



# INSIGHTS

from

## Engaged Patients

**An analysis of the inaugural Inspire Survey**



[www.inspire.com](http://www.inspire.com)

September 2015

# Insights from Engaged Patients



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# Introduction

Brian Loew, CEO, Inspire

At Inspire, we believe deeply in patient centricity and the idea that everyone involved in healthcare needs to think about patients first and foremost.

We also believe that patients' knowledge and perspectives can meaningfully contribute to medical progress. The good news is that patients are ready and willing to share what they know: this report distills the participation of 13,633 Inspire members from 100 countries and six continents.

This inaugural report is the first edition of what we hope will become a resource for all the participants in our healthcare system. As we will do our part to keep the information flowing, we hope you will share your perspectives as well, and let us know what more you'd like to learn.

Together we're better,

A handwritten signature in black ink, appearing to read 'Brian Loew'.



# Executive Summary: Insights from Engaged Patients

By Dave Taylor, Director of Research, Inspire

“Collaboration,” says one Inspire member, “is a good thing.” Findings from the 2014 Inspire Annual Survey demonstrate that patients increasingly want to engage more in their care, but that there are barriers which must first be overcome to achieve true shared decision making.

In this survey of our members, over half of the 13,633 respondents reported proactively initiating the discussion around new treatment options with their physician. In fact, almost 90% of all Inspire members who took the survey indicated that they ask their doctor about other potential treatment options at least once a year. When it comes to actually making treatment decisions, nearly 70% said they make treatment decisions in collaboration with their doctor. The combination of these elements provide a strong foundation for a patient-centric healthcare model as so many of these patients embodied the sentiment shared by one of our respondents, “you have to **ADVOCATE** for yourself!”

While the survey provides great promise for the future of healthcare, it also highlights several limitations that will impede the much-needed progress.

As we are moving towards a strong electronic/mobile-based world in healthcare, many patients don’t have the necessary platforms to connect to these resources. Almost three-fourths of patients claimed they have never used a smartphone app to assist with their healthcare needs. Of these respondents, less than half felt that apps would be a helpful tool for them. As one member articulated, “It assumes one has smartphones and apps

at one's fingertips. Some do. Some don't. Elders may be less likely to." While the older patient population is far less receptive to mobile apps for healthcare, privacy concerns are also a limiting factor for widespread adoption.

In addition to the ground that has yet to be covered regarding technology in healthcare, financial difficulties remain a common problem and have seemingly intensified during 2014 in the U.S. 50% of patients taking the survey cited having trouble with the cost/affordability of treatment at some point in time. Paying for the treatments themselves as well as supportive (OTC) medications were the two areas patients struggled with the most.

As one survey respondent noted, "The more I inform myself with accurate information on the medications taken, or the medications available, the more I am able to have meaningful conversations with the doctors concerning treatment."

**"Fifty percent of patients taking the survey cited having trouble with the cost/affordability of treatment at some time."**

Further adding to the financial difficulties that so many patients have faced, 2014 was an evolutionary year for healthcare in the U.S. as the Affordable Care Act went into place. As a result of

this legislation, 60% of U.S.-based respondents say their insurance premiums increased last year, another 48% saw their in-office copays increase, and 64% reported having at least one of their medications switched to a generic equivalent by their insurance company.

In this inaugural run of the Inspire Member Survey, many elements of the current healthcare landscape, both good and bad, were brought to light. While this data can help to support or offer course-correction guidance on many actions the industry is currently undertaking, the true power of this data will be monitored over time as the pharmaceutical industry, patients, and all other key players continue to evolve.

# About this analysis

Throughout this report, the main data points shown represent the aggregated results of all 13,633 survey respondents.

In addition to an overall readout of the survey findings, the Inspire team also analyzed various subgroups of respondents (detailed below) in an effort to deliver a comprehensive readout of this enormous dataset.

**Gender Splits:** Comparing Male and Female respondents

**Age Groups:** Assessment of respondent differences as they 'age' (< 30 years old, 31-40 y/o, 41-50 y/o, 51-64 y/o, 65+)

**Health Condition Groups:** Using the ICD-9/10 coding guidelines in conjunction with key areas of interest among the health community, Inspire coded each response based on the health conditions that affect that individual respondent.

The five largest health condition groups represented in this survey were Oncology (i.e. all types of cancer and cancer-related issues), Autoimmune (Rheumatoid Arthritis, Psoriasis, etc.), Metabolic (Type II Diabetes, High Cholesterol, etc.), Neurologic (Multiple Sclerosis, Parkinson's Disease, etc.) and Respiratory (Pulmonary Fibrosis, COPD, etc.)

Where notable differences were discovered among the subgroups or against the overall findings, these insights have been called out throughout the report.

