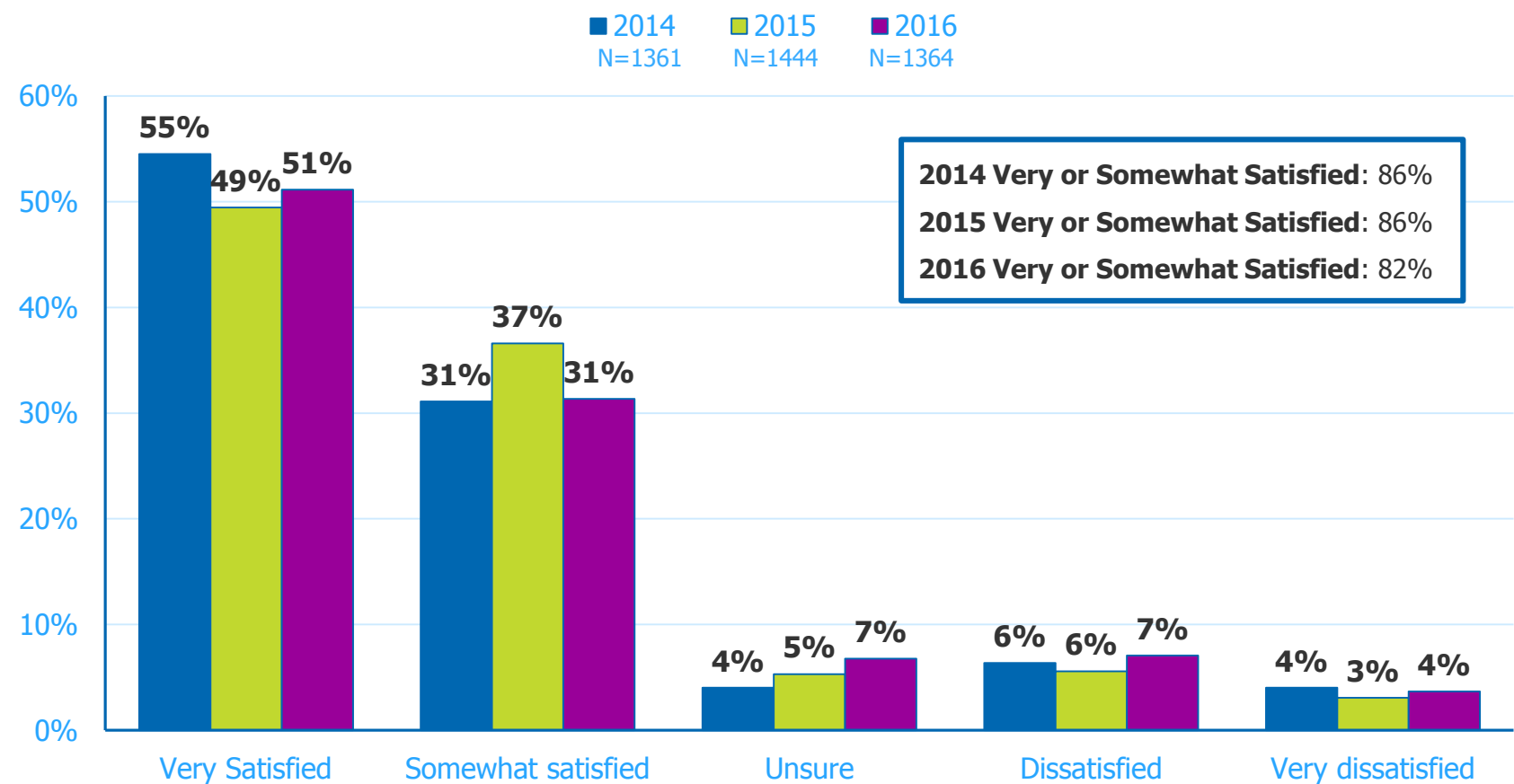
Satisfaction with Private Health Insurance



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



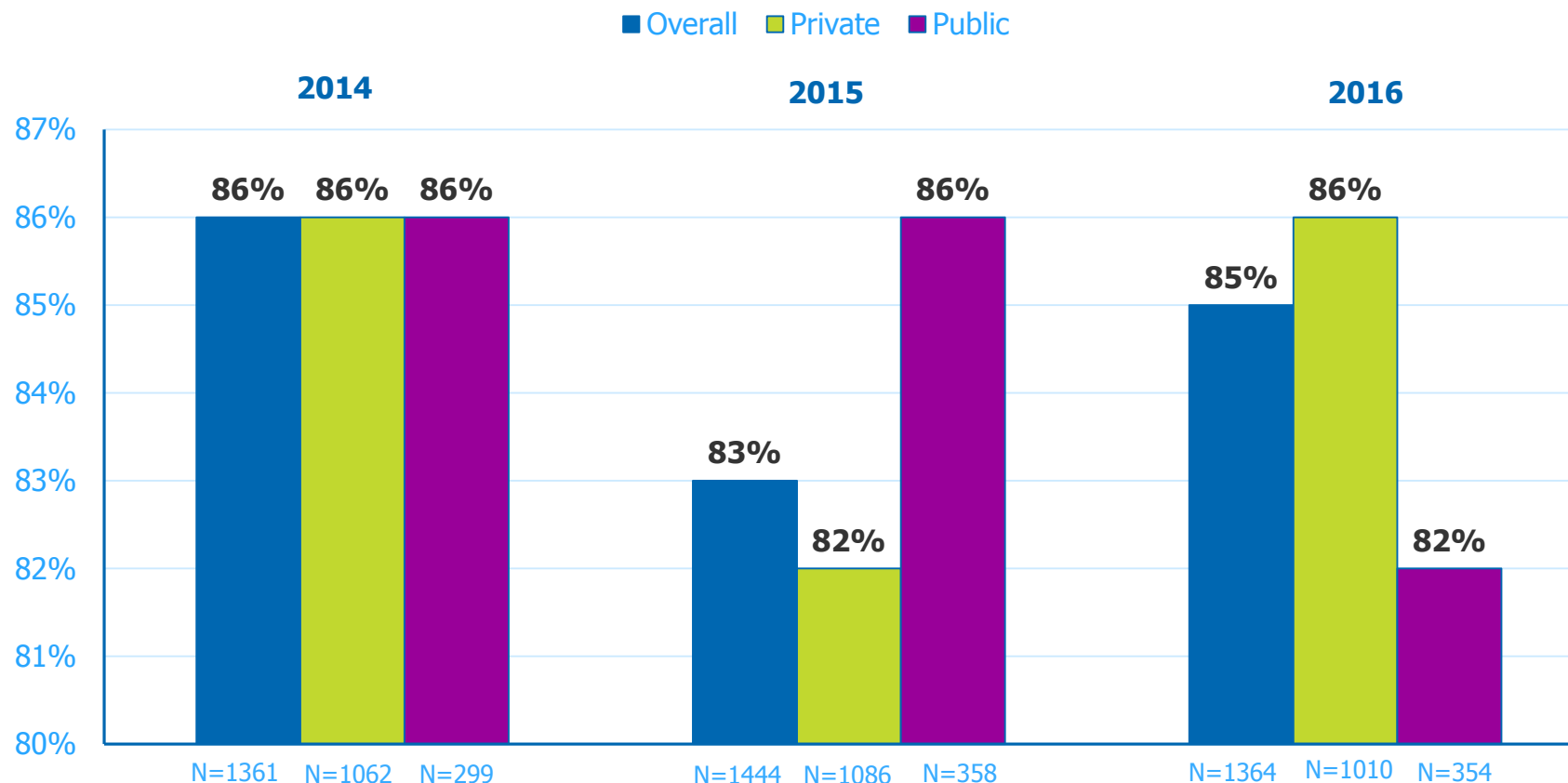
Satisfaction with Public Health Insurance



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



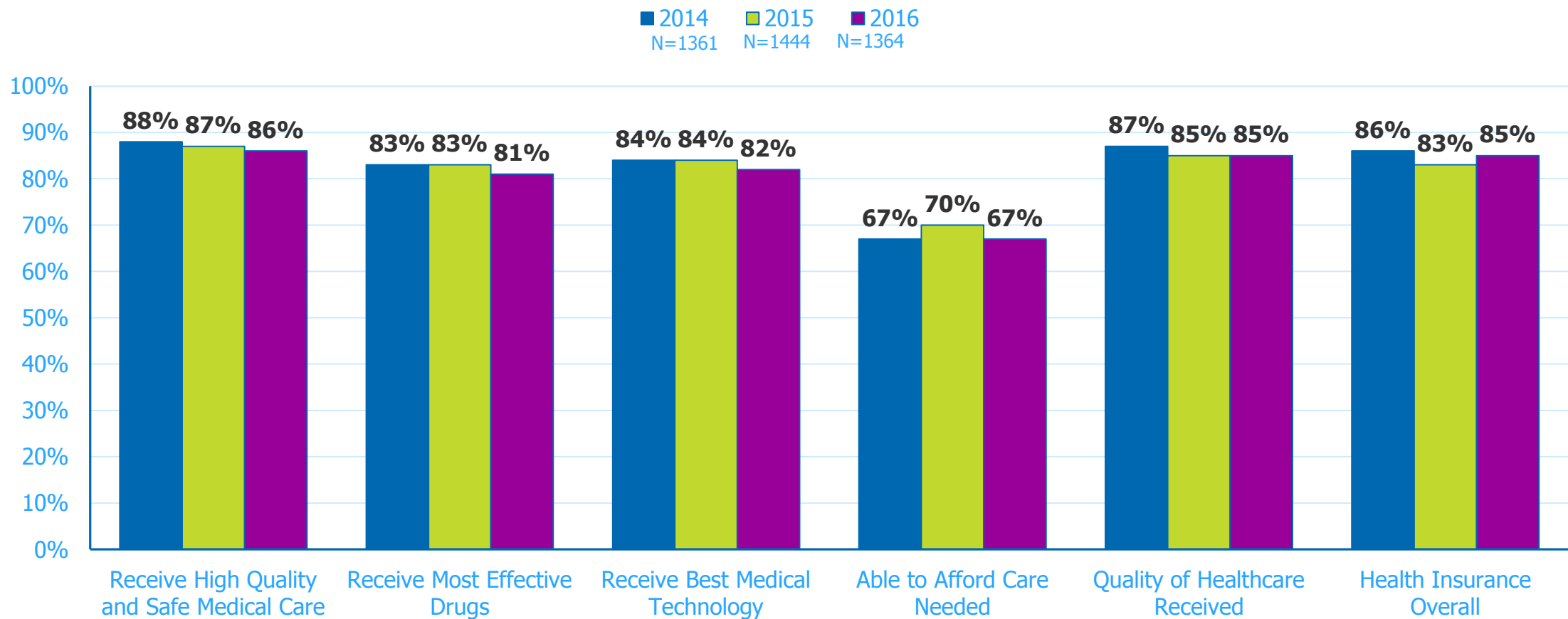
Very to Somewhat Satisfied with Health Insurance



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



Overall: Very to Somewhat Confident or Satisfied with...

