

Perspectives and Recommendations on Gout Prevention, Care and Existing Disparities Utilizing Medicare Data

*The National Minority Quality Forum (NMQF)
The Alliance for Gout Awareness (AGA)*

Background

Gout is a chronic disease that affects more than nine million people in the United States and afflicts patients with intense, painful symptoms. It is a misunderstood disease, frequently undiagnosed or misdiagnosed. The social stigma regarding gout can also lead to patients' reluctance to report the condition and seek treatment.

Gout is caused by increased levels of uric acid, a naturally occurring waste product, in the body. It is a form of arthritis that can result in sudden, intense pain and swollen joints. Hereditary factors may lead to incidences of gout, although certain foods and medications can also trigger episodes. Patients with gout are at heightened risk for several chronic conditions, while some chronic conditions like kidney disease can increase risk of gout. Left untreated, gout attacks can become more frequent, prolonged and debilitating.

A lack of education about the disease, even among health care providers, has allowed social stigmas to persist and has prevented open discussion about gout, its related genetic factors and disparities in diagnosis and treatment. While effective treatments exist, greater awareness is needed to ensure patients can receive timely treatment. As with other chronic conditions, the severity and consequences of gout are especially troubling in ethnic and racial minority communities, evidenced by tables and index maps included in this paper, based on U.S. Centers for Medicare and Medicaid Services (CMS) claims data. Further study is available through online resources accessible in the NMQF "Chronic Gout" index at www.mypalc.org which is described below.

Gout Index: The Data

The multitude of patients with gout, its intense symptoms and the harmful social stigma all contribute to a need for enhanced awareness. This need prompted the National Minority Quality Forum to launch a project in 2021 aimed at better understanding gout and its impact on patients, specifically Medicare beneficiaries.

The project began with an analysis of data obtained from the Centers for Medicare and Medicaid Services. It focused on the geographic, socioeconomic, racial and ethnic prevalence of gout cases, as well as health care utilization and cost information.

To generate a foundation of information about gout, NMQF created the Gout Index. The Gout Index is comprised of aggregated chronic gout claims data from the 2016 and 2017 Master Beneficiary Summary Files (including Chronic Condition and Cost and Utilization Segments), Medicare Outpatient, and Carrier Files.

For the purposes of the index, the definition of a chronic gout patient was a patient with two or more claims per year over two or more years. The data was further stratified to differentiate between systemic gout and uncontrolled gout. The main difference is that uncontrolled gout

involves refractory and more complex cases. This data enabled mapping of gout prevalence by zip code, congressional district, state, race and ethnicity. Hospitalization rates according to those criteria, as well as systemic and uncontrolled gout-related costs to the Medicare system, were also charted. For the purposes of this paper 2016 data are used for analysis.

The Gout Index shows, for example, significant regional disparities in systemic gout incidence rates, with states in the southeast (Virginia, North Carolina, South Carolina, Alabama, Mississippi, Louisiana) all registering prevalence rates in a disproportionately high 5.51 to 6.78 percent range compared to rates as low as 1.03 percent elsewhere in the country. And yet, the data also shows that Medicare spending rates on gout acute events has been comparably lower than in other states and regions where there are fewer per-capita reported gout cases. The data also shows differences in hospitalization rates (admissions) compared to emergency room visits in some regions and various population demographics. For the purposes of the index when these two statistics are combined the category is entitled encounter rates. For example, queries of gout in Asian populations shows a difference between the rate of hospitalization and emergency room visits of beneficiaries when looking at data for systemic gout compared to data for uncontrolled gout. A similar observation exists in other populations to varying degrees of difference. An explanation and focus on why these differences exist is not for the purposes of this paper introducing the index. Further study would be a worthy topic in future forums and papers.

Researchers, health educators, advocates and consumers may pursue their own queries about disease demographics, statistics, costs, and geographic distribution by accessing the NMQF Chronic Gout Index at www.mypalc.org. Index features allow unique functionality to view results in many ways including maps, tables, charts, and lists (with ability to sort and filter by rank/order. Views by state, county, MSA, zip code, and congressional and legislative districts are available. The index provides a lens for gaining a new perspective and a better understanding for creating and focusing interventions to improve care where it is needed most.