# Patients are well prepared for doctor visits

# 55%

**Of patients go to doctor appointments with someone else on a regular basis**



## Inspire Insight

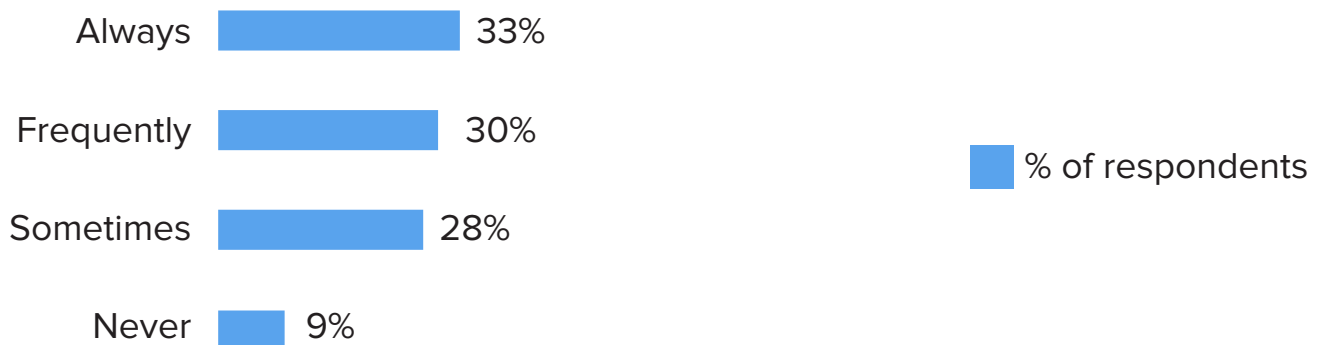
Respiratory and Metabolic patients most frequently go to doctors appointments with someone else

Women are slightly more likely to go with someone else than men

While the frequency of using 'the buddy system' increases among older patients, it is not an overwhelming swing as one might expect

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## Frequency of going to doctor appointments prepared with notes and/or questions

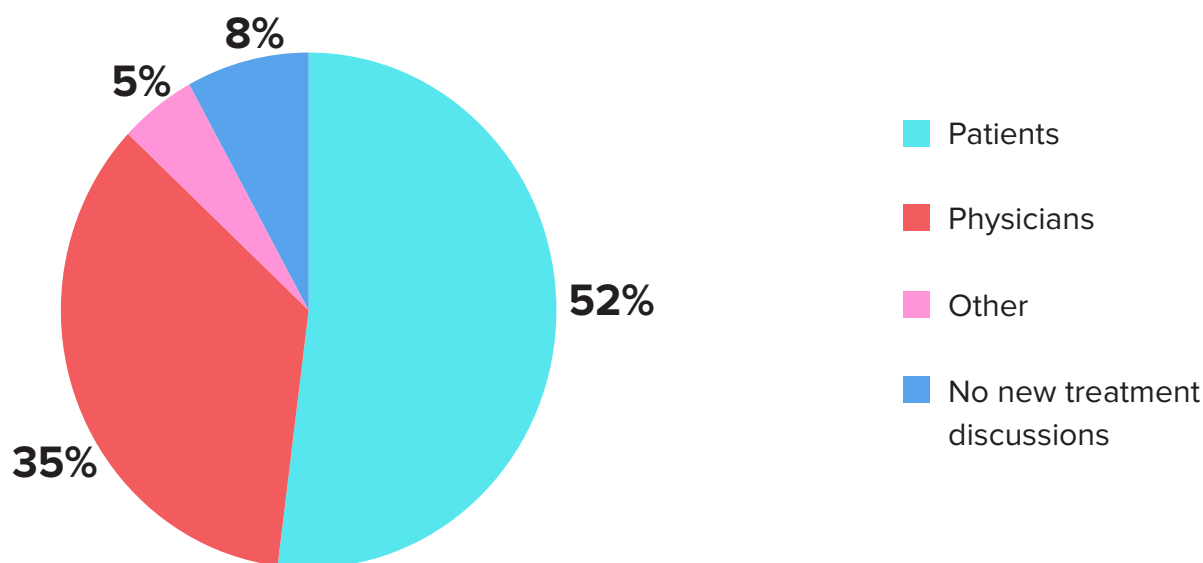


## Inspire Insight

Patients in the Oncology, Neurology and Respiratory categories go to doctor appointments prepared with notes more frequently than those with chronic conditions (Autoimmune, Metabolic)

# Patients are highly involved in their treatment decisions

As shown below, patients are largely responsible (52% of the time) for initiating new treatment discussions



## Inspire Insight

Women are more likely to start the conversation around new treatment options than men (54% vs. 47%)

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# 45%

Of patients ask about other treatment options at least once every other visit

# 89%

Of patients ask about other treatment options at least once a year



## Inspire Insight

Younger patients more frequently ask about new treatment options than older patients



# When it comes to *making* the treatment decision...



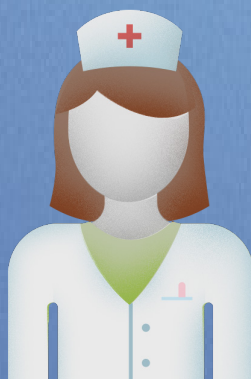
69%

of patients said it was a collaborative effort with their physicians



20%

of patients said the decision is made either “mostly” or “entirely” by themselves



11%

of patients said the decision is made either “mostly” or “entirely” by their physicians



## Inspire Insight

Younger patients claim they play more of a role in driving treatment decisions; however, as the population ages, there is more of a focus on collaborative decision making

# Patients receive condition and treatment education from numerous sources

Patients most often received “**Condition-specific information**” followed by “**Drug-specific information**” from both their doctors’ offices and their insurance companies