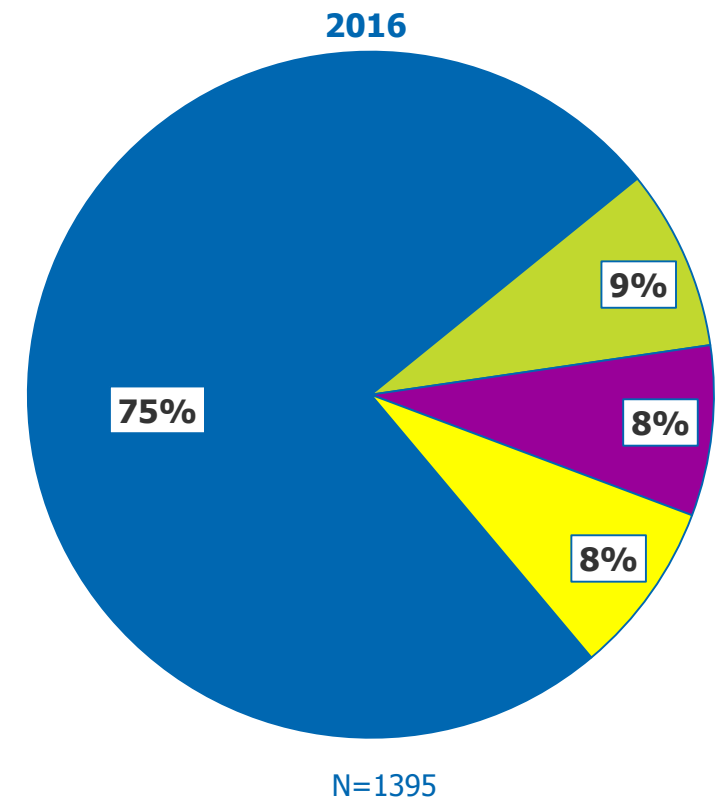
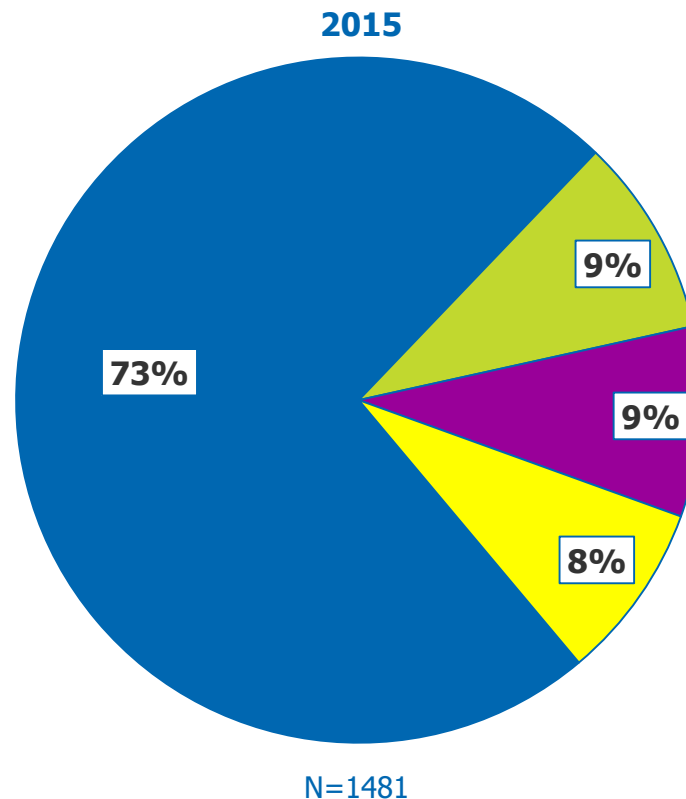
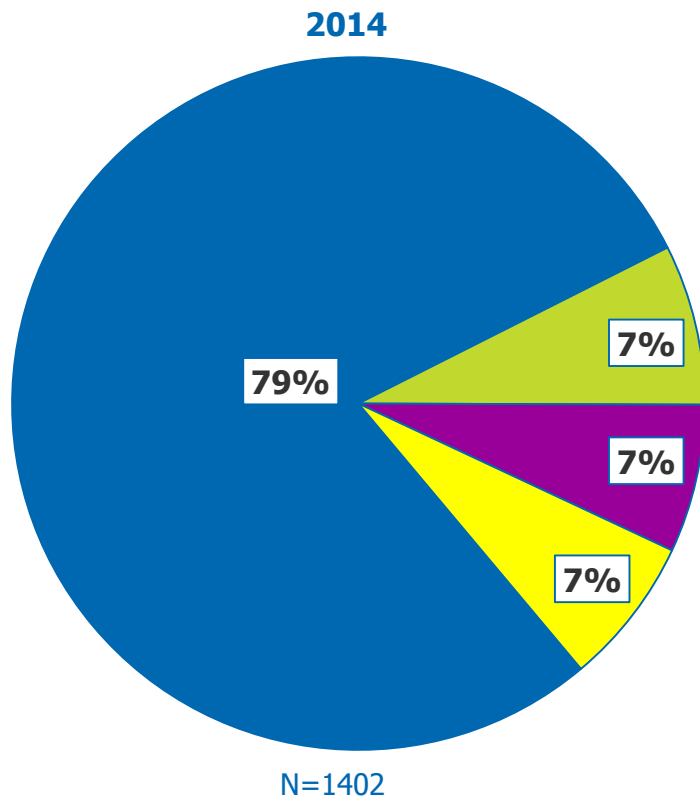


Q14a. If the person with PI were to get seriously ill, how confident would you be that the person would...
Base: All Private and Public Insured Persons with PI



Knowledge of Monthly Premium Cost

■ Yes ■ No ■ Don't have premium ■ Not sure



Q8. Do you know how much you pay for your health insurance premium each month?
Base: All Insured Persons with PI



Costs of Health Insurance

Monthly Premium Cost

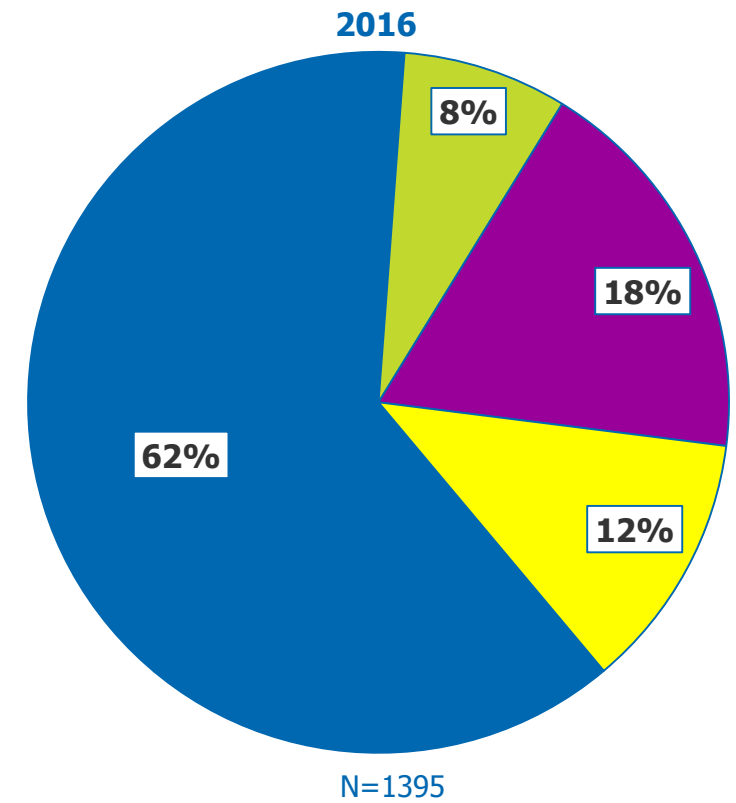
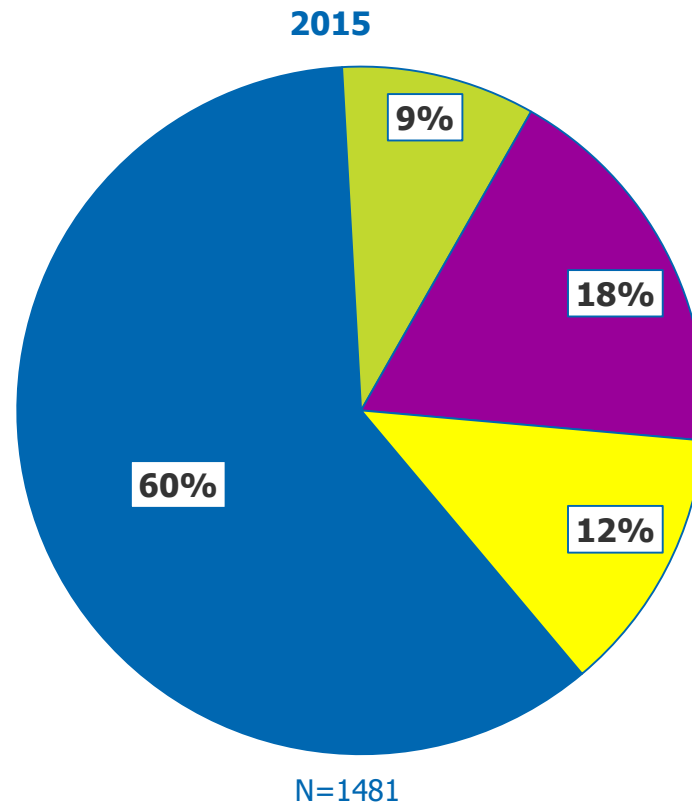
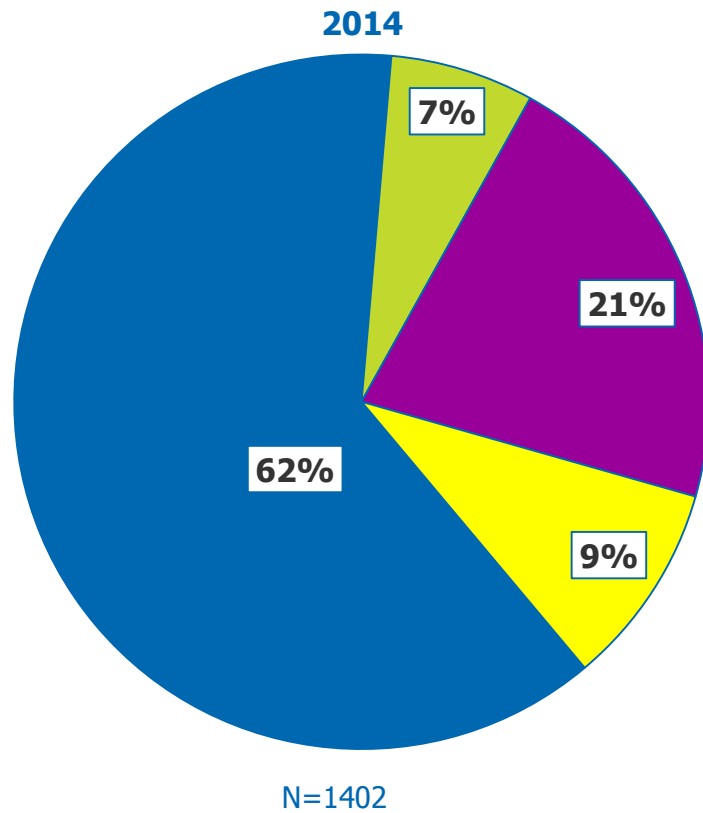
	2014 N=1008	2015 N=1063	2016 N=1031
Average	\$413.53	\$421.78	\$446.90
Median	\$300.00	\$300.00	\$292.00