This Centers for Medicare and Medicaid Services data yielded four key observations:

1. Underserved populations exist in the United States, identifiable by geography, race and age cohorts.
2. Disparities exist for cohorts across prevalence, numbers and resources spent by the Centers for Medicare and Medicaid Services.
3. Gout varies in severity with refractory cases associated with higher morbidity and costs.
4. A range of potential causes, consequences and possible solutions exist.

The data provided greater granularity within these broad observations including, specifically (as detailed in the table below):

- Asian and Black population cohorts experienced a high relative prevalence of gout.
- Black beneficiaries had higher relative hospitalization rates, emergency room visits, encounter rates and costs.
- Hispanic beneficiaries have a relatively lower number and prevalence of systemic and uncontrolled gout than other groups (2.22 prevalence, 20,000 count for systemic gout).

Population	# (000's)	Prevalence % of Medicare for pop listed	Hospitalizat ion Rate (w/o ER)	Hospitalization Encounter Rate (with ER)	Cost per Beneficiary (\$)
Systemic Gout					
All	1,604	4.10	.67	1.42	19,552
Asian	46	5.53	.44	.93	16,842
Black	220	5.72	.83	2.01	24,432
Hispanic	20	2.22	.75	1.74	24,703
Uncontrolled Gout					
All	36	.09	.80	1.64	23,651
Asian	1.0	.12	.62	1.31	22,889
Black	4.2	.11	1.06	2.46	30,630
Hispanic	.4	.05	.82	1.93	25,543

Source: NMQF "Chronic Gout Index." Available at www.mypalc.org. Index includes search and sort functionality by statistics, geographies and demographics with map or table displays.

Advisory Committee Analysis of Gout Index Data

To better understand the real-world aspects of the data and identify its implications, NMQF partnered with the Alliance for Gout Awareness to host an advisory committee of patients and health care providers. Committee members examined the data and determined ideal recommendations to combat gout.

Racial and Geographic Breakdowns

Advisory committee members noted that regions with a high prevalence of gout like the Carolinas showed relatively low cost and hospitalization numbers, while some regions with low prevalence had higher costs and hospitalizations. This may indicate the medical establishments in the former regions have an increased awareness and understanding of gout, leading to improved outcomes.

The data demonstrated a high prevalence of gout in the southeast United States. The committee considered that these states typically lag in public health investment; have a cultural affinity for types of food that can contribute to gout flare ups; and have more limited access to higher priced, less processed food.

"These are populations that have increased risk for cardiometabolic diseases and often don't get the best care," one committee member said. "We know that, in so many of the higher risk communities, the store attached to the gas station is the only place to food shop."

The data also revealed an overlap between obesity prevalence maps and the Gout Index, suggesting that policymakers need to be made aware of this connection.

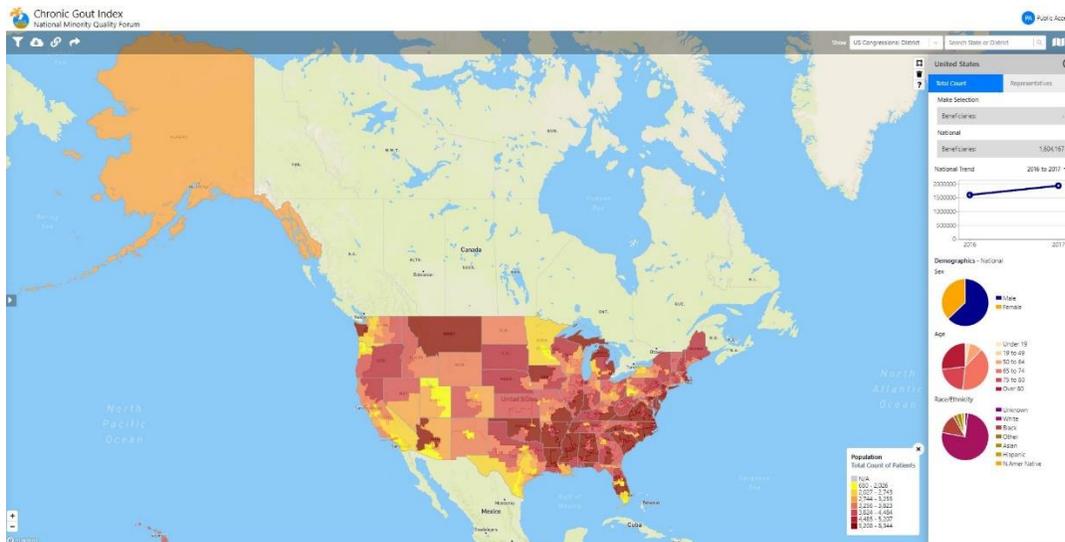
One important topic of discussion was additional information that should be accumulated and disseminated. More data on additional racial and ethnic subgroups, the breakdowns of costs for treatment of uncontrolled gout among Black and Asian populations and a more extensive look at the patient journey would help improve understanding of gout.