45%

Of patient received educational materials from their physicians’ offices

14%

Of patients received educational materials from their insurance companies



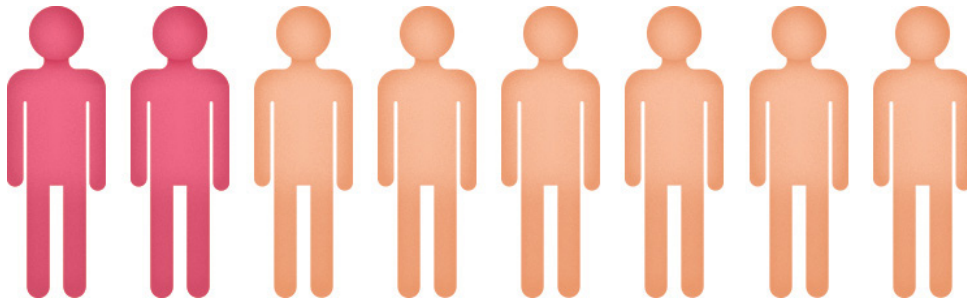
## Inspire Insight

Oncology and Metabolic as well as older patients were more likely to get information at their doctors’ offices



## Inspire Insight

Metabolic patients were most likely to receive educational materials from their insurance companies



## 25% of patients received educational information from their pharmacies

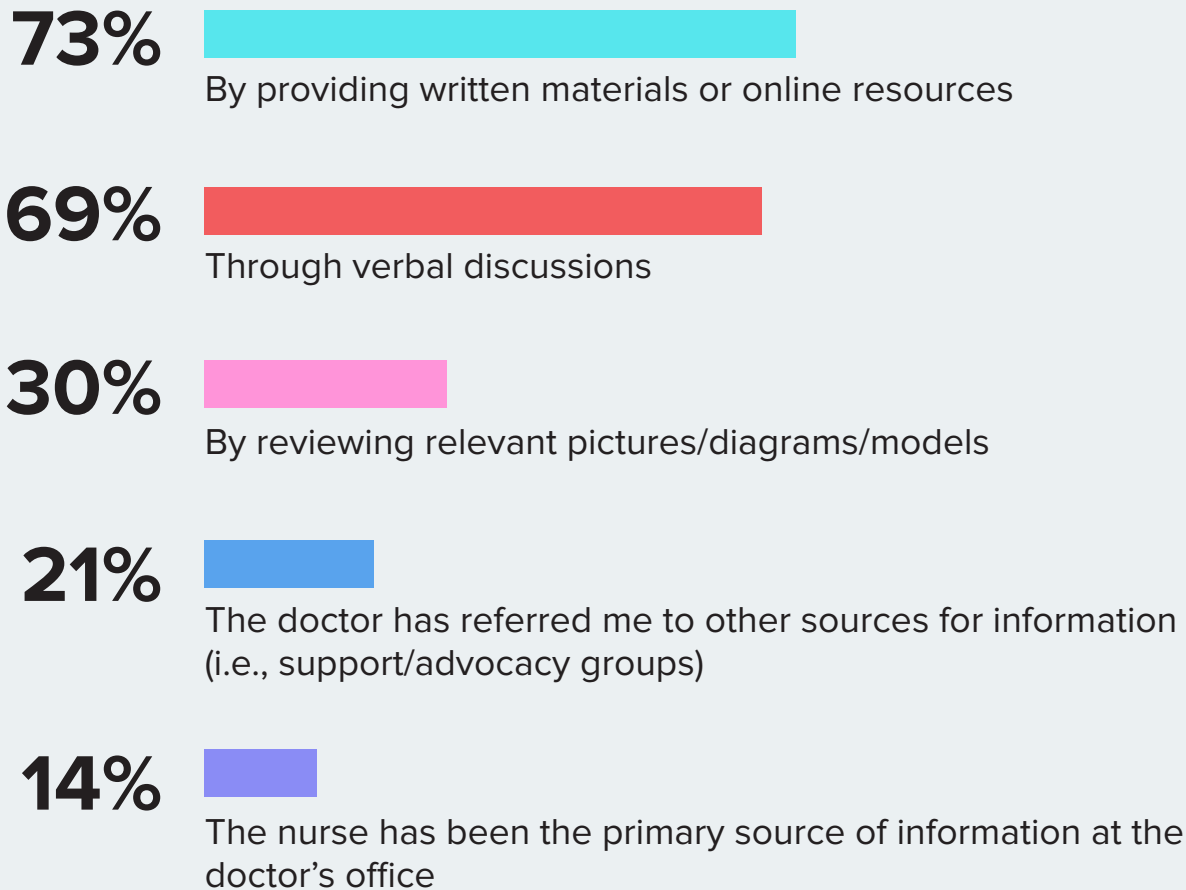
These patients primarily received materials related to medications with only a small amount of “Condition-specific information”



## Inspire Insight

Metabolic and Autoimmune patients were most likely to receive materials at the pharmacy; the distribution of materials increased across older patient age groups

# How physicians provide information to patients



## Inspire Insight

Oncology patients were **least likely** to get written materials from their physicians

Oncology patients were however **most likely** to review pictures/diagrams/models and to get nurse support

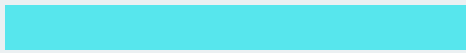
Women were more likely than men to get educational support from their physicians across all mediums except receiving referrals to external sources

While verbal education increases as patients age, all other forms of education decrease

# Patients reported that a number of various tools/materials would be helpful for them to use with their physicians

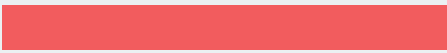
Recommended tools to help patients during doctor's visits

**59%**



Electronic, Detailed Symptom Tracker (What symptoms? When? How severe?)

**57%**



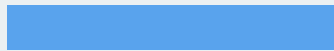
Access to online webinars or in-person conferences/speaker sessions to learn more about your condition

**47%**



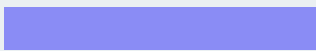
Support materials for friends/family members detailing your condition and its symptoms

**42%**



Printed, Detailed Symptom Tracker (What symptoms? When? How severe?)