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



Knowledge of Yearly Deductible

■ Yes ■ No ■ NO deductible ■ Not sure



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



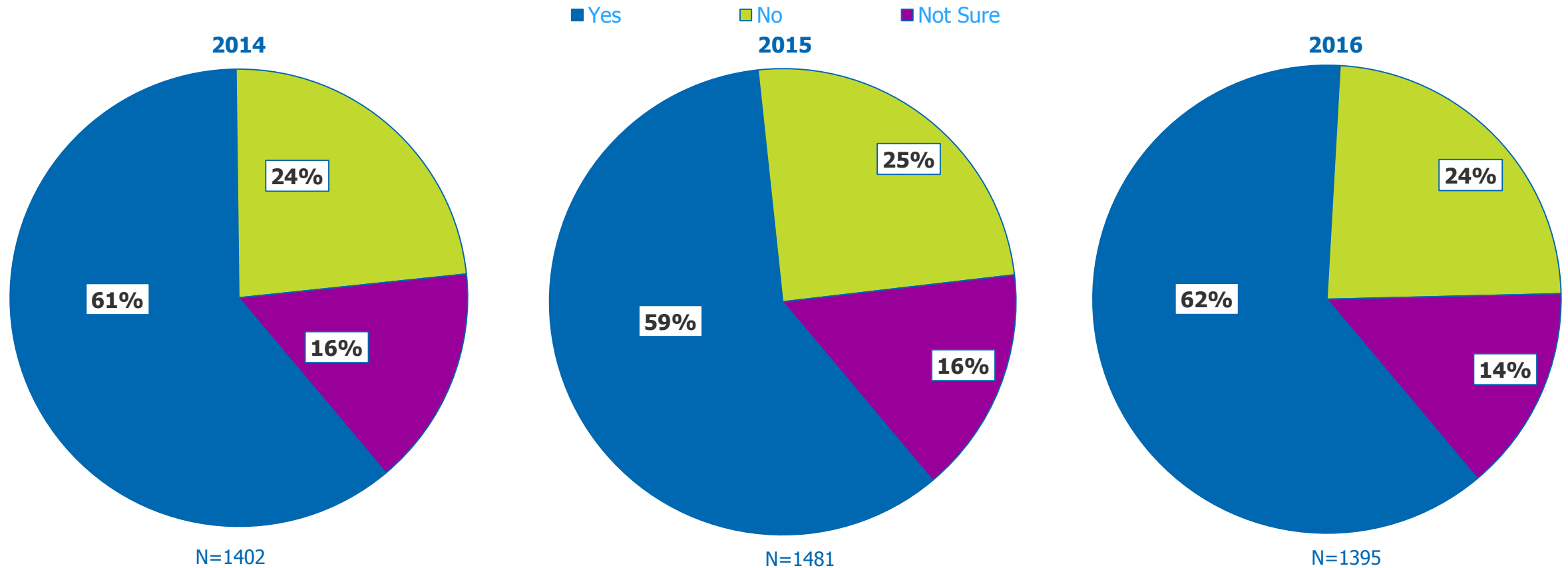
Yearly Deductible

	2014 N=866	2015 N=882	2016 N=857
Average	\$2018.51	\$2134.60	\$2155.99
Median	\$1450.00	\$1500.00	\$1500.00

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



Knowledge of Max Out-of-Pocket



Q12. Does your insurance have a maximum out-of-pocket amount you must pay each year before your health insurance plan pays 100%?
Base: All Insured Persons with PI



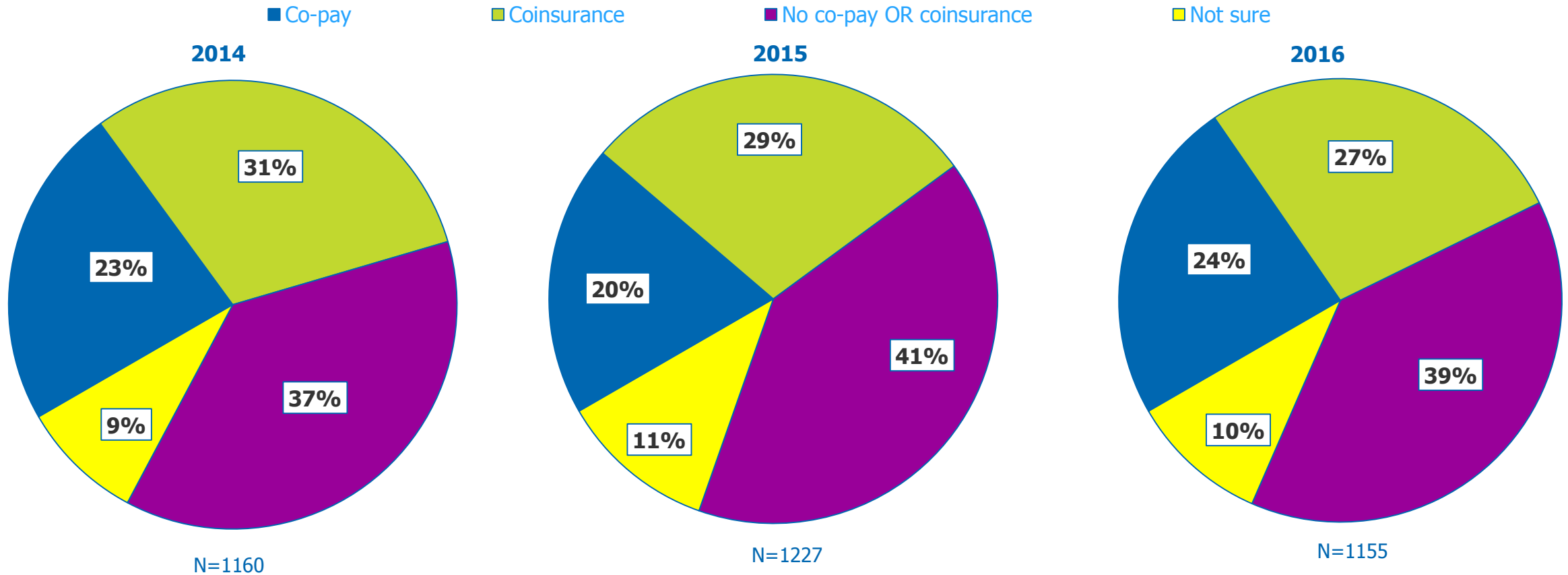
Max Out-of-Pocket

	2014 N=808	2015 N=819	2016 N=806
Average	\$4366.34	\$4688.52	\$4599.57
Median	\$4000.00	\$4290.00	\$4000.00

Q13. What is the maximum amount of your yearly, out-of-pocket expenses for healthcare?
Base: All Insured Persons with PI who Know the Amount of Their Max Out-of-Pocket Expenses



Co-pay or Coinsurance for Ig Therapy



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



Monthly Cost for Ig Therapy

Co-pay	2014 N=226	2015 N=212	2016 N=214
Average	\$223.10	\$453.32	\$346.20
Median	\$69.00	\$80.00	\$100.00
Don't Know the Cost	16%	23%	21%

Coinsurance	2014 N=233	2015 N=190	2016 N=183
Average	\$651.71	\$562.41	\$573.61
Median	\$333.00	\$355.00	\$300.00
Don't Know the Cost	33%	43%	41%

Q47a. How much is your monthly co-pay for Ig therapy treatment?

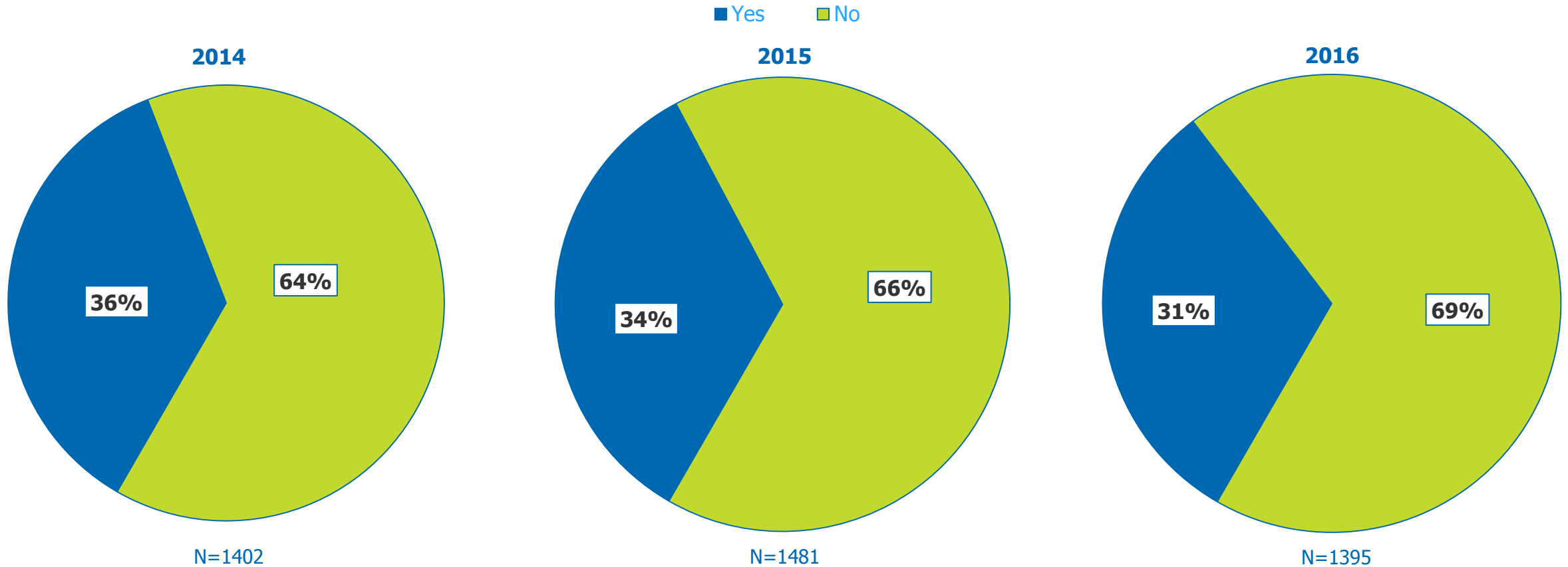
Base: All Insured Persons with PI Currently Receiving Ig Therapy who Have a Co-pay

Q48c. How much do you have to pay for the person's coinsurance for each month of Ig therapy treatment?

Base: All Insured Persons with PI Currently Receiving Ig Therapy who Have Coinsurance



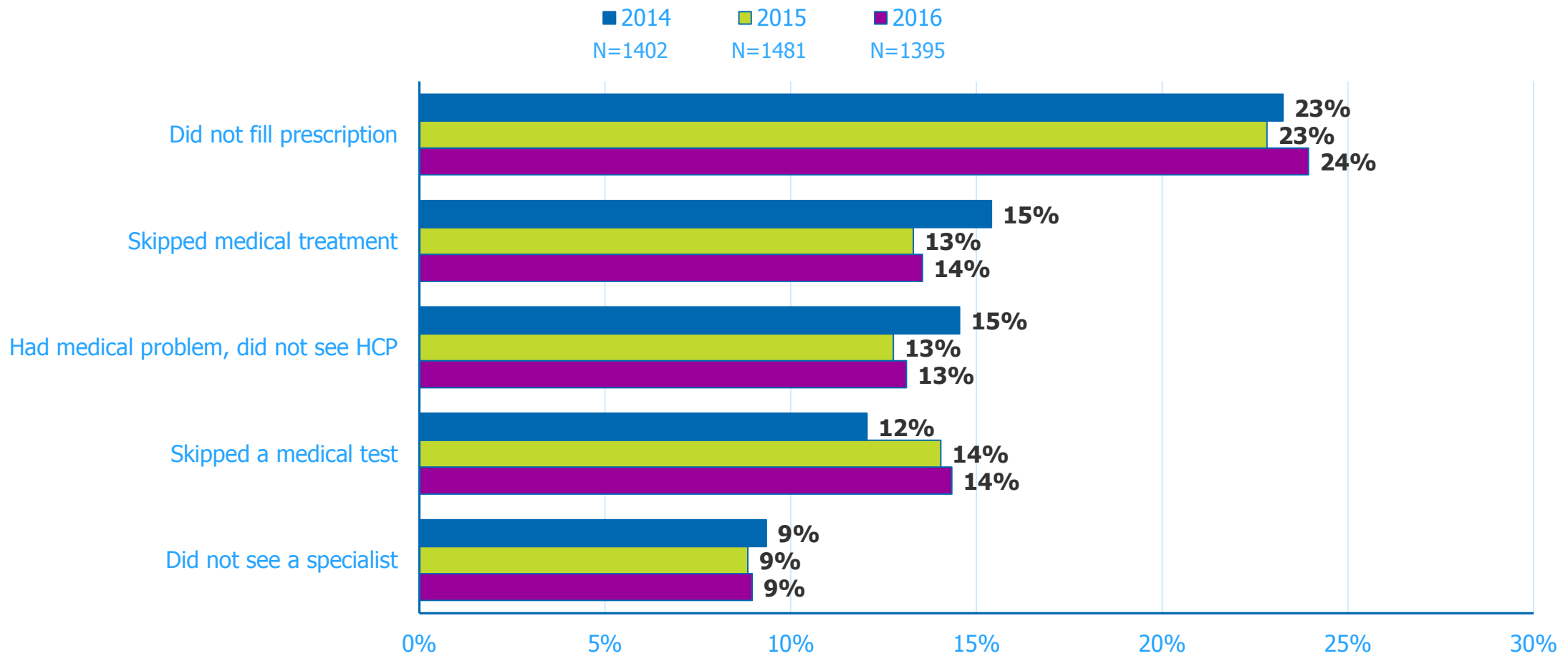
Problems Paying Medical Bills



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



Impact of OOP Health Insurance Costs



Since January 2014/2015/2016, was there any time when the person _____ because of out-of-pocket costs?
Base: All Insured Persons with PI