“Patients suffering from gout have other complications that can contribute to their cost of care or increased need for services. The data only presents the cost of treating the gout event, but not the cost to treat the other medical conditions that the gout patient may have had at the time.”

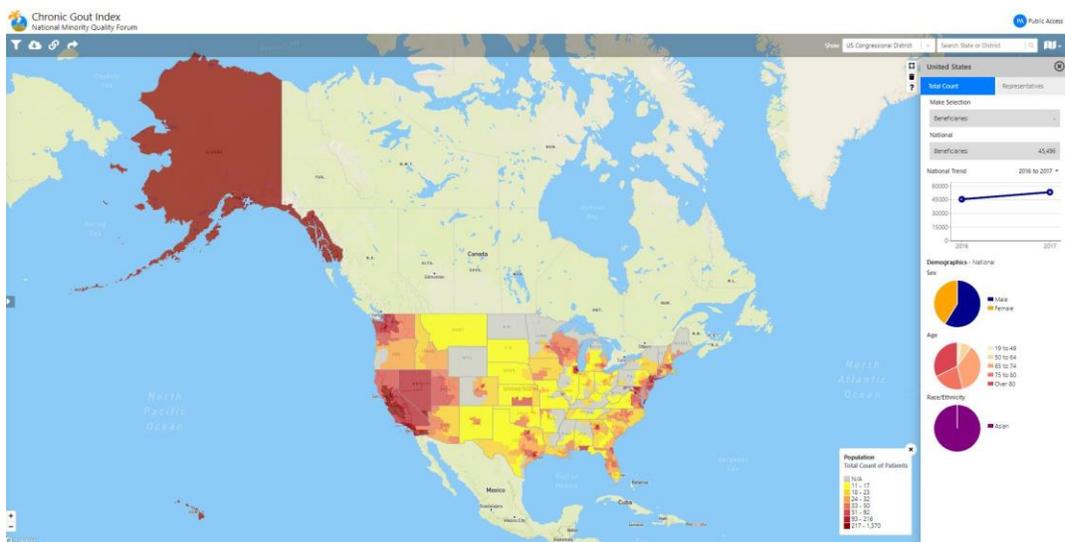
The advisory committee also discussed the need to target interventions along both racial and geographic lines, reaching populations like Asian Americans in Southern California and African-Americans in the southeast United States.

Mapping Systemic Gout by Congressional District and Metropolitan Statistical Area

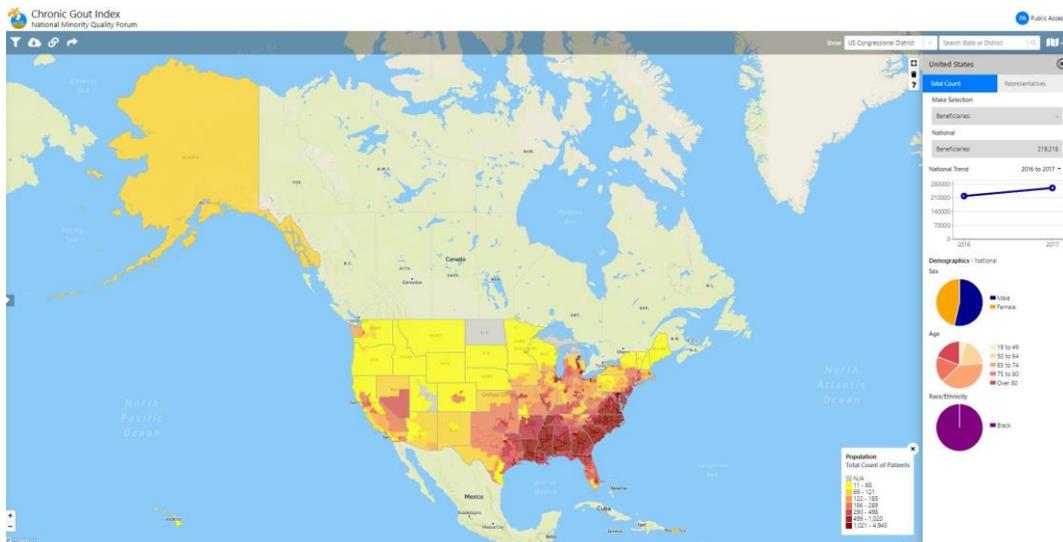
(displayed in standard view, zooming in and out, plus viewing by specific state and district are possible when using the index online at www.mypalc.org)