**40%**



Tips/tactics around better ways to communicate with your physician(s)



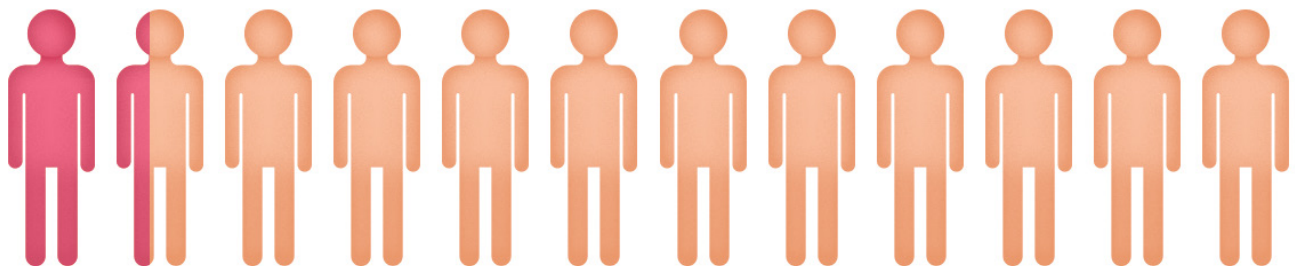
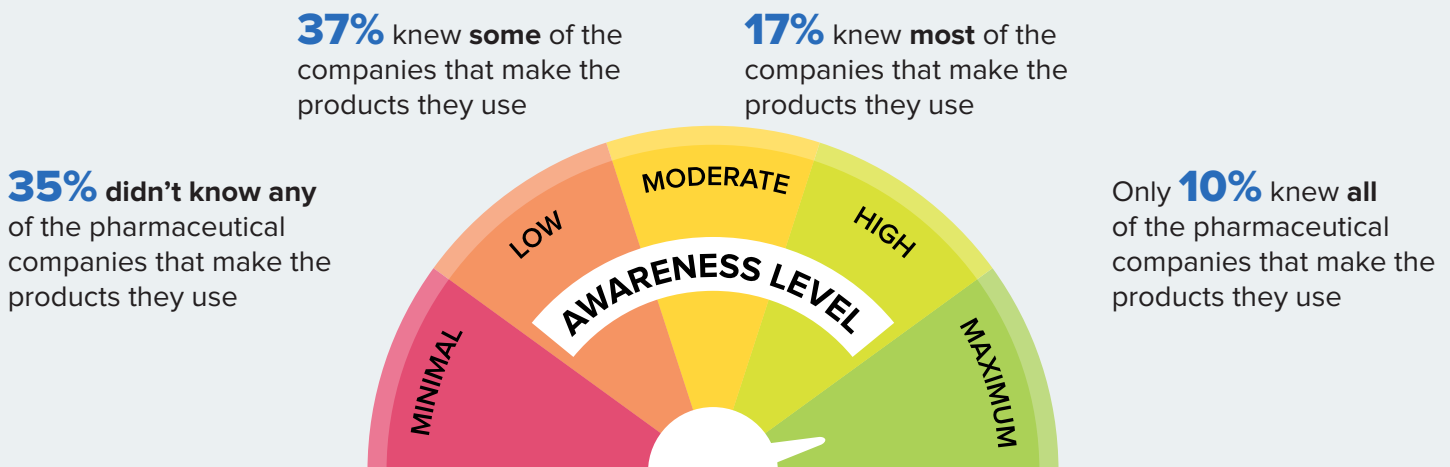
**Inspire Insight**

As patients age, there is less insistence on an electronic symptom tracker; however, all other solutions remain viable options

# Relationships between patients and pharmaceutical companies are limited

The majority of patients had limited, if any, knowledge of the pharmaceutical companies that produce their medications

There were better awareness levels among those with chronic conditions (Respiratory and Autoimmune)



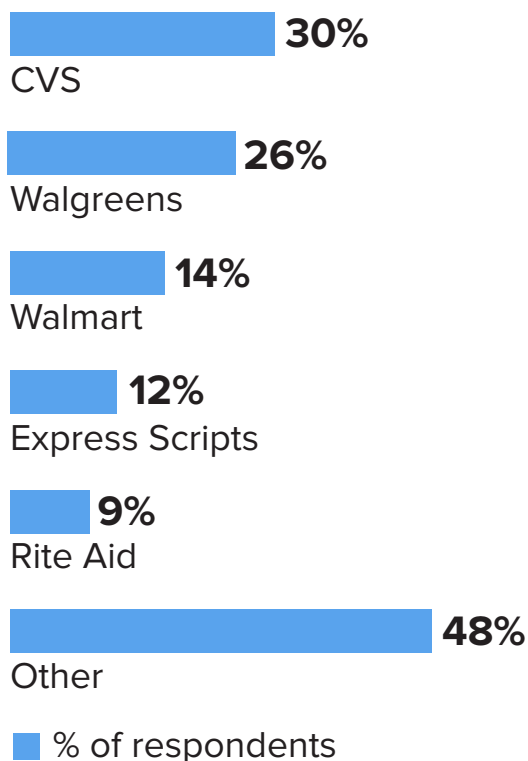
Only 12% of patient felt that they had a 'relationship' with the companies that made their medications - slightly more prevalent among Autoimmune patients

At best, patients consider these relationships to be 'limited'