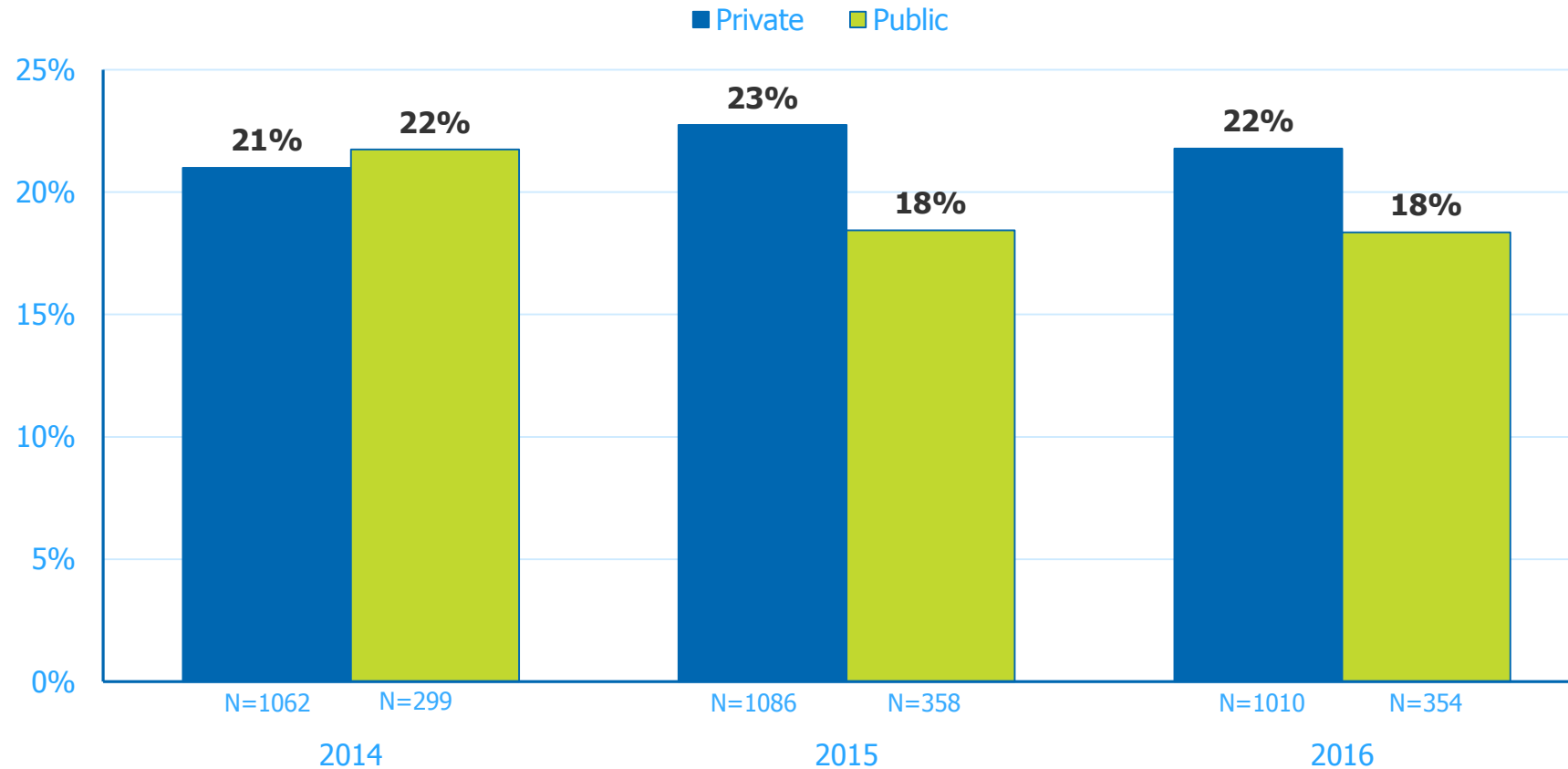
Actions Taken in Order to Pay for Healthcare

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

Q27. Since January 2014/2015/2016, have you done any of the following in order to pay for the person's healthcare costs.
Base: All Insured Persons with PI



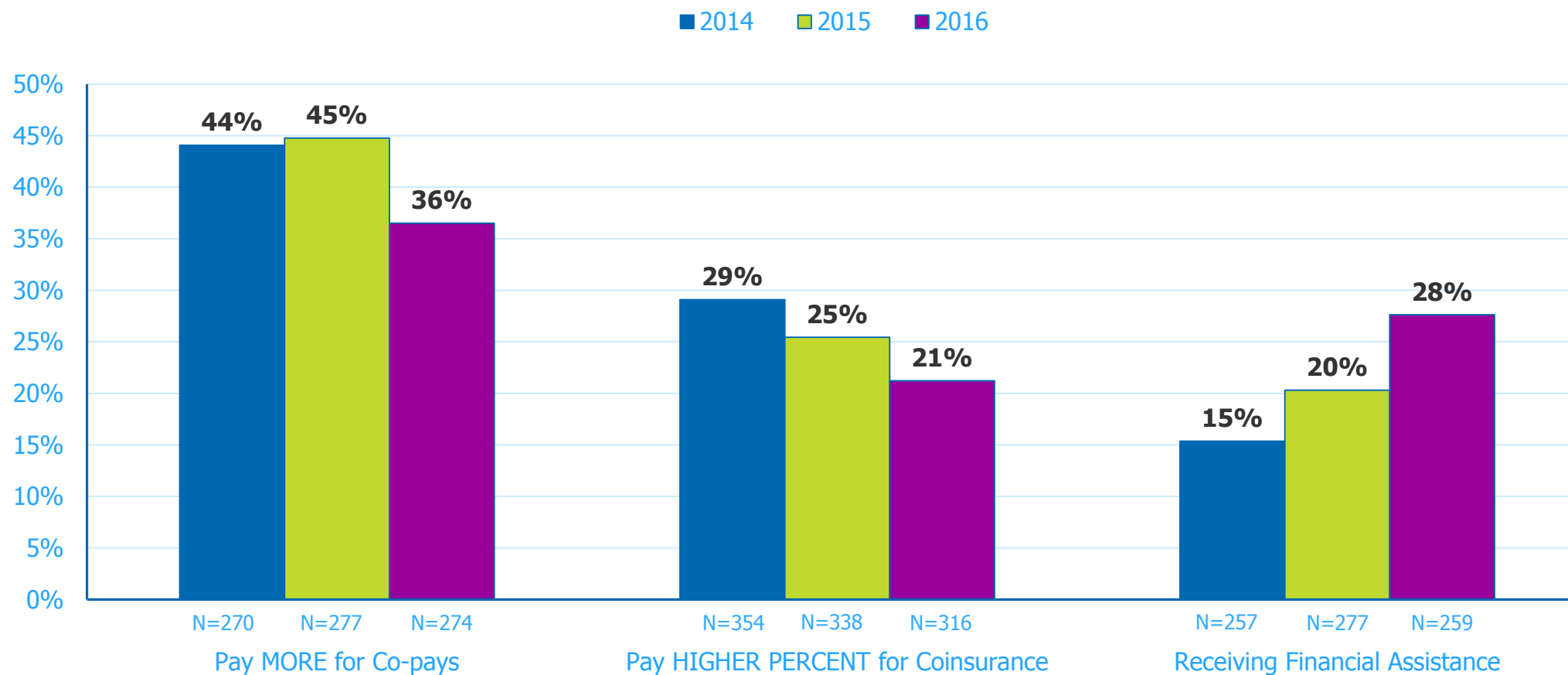
Had Problems Affording Healthcare Specialists Due to Health Plan Rules



Q17b. Since January 2014, as a result of your health plan's costs sharing, has the person with PI had any problems affording visits to any healthcare specialists?
Base: All Private or Public Insured Persons with PI

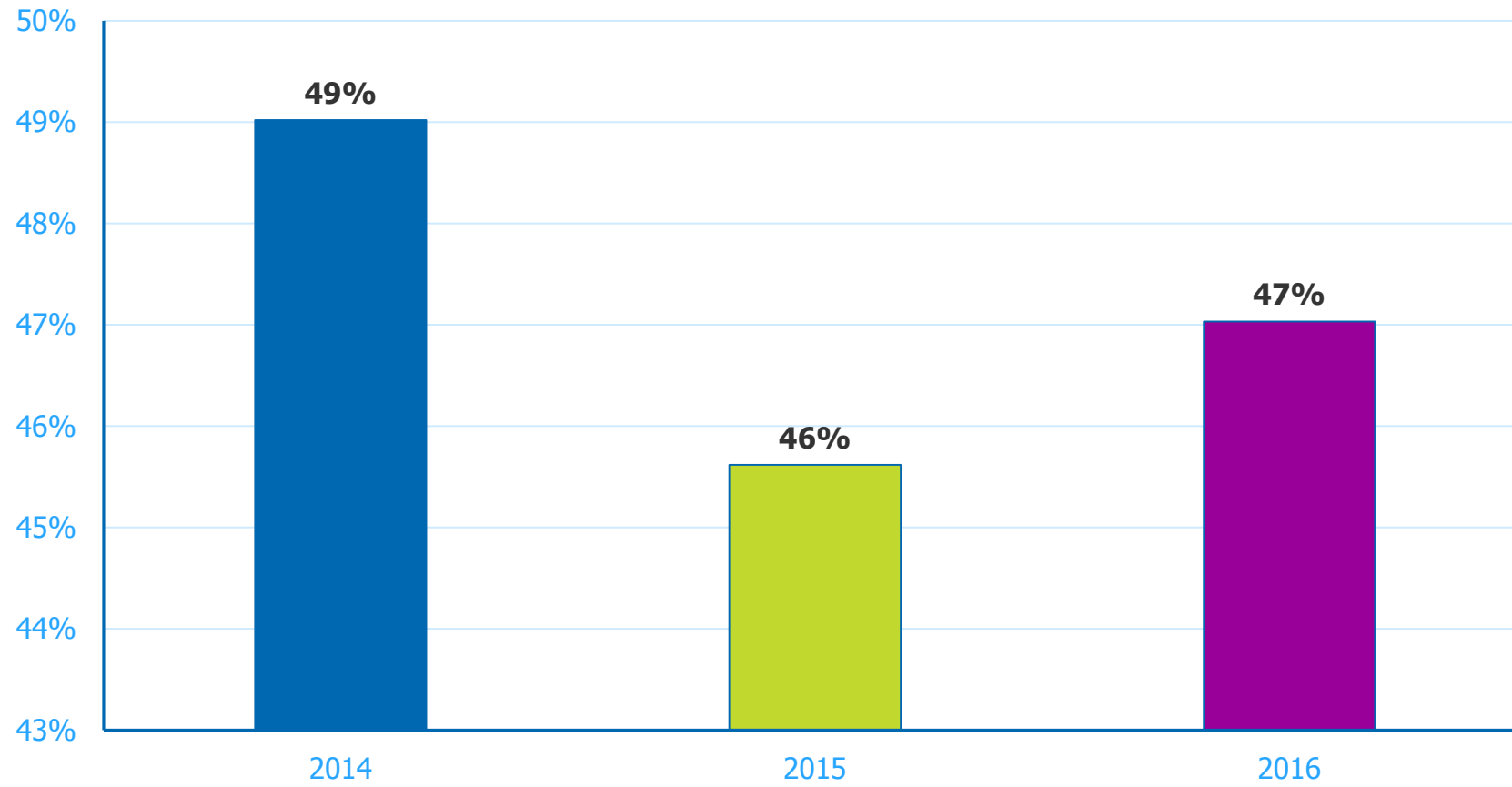


Other Insurance Issues



Q47b. Since September 2013/2014, what changes, if any, have you experienced in the amount of the co-pays for the Ig therapy?
Q48d. Since January of 2014/2015/2016, what changes, if any, have you experienced in the percent of coinsurance you have to pay?
Q50a. Is the person with PI currently receiving any financial assistance for co-pay, coinsurance or health insurance premium expenses?
Base: All Insured Persons with PI Currently Receiving Ig Therapy