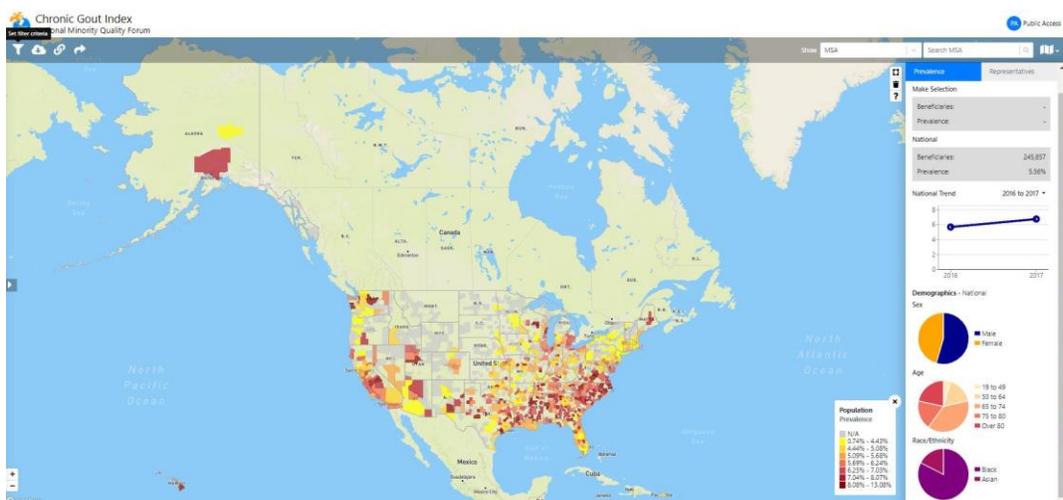
Systemic Gout, All Medicare FFS Beneficiaries Count by Congressional Districts, 2016



Systemic Gout, Asian Medicare FFS Beneficiaries Count by Congressional Districts, 2016



Systemic Gout, Black Medicare FFS Beneficiaries Count by Congressional Districts, 2016



Systemic Gout, Asian AND Black Medicare FFS Beneficiaries Prevalence by Metro Area, 2016

Cost of Care

The Gout Index mapping shows relatively high per-capita costs for gout cases in pockets of the country, particularly sections of the East Coast and the Southeast. The committee saw this as an effect of the broad lack of understanding about the seriousness of gout and of the comorbidities that affect many gout patients.

An advisory committee member said, “Too often, patients are getting treated for severe symptoms in an emergency room setting where costs are higher because they either don’t have access to preventive care or aren’t sufficiently invested in their own care.” (A [study of gout patients](#) in Hawaii found that the mean cost of emergency room visits was 3.4 times the cost of outpatient visits.)

They added, “Policymakers have to understand that gout isn’t a disease where you take some Advil and it gets better. They have to understand the damage it causes both mentally and physically.”

The committee also discuss the need for patient-centered care involving holistic treatments. Many gout patients may suffer from one or more chronic conditions and health care providers need to find treatments to help the whole person, not just one condition at a time.

Without sufficient investment in prevention and education though, gout costs could skyrocket and become devastating for patients.

National Minority Quality Forum: Gout Index Observations, Medicare FFS 2016 by Congressional District

Population	# (000's)	Prevalence % of Medicare for pop listed	Hospitalization Rate (w/o ER)	Hospitalization Encounter Rate (with ER)	Cost per Beneficiary (\$)
Systemic Gout					
All	1,604	4.10	.67	1.42	19,552
Asian	46	5.53	.44	.93	16,842
Black	220	5.72	.83	2.01	24,432
Hispanic	20	2.22	.75	1.74	24,703
Uncontrolled Gout					
All	36	.09	.80	1.64	23,651
Asian	1.0	.12	.62	1.31	22,889
Black	4.2	.11	1.06	2.46	30,630
Hispanic	.4	.05	.82	1.93	25,543

Source: NMQF “Chronic Gout Index.” Available at www.mypalc.org. Index includes search and sort functionality by statistics, geographies and demographics with map or table displays.