'Relationship quality' increases with age – likely due to increased utilization of patient assistance programs

# Many patients know and trust their pharmacists

## Pharmacies used in 2014

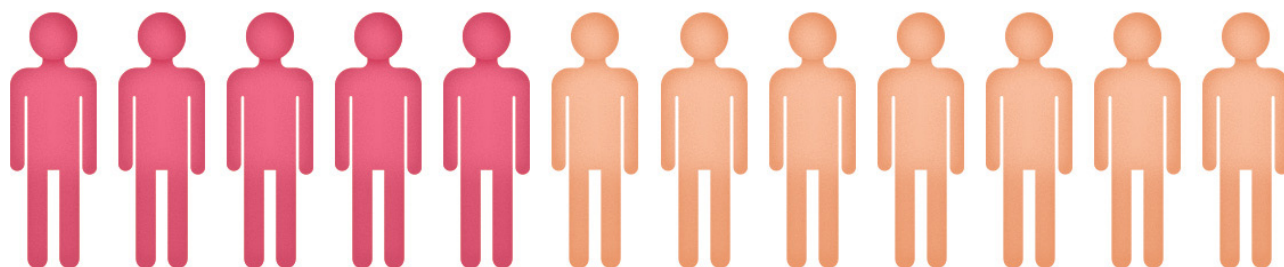


## Patients used a variety of outlets to fill their prescriptions

“Other” represents dozens of pharmacy providers, both U.S.-based and international – none of which comprises more than 2% of the market on their own

Among the “Other” retailers noted, Costco was the most prevalent

A compilation of grocery store chains (Publix, Albertson’s, Harris Teeter, etc.) collectively made up a large part of the “Other” pharmacies used



Unlike with pharmaceutical companies, 41% of patients reported having a ‘relationship’ with their pharmacist, even more so among Respiratory patients

The vast majority of patients felt their ‘relationship’ with their pharmacist was ‘good.’

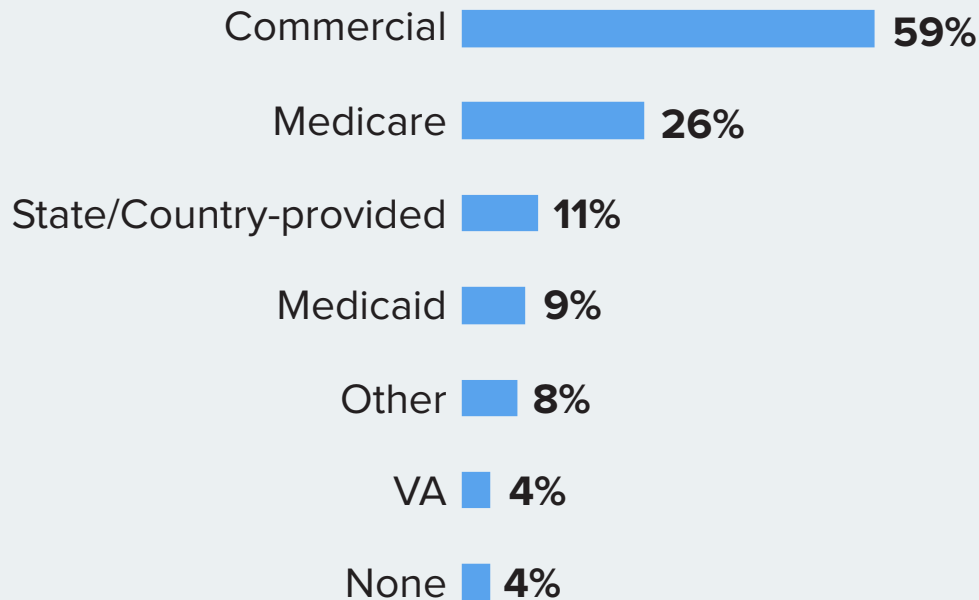


## Inspire Insight

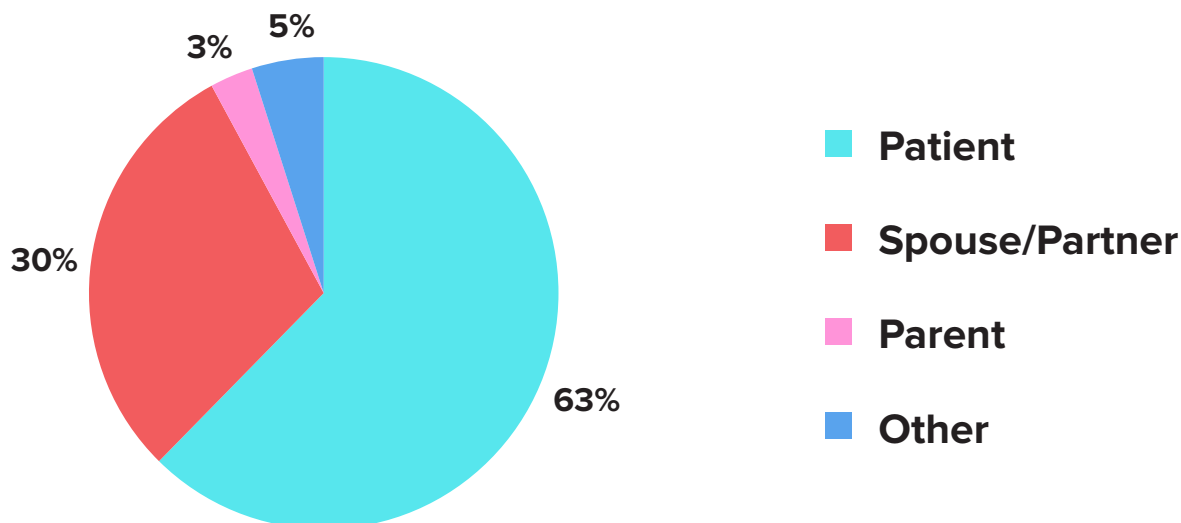
The amount of patients who reported having a ‘relationship’ with their pharmacist increases with age, likely due to the increased frequency of visits and medication regimens