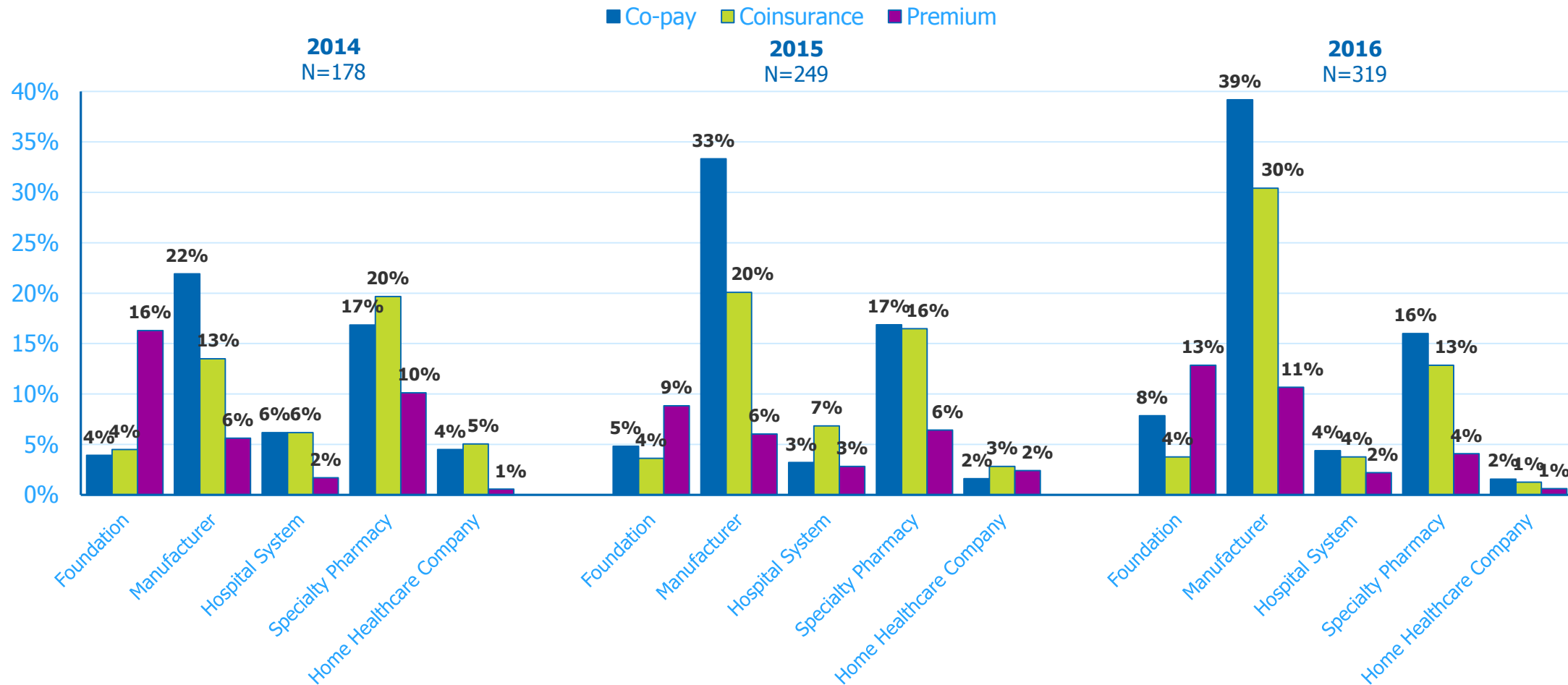
Financial Burden: >10% of Household Income Spent on Healthcare



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



Sources of Financial Assistance

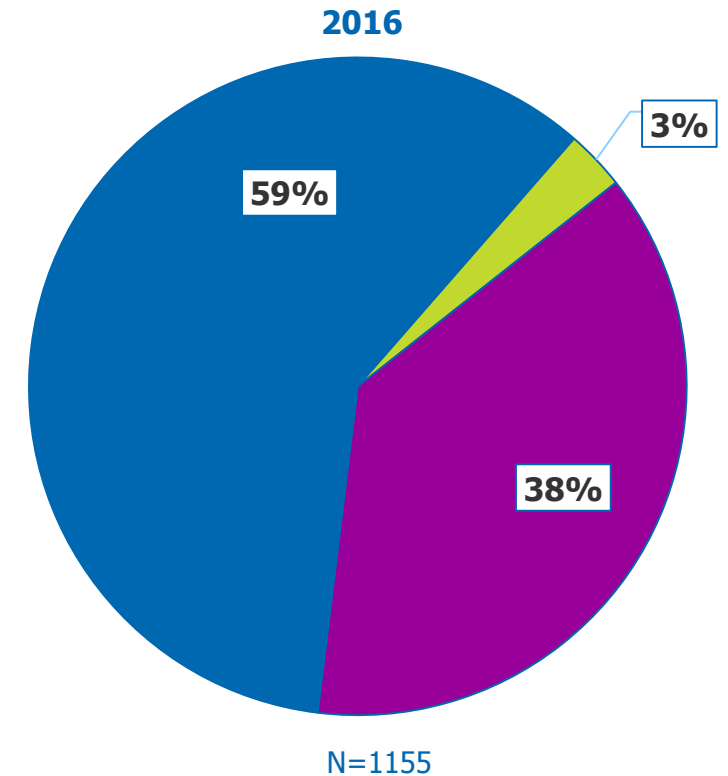
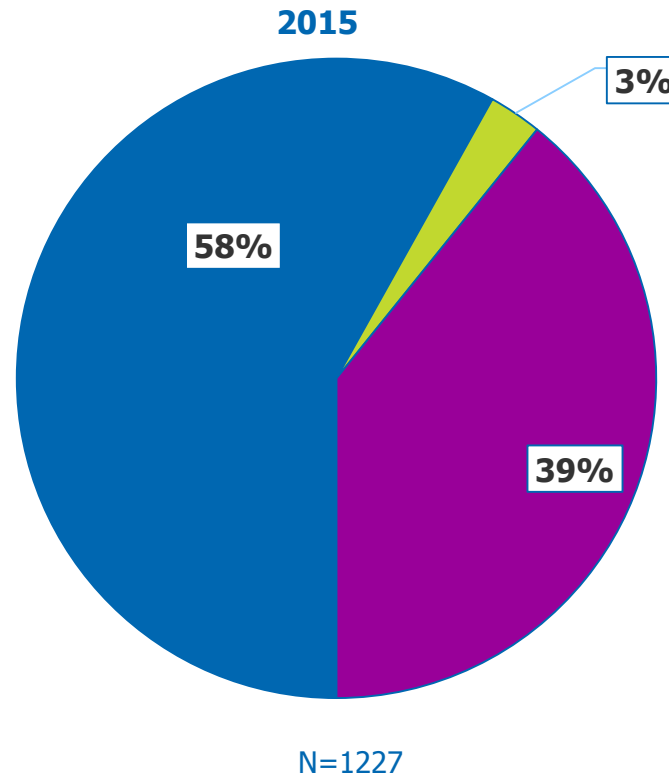
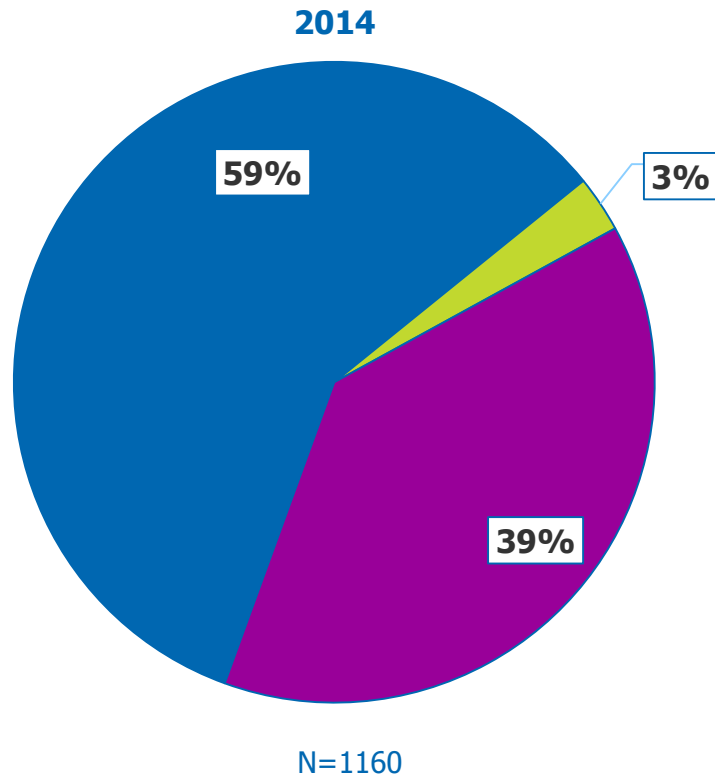


Q50b. What type of organization gives the person assistance and what type of payment do they help with?
Base: All Insured Persons with PI Currently Receiving Ig Therapy who Receive Financial Assistance

Immunoglobulin Replacement Therapy

IVIG and SCIG Insurance Coverage

■ Yes ■ No ■ Don't Know/Not Sure

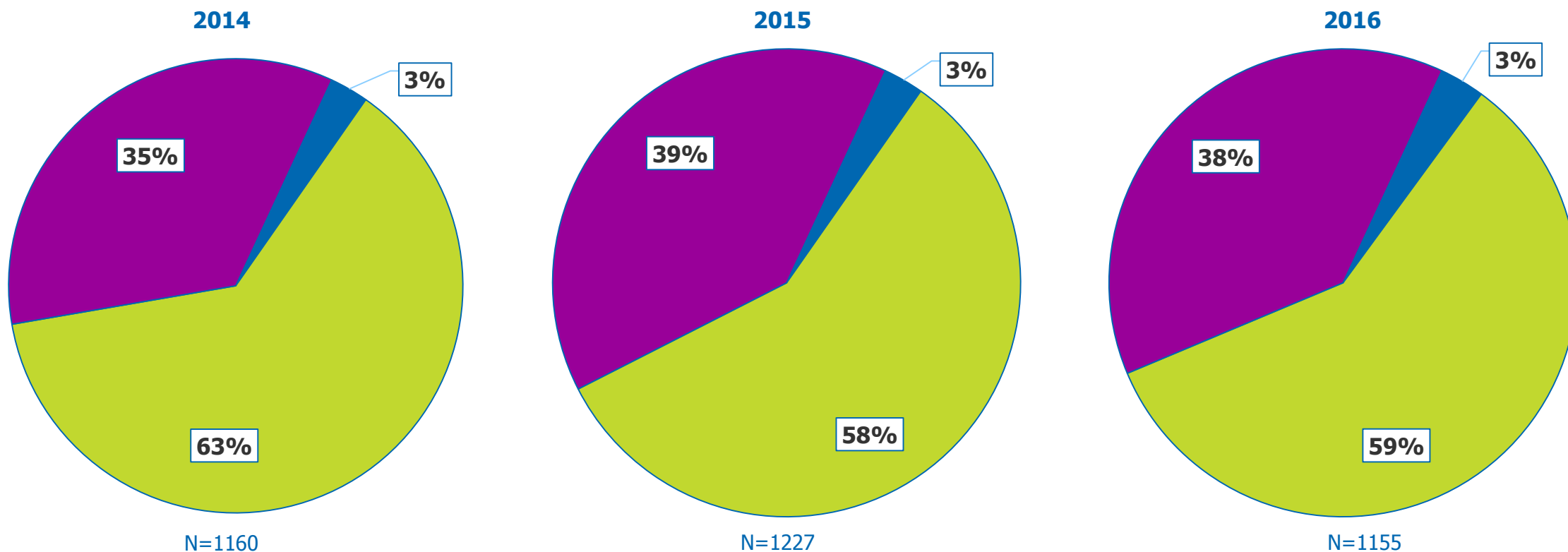


Q42. Does the person's insurance plan cover both SCIG and IVIG?
Base: All Insured Persons with PI Currently Receiving Ig Therapy