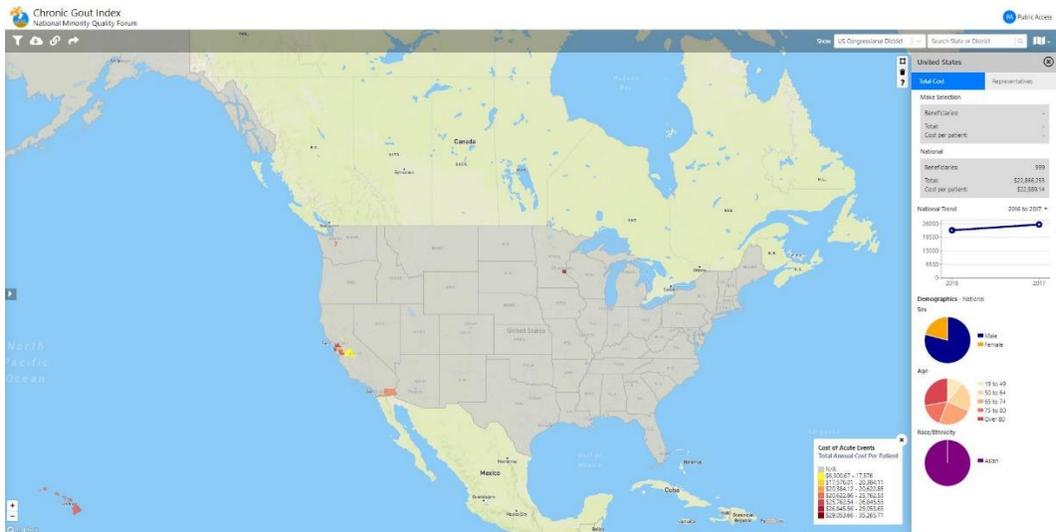
Uncontrolled Gout and Provider Understanding

Data presented on ICD codes (ICD codes are a standardized method to identify diseases and symptoms known as the “International Statistical Classification of Disease and Related Health Problems” and listed by the World Health Organization) that were used to define uncontrolled gout prompted a discussion on the impact of an uncontrolled variation and how to address it. Greater understanding on the part of providers and tools for patients to better report the problem would benefit patients suffering from uncontrolled gout.

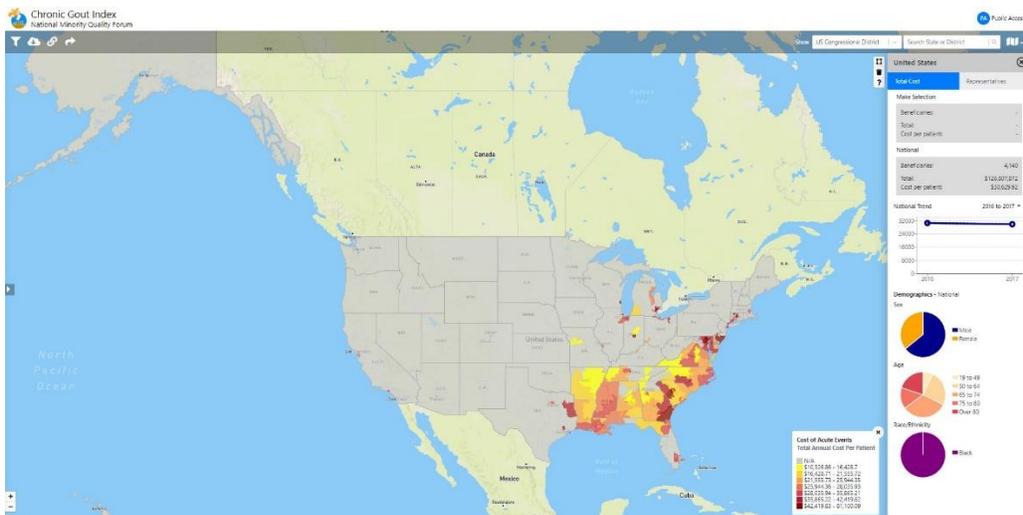
There was considerable concern that clinicians don’t give patients’ quality of life sufficient weight while determining if they have a serious health condition.

“Education on both sides is key,” one committee member stated. “Patients could be helped with tools around talking points and the importance of tracking flares so clinicians can see severity. Clinicians need to truly understand impacts on quality of life, perhaps recorded patient vignettes on things they have to miss out on when they experience flares.”