# Cost and insurance is taking a toll on patients in their disease management

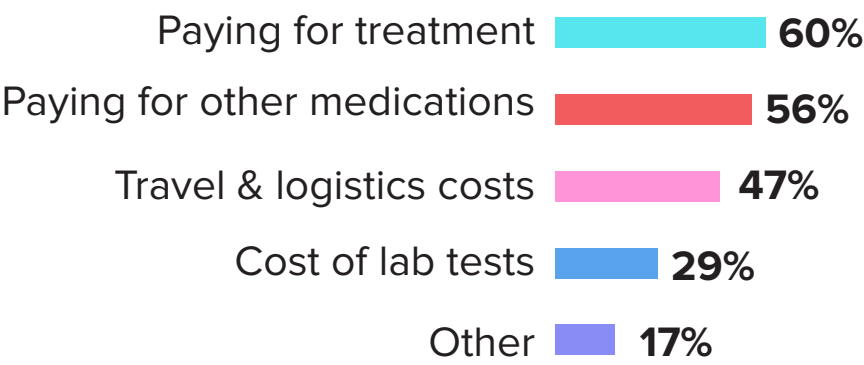
## Patient Insurance Status - 2014



There was roughly a 2/3 – 1/3 split among patients and their spouses/partners as the primary insurance holder



# Financial difficulties experienced by patients



50%

Of patients have ever experienced difficulties with the affordability/ cost of their medications



## Inspire Insight

Oncology patients were **least likely** to have difficulty

Neurology patients were **most likely** to have difficulty

Women were more likely than men to report having difficulty

Those who reported having financial difficulties decreases with age

Slightly more than half of all patients have gone without a prescribed medication for one reason or another





# Patients widely observed increases in the costs associated with their healthcare

The impact on patients' insurance premiums, office copays, ancillary treatment costs and prescription medications was greater within the U.S. than among international respondents

## 55%

**Of patients experienced an increase in their insurance premiums**

"My insurance premiums increased by 13% each of the past two years and I had to move to a lesser insurance coverage plan because I can't afford to keep the better coverage I used to have."

## 44%

**Of patients saw their doctor's office copays increase**

"Copay for my Drs (all considered Specialists by my insurance) has gone from \$40 to \$80 per visit in one year!"

## 37%

**Of patients reported increases in ancillary treatment costs**

"Also, when I go to a lab I now have to pay up front hundreds of dollars until insurance funds because I don't have an HMO."