Health Plans and Dosage Limitations

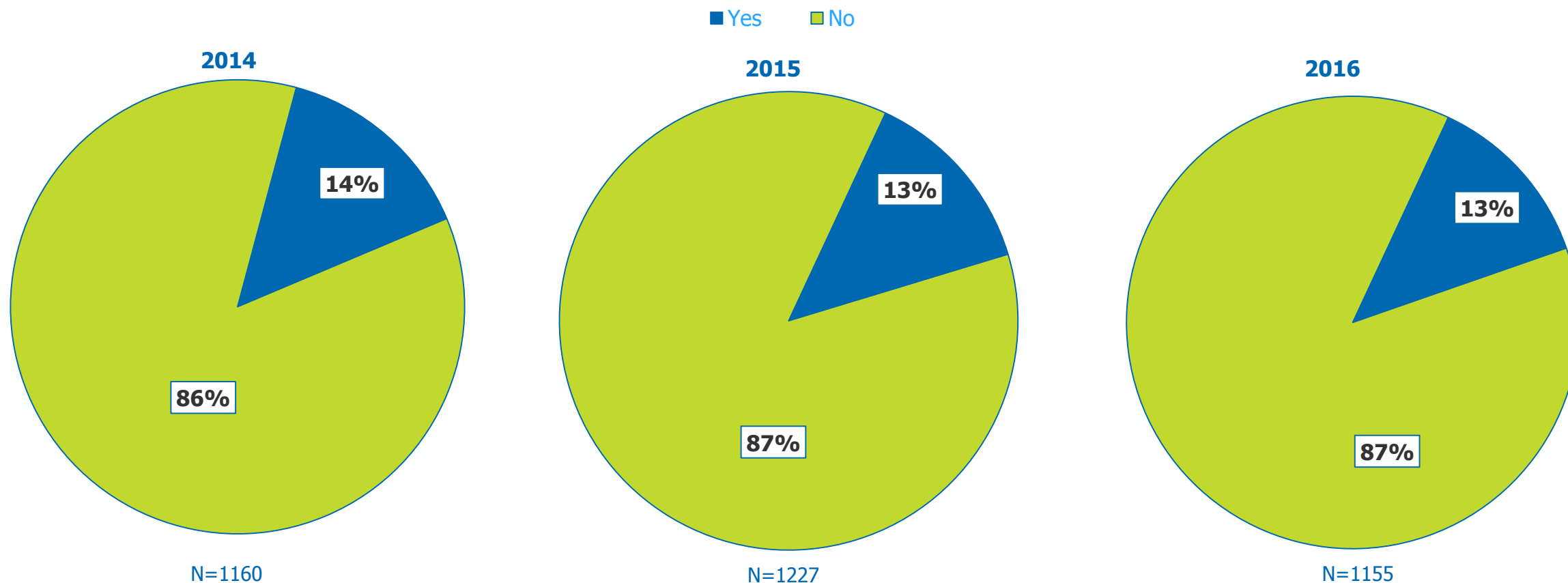
■ Grams of Ig are limited ■ Grams of Ig are NOT limited ■ Don't Know/Not Sure



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



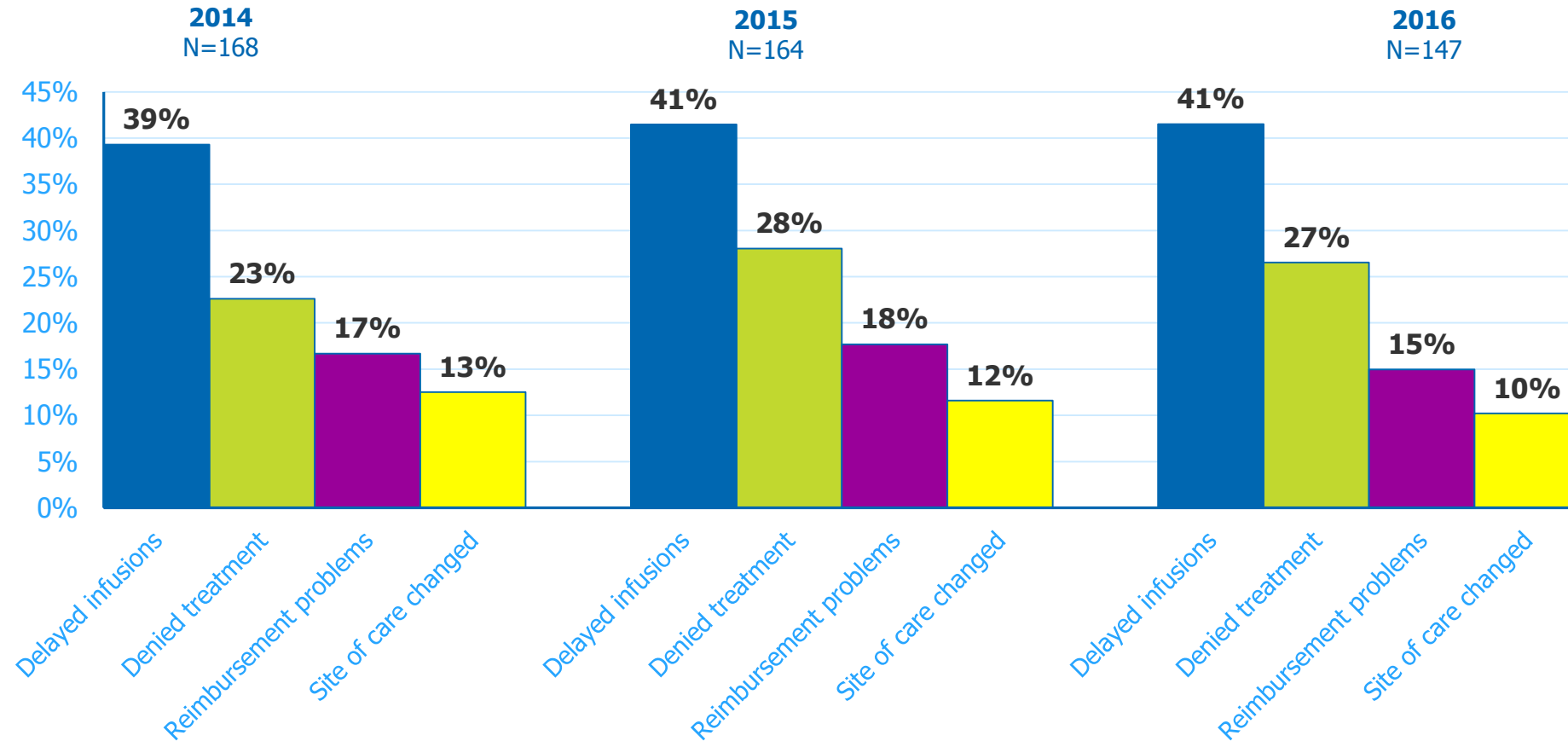
Problems Receiving Regular Infusion



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



Due to Health Plan Rules...



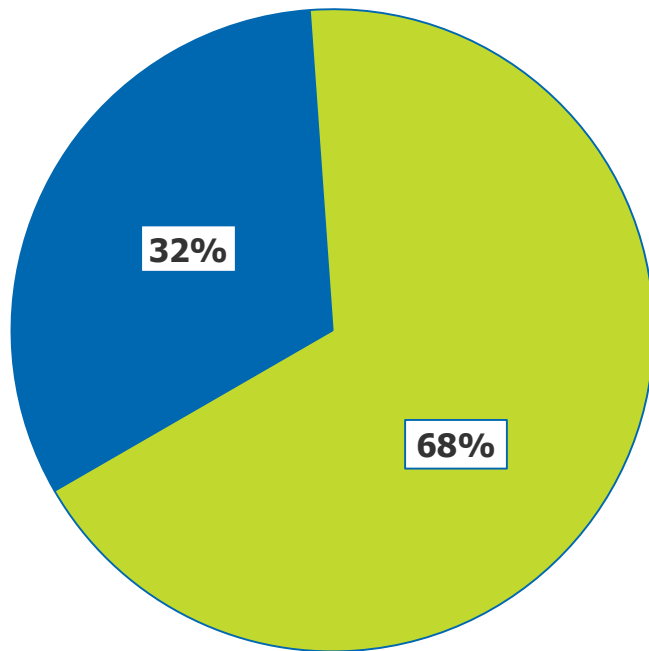
Q51b. Since January 2014, which of the following events, if any, has the person experienced due to health plan rules?
Base: All Insured Persons with PI Currently Receiving Ig Therapy