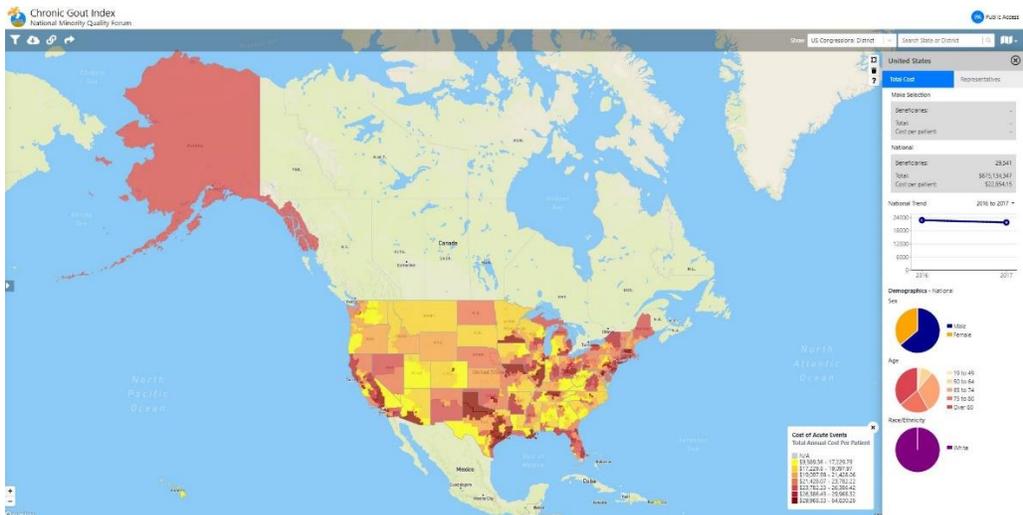
While the number of individuals with uncontrolled gout is less than those with systemic gout, defining it makes it easier to identify heavily impacted communities. The Gout Index maps demonstrate that interventions can be targeted down to the physician and zip code levels. Below are maps of costs for uncontrolled gout by congressional district. The maps vividly demonstrate where uncontrolled gout is most problematic. They are segmented based on Asian, Black, and White populations.



Uncontrolled Gout, Medicare FFS Asian Beneficiaries Total Costs by Congressional Districts, 2016



Uncontrolled Gout, Medicare FFS Black Beneficiaries Total Costs by Congressional Districts, 2016



Uncontrolled Gout, Medicare FFS White Beneficiaries Total Costs by Congressional Districts, 2016

Future Data Collection to Improve Understanding and Combat Disparities

After reviewing the Gout Index data, advisory committee members identified additional data sources that would help policymakers better understand the impact of gout. Members recommended:

- Collecting data on how class, income and language barriers affect hospitalization and cost of care.
- Generating a comparison of gout treatment and outcome statistics between Medicare and private insurers to determine where improvements are needed.
- Creating a side-by-side comparison of the average Medicare patient costs in each state and the cost to treat gout patients with comorbidities, leading to a better understanding of the overall cost impact and the potential savings from successfully addressing it.
- Improving understanding of the gout patient's journey, starting with the first signs of the disease until diagnosis and treatment, to ascertain how quickly patients are seeking treatment after symptoms occur and how much time is involved in diagnosing gout.

Assessing the Disruptive Impact of Comorbidities

Committee members were provided a list of comorbidities often experienced by gout patients and were asked to assess their respective impacts on daily life activities. Those cited most frequently as the most problematic comorbidities were:

- Chronic kidney disease
- Chronic obstructive pulmonary disease
- Heart failure
- Hypertension
- Ischemic heart disease
- Spinal cord injury

Advisory Committee Policy and Community Areas of Focus

The role of the advisory committee was to utilize the collected data, along with their own collective expertise on the subject, and develop consensus perspectives and recommendations on how the U.S. health care system can more effectively address gout as a serious chronic disease.

Importance of Prevention, Early Interventions and Support Systems

Data and discussion revealed a need for strengthening the role of healthcare providers in identifying gout cases, encouraging preventive care, improving medication management and treating comorbidities. It was evident that patient education about gout needs a great systemic approach.

“Providers need to really focus on providing culturally competent care and address the health literacy of both patient and family members,” highlighted one committee member.