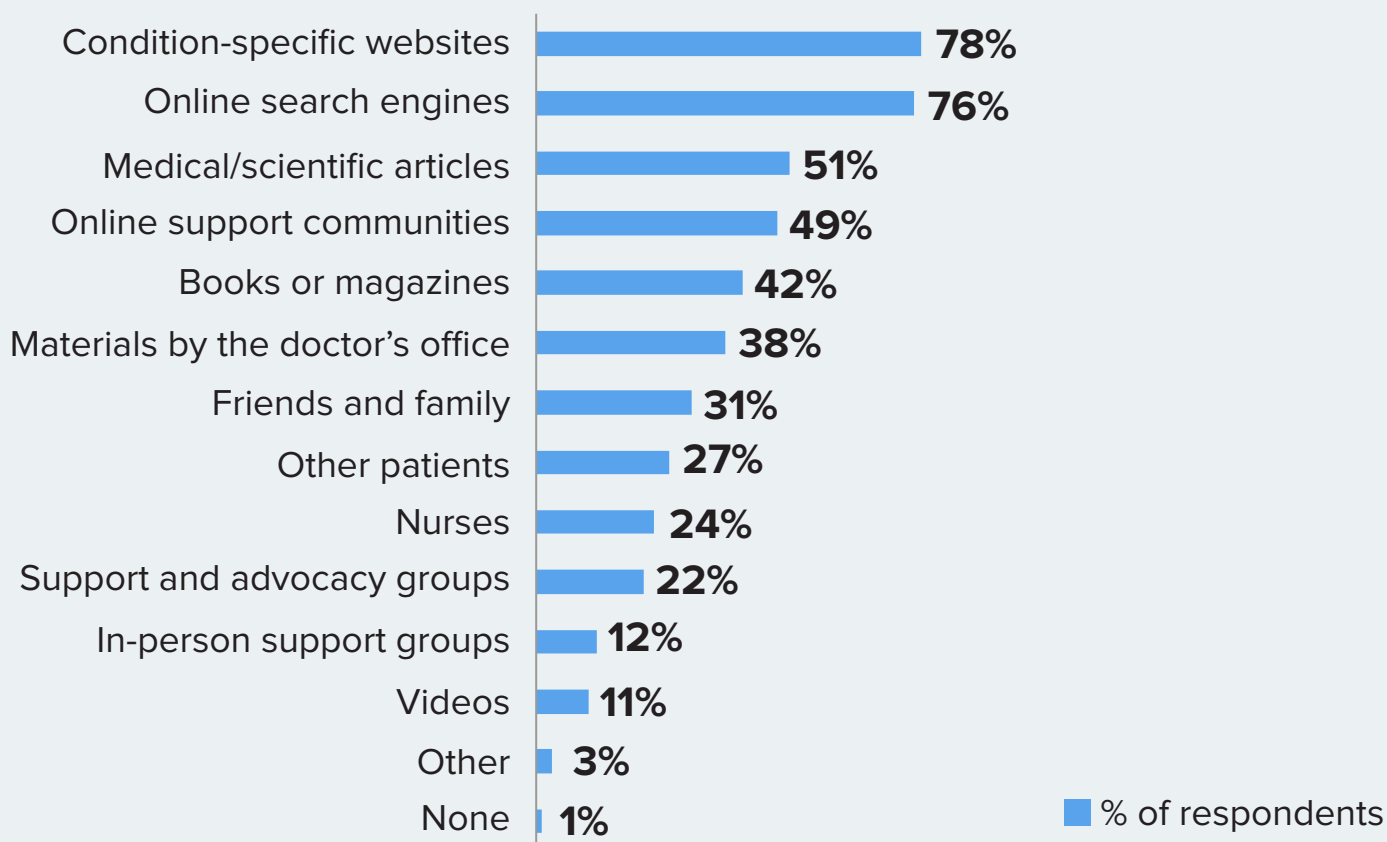
## 60%

**Saw at least one of their medications switched to a generic equivalent by their insurance company**

"Insurance company switched my long-term mail-order prescription to a generic without notifying me first."

# Usage of eHealth resources is expanding, but with room to grow

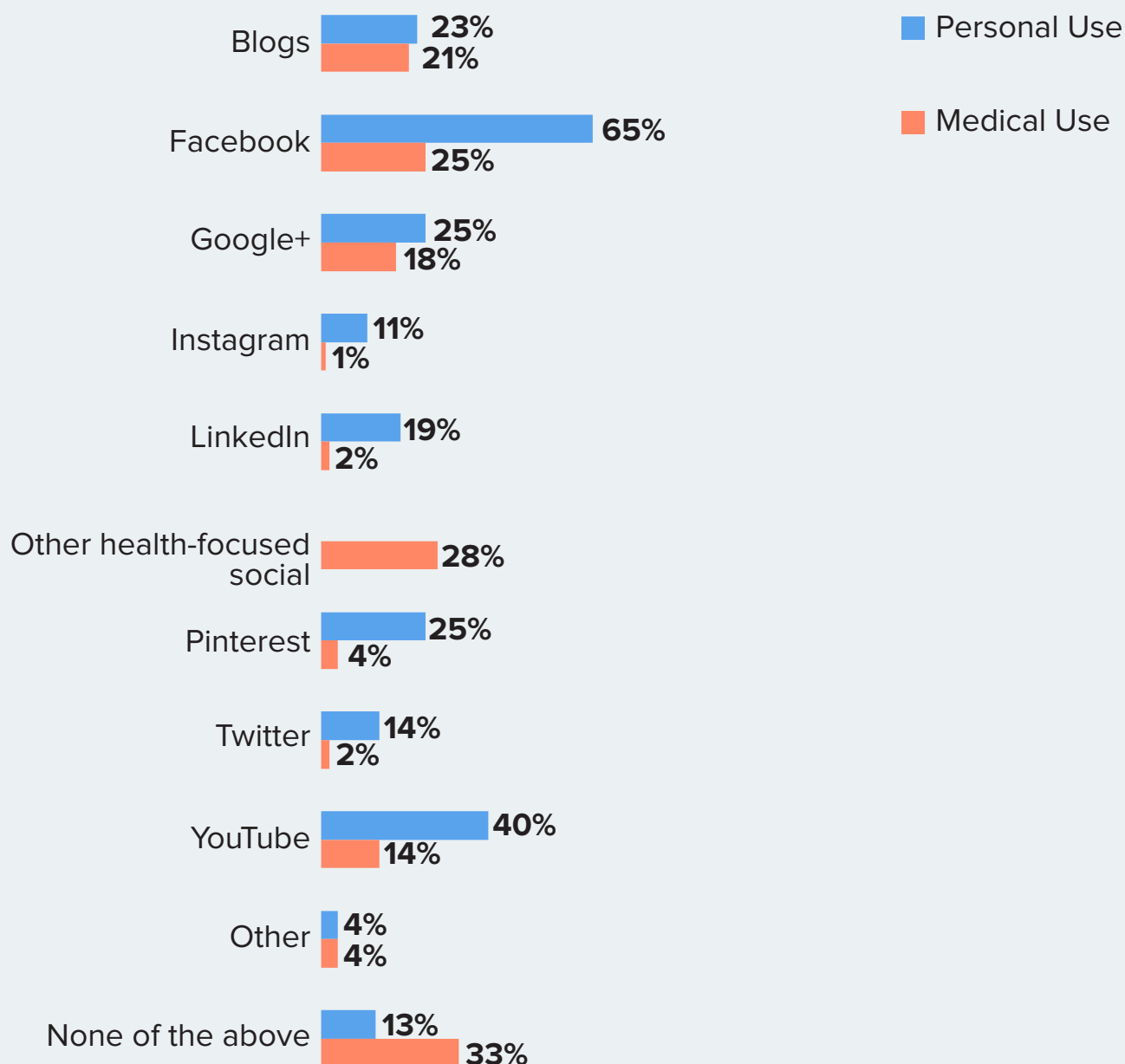
In addition to Inspire, patients use a number of sources for information