Delayed or Skipped Ig Therapy in Past Year

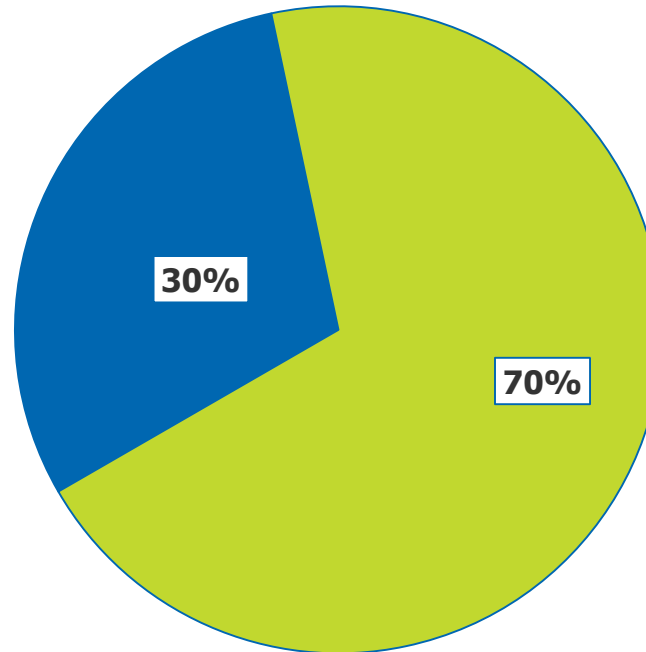
■ Yes ■ No

2014



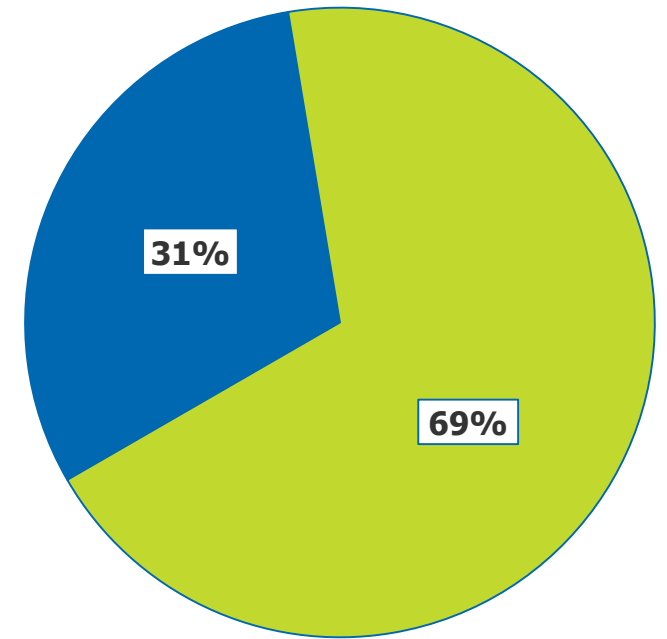
N=1160

2015



N=1227

2016

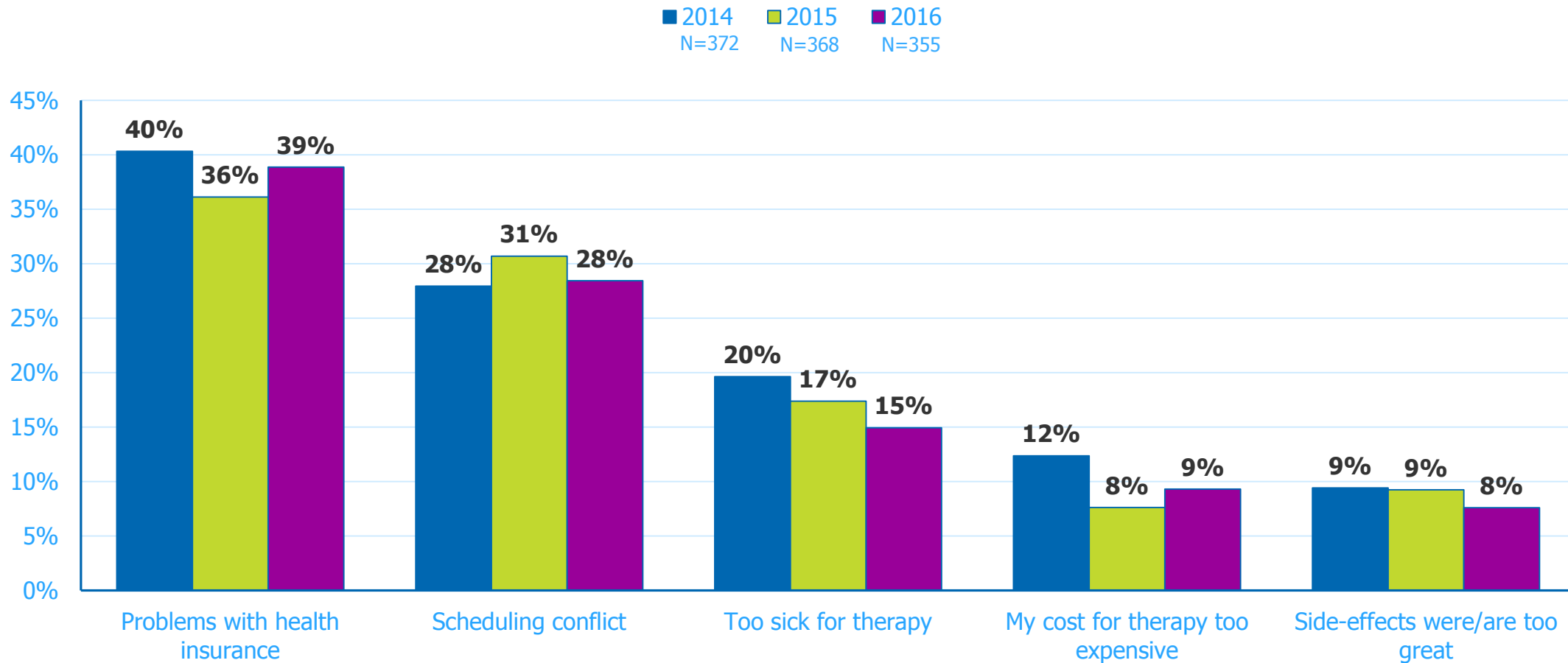


N=1155

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



Reasons Why Ig Therapy was Delayed or Skipped in Past Year



Q45c. What reason(s) did the person with PI have for skipping or delaying their Ig therapy?

Base: All Insured Persons with PI Currently Receiving Ig Therapy Whom Delayed or Skipped Ig therapy in the Past Year



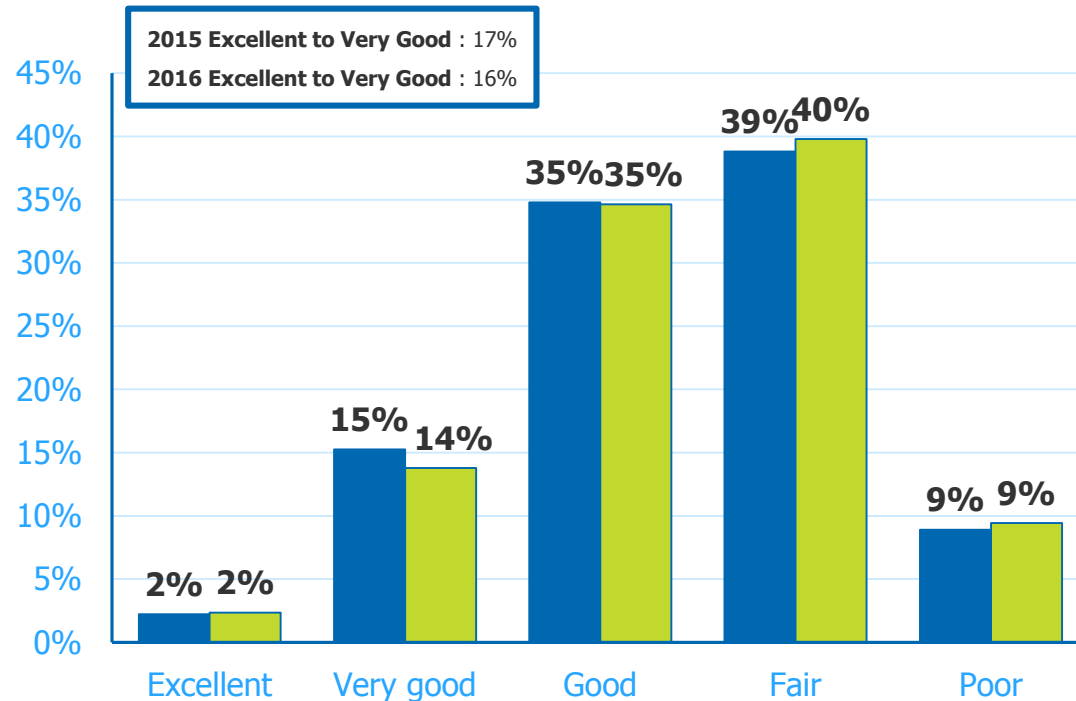
General Health and Well-being

General Health

Adults with PI

■ 2015
N=1167

■ 2016
N=1146



Children with PI

■ 2015
N=337

■ 2016
N=268

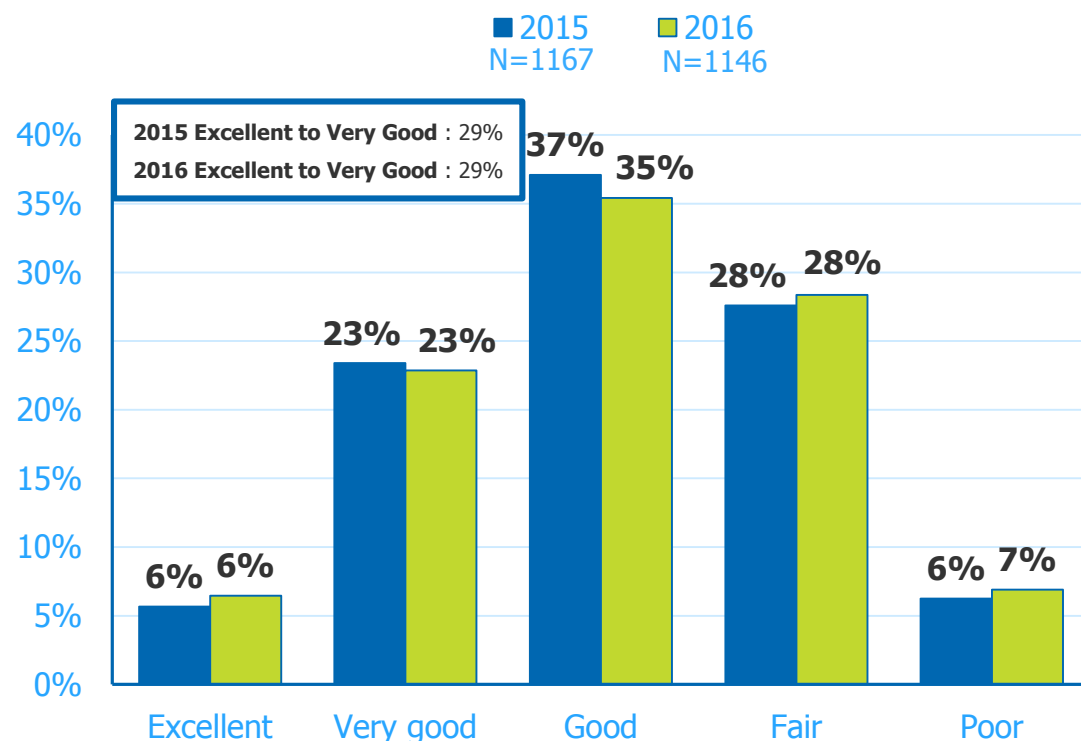


Q1a_pt. In general, would you say your health is:
Q1a_chld. In general, would you say their health is:
Base: All Respondents