“At the same time, other health care providers such as pharmacists need to be leveraged to provide greater ongoing support. Patients that suffer from gout don’t have just one illness to focus on at a time but several comorbidities that can contribute to triggering their gout episodes and impacting their ability to manage the disease. Preventive care is often the last thing on people’s minds when life happens, but it is something that needs to be more of a primary talking point when getting people to focus on overall health and well-being.”

Emergency department physicians who might be the first provider to diagnose someone suffering from gout also need more education. One committee member said, “We need a robust approach for getting in front of these physicians in that setting to identify these symptoms and offer appropriate suggestions.”

Other related recommendations included:

- Involving families in care communications because of the possible genetic component.
- Providing patients with digital tools to log gout flares to assist physicians with medication management and lifestyle modifications.
- Encouraging policymakers to pursue insurance plans with reasonable co-pays to shift costs from expensive emergency room care to primary care.

Addressing the Damage of Disparities

Advisory committee members detailed various types of disparities that gout patients face, from a greater degree of misdiagnoses to a lack of access to resources that can reduce the risk of a flare.

One participant said, “General internist societies create confusion around gout treatment by generating incorrect recommendations, trying to undo the mistakes they made in diabetes treatment.”

Some providers are mismanaging medication for gout patients, making it difficult for patients to control the disease. An expert in health education noted that the Gout Index showed that areas of lower gout prevalence typically have worse patient outcomes, indicating that there were information voids in these predominantly rural and underprivileged areas.

There was considerable focus on the need to address broader health inequities in our society that have a severe effect on gout patients.

“If you don’t have access to health care, if you live in a food desert, if you have a low level of health literacy, you are often left dealing with poorer health outcomes,” one committee member explained.

Poor financial circumstances can impair a patient’s ability to control their gout. They might not have the money or accessible transportation to travel to get groceries, let alone go to a rheumatology appointment.

Committee members reacted positively when presented with policies to address disparities in care. Policies that received praise emphasized focusing education on specific populations and communities about gout symptoms and seeking care; focusing on physician education to recognize gout and specific uncontrolled gout; developing programs to reduce high costs and utilization associated with uncontrolled gout; improving patient access to gout experts and

treatments; and developing programs to support families and patients experiencing poor quality of life from hardships of living with gout.

The Importance of Early Diagnosis and Treatment

Committee members strongly emphasized the importance of early diagnosis to avoid permanent joint damage and chronic pain and to slow the progression of the disease. A lack of understanding about gout among both patients and clinicians often serves as a barrier to identifying the disease early.

Many patients may not realize the pain they're experiencing is something beyond an accidental bump. They may not realize something is wrong until they've experienced symptoms repeatedly.

One committee member added, "On the clinician side, they need to really look at the patient noting where the pain is, what it looks like, and thinking about why this might be without dismissing them and telling them to take some pain meds and see if it gets better in a few days."

The committee said that medicines provide an opportunity to manage symptoms and maintain a normal, productive health status, but there is a danger that patients see these treatments as quick cures without understanding the lifestyle changes that must also occur to prevent gout flares.

Conclusion & Recommendations

Having reviewed the Centers for Medicare and Medicaid Services' claims data on gout prevalence, cost and hospitalizations, the advisory committee agreed upon the necessity of a multi-faceted approach to improve health and quality of life for Americans afflicted with gout. Their recommendations included:

- Enhance physician and patient education through payer, organized medicine and patient advocacy programs at the federal, state and local level with a focus on improving diagnosis.
- Encourage community interventions including disease awareness, healthy food options and patient support.
- Incorporate gout into congressional approaches to improve health equity, especially those efforts related to chronic disease, access to treatment and reduction of stigma.
- Advance research and innovations in public and private sectors to treat and cure gout.

By taking these steps, gout can be better managed, more episodes can be prevented, an enhanced degree of health equity can be achieved, and associated health care costs can be contained.

The Gout Index Advisory Committee and Acknowledgements

The National Minority Quality Forum is grateful for the individual advocates and experts who offered insight and provided their time and effort to this project, its partnership with the Alliance for Gout Awareness and the sponsorship from Horizon Therapeutics that enabled this initiative's data platform.

NMQF collaborated with the Alliance for Gout Awareness in assembling an advisory committee comprised of health care experts and patient advocates. The advisory committee included participants from:

- American Kidney Fund
- Arthritis Foundation
- National Kidney Foundation
- NOVA ScriptsCentral
- University of Alabama at Birmingham
- Alliance for Patient Access