## Inspire Insight

Not only are they among the most frequently used sources for information, patients also found online sources to be most helpful

# Usage of social media



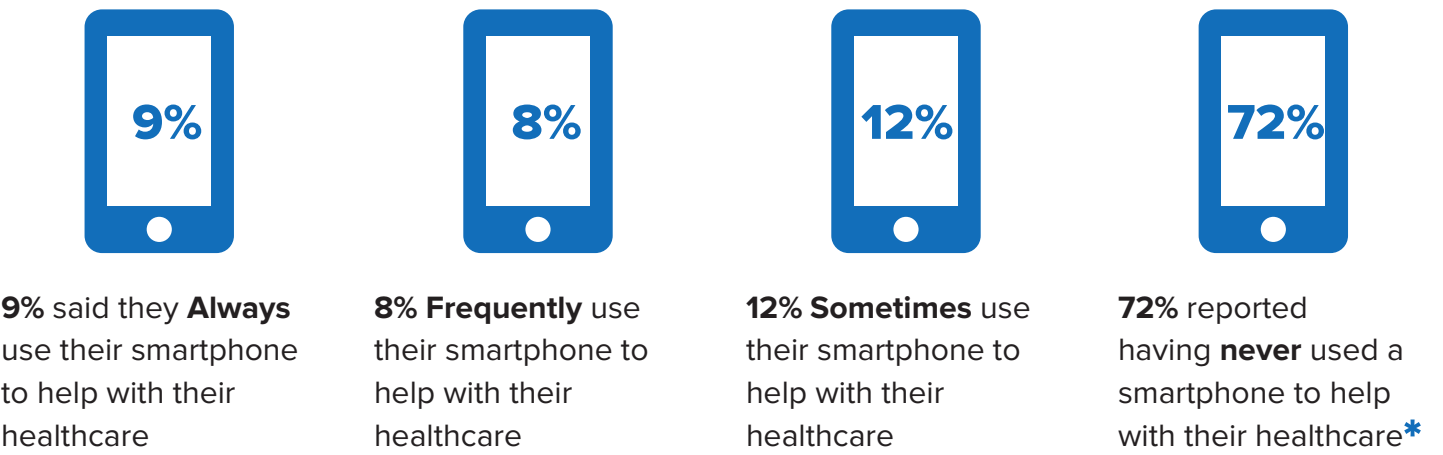
## Inspire Insight

Use of social media is much greater among women than men, both personally and for health purposes

Personal social media usage is also strongest among younger patients with steep drop-offs occurring with older age groups starting at 41+

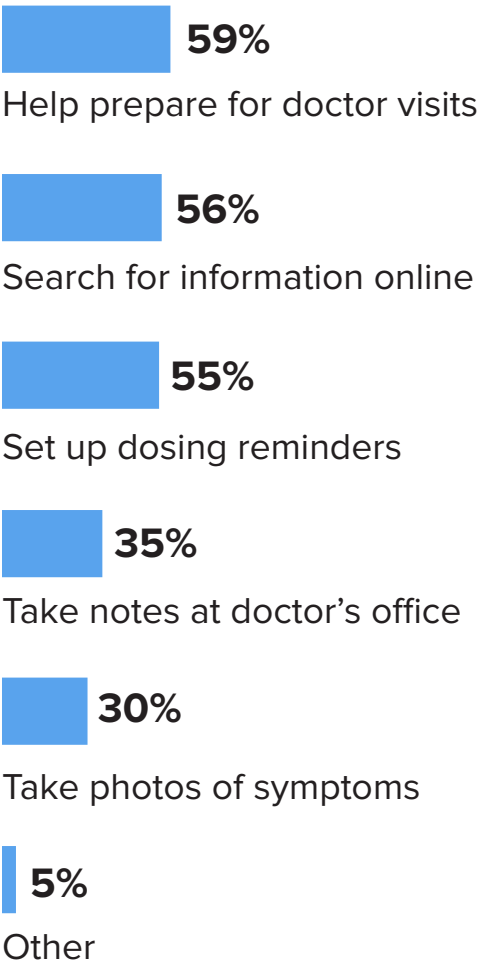
Social media usage for health purposes, stays relatively consistent as patients age, decreasing only among the 65+ age group.

# Mobile app usage for healthcare is still relatively uncommon



\* Less than half of these patients felt that conceptually, a smartphone app would be a helpful tool for them

## How mobile apps are used:



## Inspire Insight

Mobile app usage is more common among younger patients

Limiting factors from mobile app usage are primarily linked to lack of smartphone ownership and varying privacy concerns

Respiratory patients are most likely to use a smartphone to “Prep for MD appointments”, “Search for information online” and “Take notes at physician’s office”

Autoimmune patients are most likely to “Take photos of symptoms”

Autoimmune and Neurological patients along with women are most receptive to using smartphone apps

# About Inspire

Inspire ([www.inspire.com](http://www.inspire.com)) is the patient engagement company. Partnering with such organizations as American Lung Association, National Psoriasis Foundation, Genetic Alliance, Ovarian Cancer National Alliance, the Arthritis Foundation, and the Alzheimer's Foundation of America, Inspire creates and manages health support communities for nearly 700,000 patients and caregivers.

We work with our pharmaceutical clients to help them interact with these highly engaged populations, from clinical trial promotion, to patient and caregiver insights, to unbranded/branded promotional activities.

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