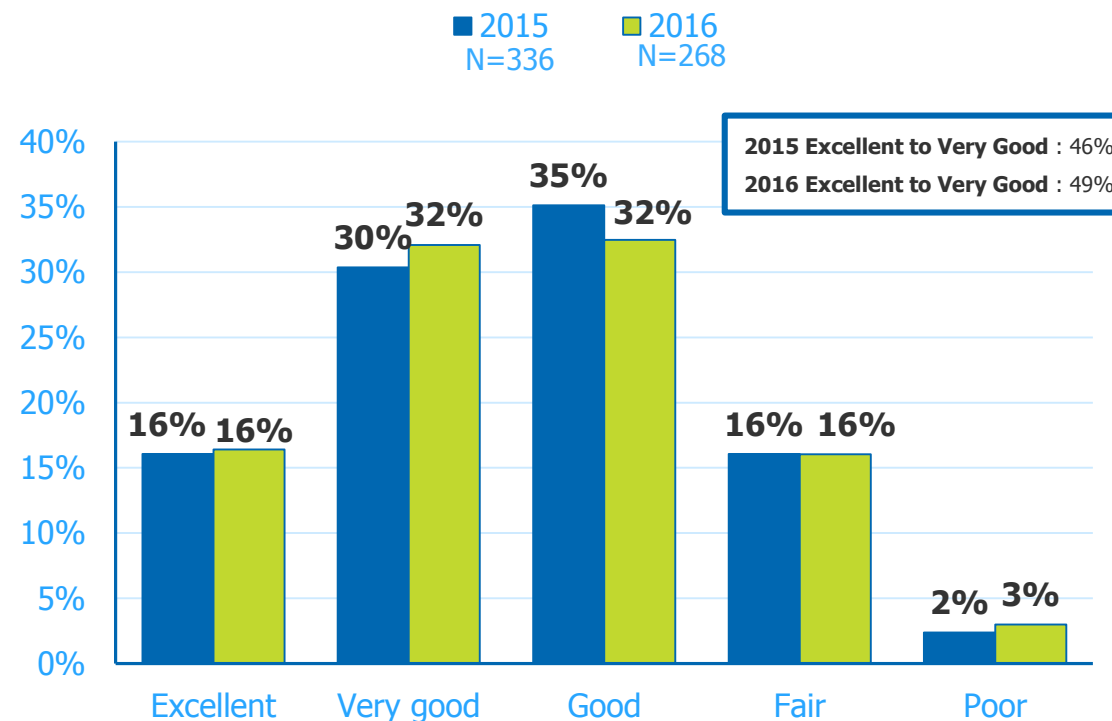


Quality of Life

Adults with PI



Children with PI



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

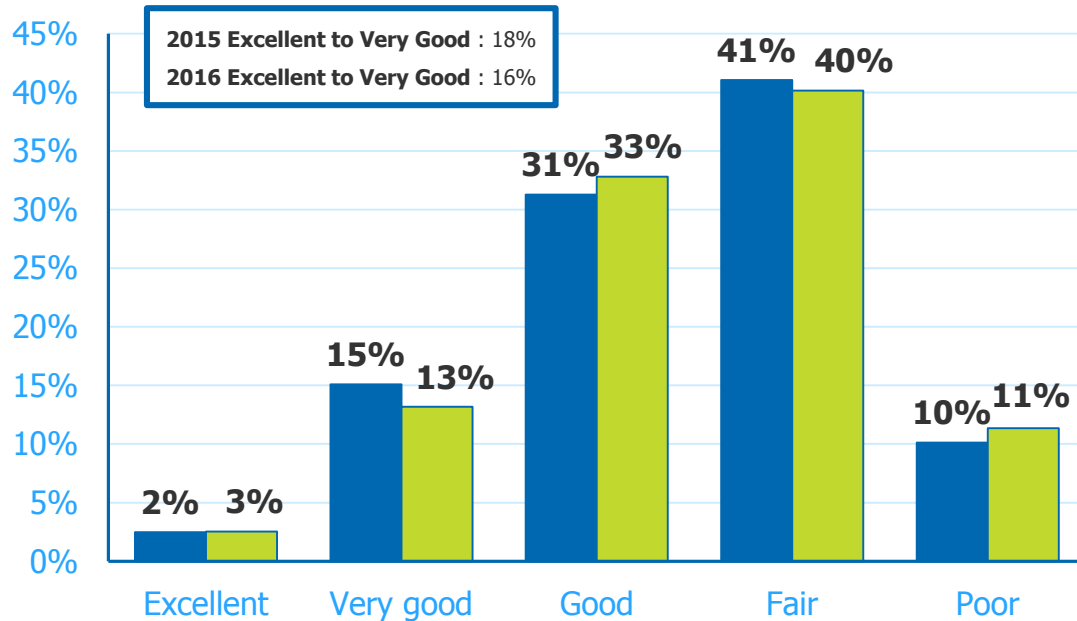


Physical Health

Adults with PI

■ 2015
N=1167

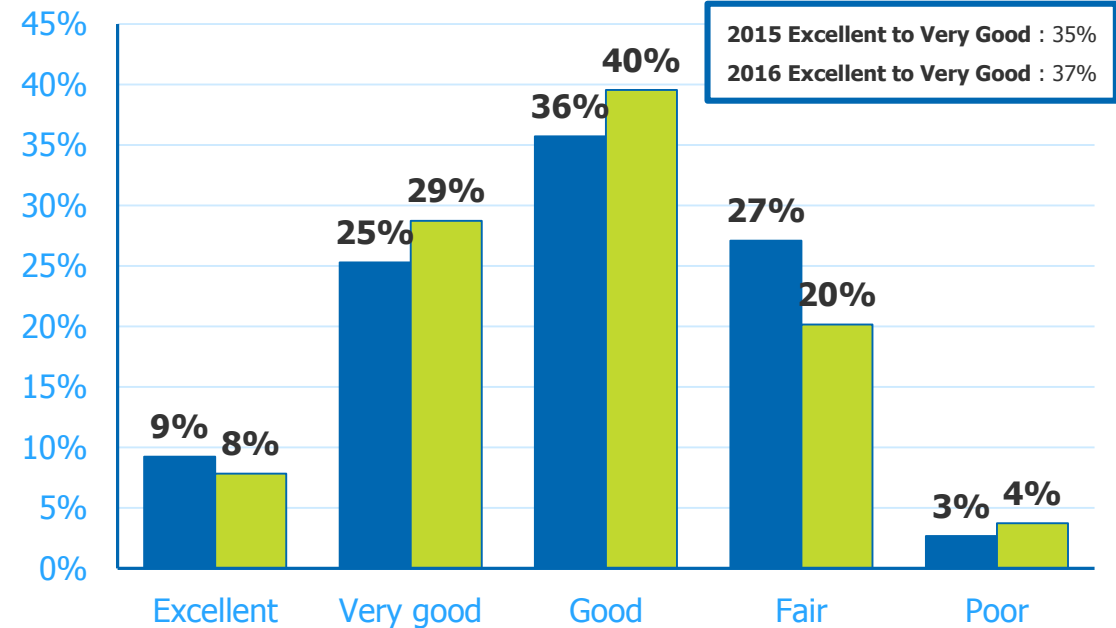
■ 2016
N=1146



Children with PI

■ 2015
N=336

■ 2016
N=268



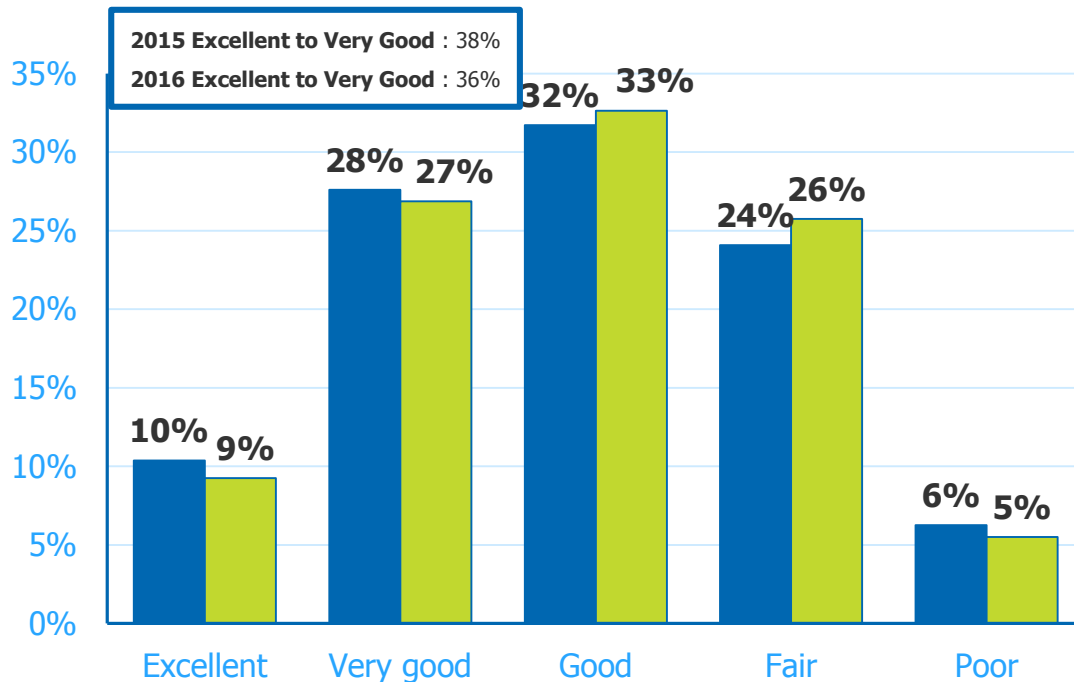
Q1c_pt. In general, how would you rate your physical health?
Q1c_chld. In general, how would you rate their physical health?
Base: All Respondents



Mental and Emotional Well-being

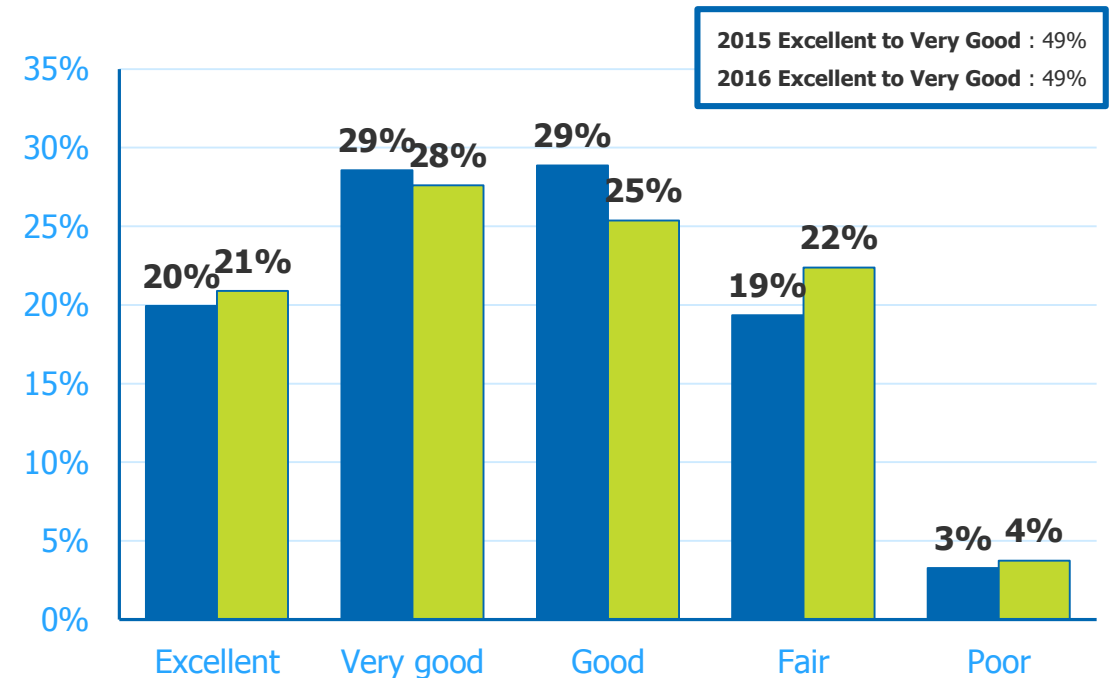
Adults with PI

■ 2015
N=1167 ■ 2016
N=1146



Children with PI

■ 2015
N=336 ■ 2016
N=268



Q1d_pt. In general, how would you rate your mental health, including your mood, and your ability to think?
Q1d_chld. In general, how would you rate their mental health, including their mood, and their ability to think?
Base: All Respondents



Demographics

Demographics: Age and Gender

	2014	2015	2016
Age	N=1394	N=1486	N=1396
0 to 14	11%	10%	8%
15 to 24	12%	11%	9%
25 to 34	9%	10%	9%
35 to 44	12%	11%	10%
45 to 54	19%	19%	20%
55 to 64	22%	24%	27%
65+	14%	16%	18%
Gender	N=1417	N=1504	N=
Male	31%	28%	27%
Female	68%	71%	73%
Other	0.1%	0.3%	0.1%
Refused	1%	0.4%	0.1%



Demographics: Race/Ethnicity and Location

	2014	2015	2016
Race or Ethnicity	N=1406	N=1488	N=1395
American Indian/Alaskan Native	1%	1%	0.4%
Asian/Pacific Islander	0.4%	0.4%	1%
Black/African-American	1%	1%	1%
Hispanic or Latino	2%	3%	3%
White, non-Hispanic	92%	92%	91%
Two or more races	3%	3%	3%
Other	1%	1%	1%
Location	N=1416	N=1504	N=1414
Northeast	17%	18%	16%
Midwest	24%	24%	26%
South	36%	37%	37%
West	22%	21%	22%



Demographics: Employment

	2014	2015	2016
Employment	N=1390	N=1478	N=1382
Employed full time	46%	43%	42%
Employed part time	9%	9%	9%
Unemployed, looking for work	3%	3%	2%
Student	5%	4%	4%
Homemaker	3%	4%	3%
Disabled/too ill to work	19%	20%	22%
Retired	13%	15%	17%
Other	4%	3%	2%



Demographics: PI Diagnosis

	2014	2015	2016
Diagnosis	N=1417	N=1504	N=1414
Agammaglobulinemia	5%	5%	4%
Ataxia Telangiectasia	0%	0%	0.1%
Chronic Granulomatous Disease	1%	1%	1%
Common Variable Immunodeficiency	61%	63%	62%
Combined Immunodeficiency	1%	1%	1%
Complement Deficiency	0.4%	1%	0.4%
DiGeorge Anomaly	0.1%	0.1%	0%
Hereditary Angioedema	0.1%	0.1%	0%
Hyper IgE Syndrome	1%	1%	1%
Hyper IgM Syndrome	0.4%	0.3%	0.3%
Hypogammaglobulinemia	11%	10%	11%
IgG Subclass Deficiency	7%	5%	6%
Selective IgA Deficiency	3%	3%	3%
Severe Combined Immunodeficiency	2%	2%	1%
Severe Congenital Neutropenia	0%	0.1%	0.1%
Specific Antibody Deficiency	3%	3%	3%
Wiskott-Aldrich Syndrome	0.4%	0.3%	0.1%
Other	3%	4%	5%
Not Sure/ Do Not Know	2%	2%	1%

Source: IDF 2014, 2015 and 2016 Health Insurance Survey



Conclusions

Take Away

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



Thank You!

