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Research Priorities in Gout: The Patient Perspective

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Gout is the most common inflammatory arthritis in adults (1). PubMed publications for gout increased 3-fold from 181 in 2000 to 552 in 2012 indicating an increased interest in gout. How should the future gout research be prioritized? There is an evolution in thinking how to set the future research agenda. The creation of Patient-Centered Outcomes Research Institute (PCORI), a public-private partnership for funding clinical and patient-oriented research in the US (http://www.pcori.org/research-we-support/priorities-agenda/), is an example of this change. PCORI recommends the involvement of patients at every stage of the research activity, including the selection of research question. Outcomes Measures in Rheumatology Trials (OMERACT), an international consortium of researchers and methodologists, pioneered active patient involvement in the development of disease outcome measures more than a decade ago (http://www.omeract.org). Multi-stakeholder involvement in research is the way of the future, yet patient participation in prioritizing and conducting research is limited. To our knowledge, there are no studies of patient input into research agenda setting for gout. Therefore, we aimed to perform a qualitative study and asked the gout patients what research should be done in gout.

Patients with a visit at our community-based outpatient clinic with an International Classification of Diseases, ninth revision, common modification (ICD-9-CM) code for gout (274.xx) during 2011-12 were invited to participate in a nominal group. We used the nominal group technique (NGT) and asked a single question to two patient groups of patients “If you were a medical researcher, what area of gout would you focus on?”

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The NGT is a variant of traditional focus group methods aimed at developing an inclusive list of issues related to a specific question, then soliciting feedback on the relative importance of these lists through rank-ordering procedures (2-4). The NGT approach promotes more even participation rates compared to focus group with an equal weighting of the input from all participants. Patients noted their responses independently on a worksheet, nominated each gout-related research question they wrote down to the group leader, elaborated, discussed and consolidated responses. Patients chose their top five responses and gave them individual rank scores from 1 to 5 (higher score indicating the top choice). These scores were aggregated for group rank-order of these gout research questions, with higher scores representing the highest ranked research questions. The Institutional Review Board at the University of Alabama at Birmingham approved the study.

Two nominal groups were conducted with 13 patients (28 patients were invited), of whom ten patients were African-Americans and 3 Caucasian; 6 men and 7 women. Mean age was 63 years (standard deviation, 10). Patient groups identified and ranked these gout research questions (**Table 1)**. The top three research questions identified in each nominal group were as follows: how does the diet affect gout? what is the effect of different medications used for the treatment of gout? and what role do genetics play in risk for gout? (group 1); research into pain and swelling associated with gout, the role of food, supplements and vitamins in causing gout and the comparative effectiveness of gout medications (group 2).

For example, in a recent research priority setting, UK gout researchers identified four research priorities (with no gout patient involvement), including whether colchicine or NSAID prophylaxis is required when titrating urate-lowering therapy, the optimal dose of colchicine in acute gout, the optimal target for uric acid level and the effectiveness of non-pharmacological interventions in gout management (5). All but one focused on pharmacological interventions. Patients in our study identified priorities that were somewhat different than those reported previously by gout researchers. Three major differences were noted.

First, patients selected several research questions that were linked to the impact of gout on patient's lives (pain, swelling, disability), which were not listed as research priorities by researchers. This finding shows that different stakeholders bring complementary perspectives that enrich and broaden the clinical research agenda related to gout, a very painful, symptomatic disease. Second, patients were interested in promoting research to prevent gout, which was very encouraging. Third, the role of diet or diet supplements in gout ranked amongst the top two priorities by both patient nominal groups. Their interest in diet and supplements for disease management was also reflected in additional research questions (What causes uric acid to build up in your body? etc.). This finding confirmed a keen interest in diet and diet supplements by the lay public. Patient priorities included comparative effectiveness research of pharmacological treatments in priorities by patients was similar to those of researchers.

A key limitation of our study was a small sample size. Because of our focus and purposeful oversampling for racial minorities that are usually understudied, the study findings may not generalizable to all gout patients. Another limitation was that some research questions

chosen by patients, such as the role of diet in gout, differences in mediation efficacy and side effects, suggested the need for more patient education rather than research. The main strengths of our study were a focus on the patient perspective and the use of NGT methodology that allowed ranking of priorities in gout research. Our study adds new knowledge to the previous priority setting exercises that included researchers only (5) and to the qualitative research in areas such as patient knowledge, beliefs and treatments (6-8).

In summary, this study highlights the priorities for gout research considered important by patients. Findings are suggestive that patients can provide a unique perspective in setting the research agenda in gout. Our findings must be interpreted considering study limitations, including small sample size and generalizability challenges. Researchers and funding agencies should now take these priorities into consideration while setting future research agenda.

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Table 1

Identification of themes by the nominal groups

Research Questions and Themes	Priority score for each question	Illustrative Quotes
Nominal group 1 (2 Caucasian, 6 African-Americans; n=8)		
How does diet affect gout?	28	• Doctors don't give you specifics (..about diet) ; Doctors should give you a sheet • What is the effect of food on gout? • All doctors don't put you on diet (you have to do it yourself) • You are “ok” if you stick by diet • Food that causes gout and foods that cause it to come on in the first place (baked chicken/baked pork; Juices, soda; Shellfish) • ..it (diet) is something we can “actually” do (something about)
Why are gout patients on different medicines? How do the medications differ based on their effects?	25	• Not everyone is on the same medicine • What stage of gout makes doctor choose one medicine over another?
Can we identify who will develop gout during their lifetime?	16	• Is it hereditary? • Find out the “genes” & make them change
How can we delay/prevent the onset of symptoms?	13	• ....is a Mystery disease...would be nice to prevent it
When you have gout, why can't you walk?	11	
We need discovery of medicines for a permanent cure of gout.	10	• Currently we only have treatments • Have “vaccine” as treatment
Are there (better ways to recognize) any warning signs (for flares)?	7	• (would allow)... “Head start” on the medication • “Finger stick” test (for early diagnosis of flare risk)
How can research medical and psychological effects of gout?	6	• When pain hits – you lose your mind • (how to) maintain good physical and mental stability?
What are the various stages of gout?	5	• Are there stages? Stages I, II, III
How does it interact with other arthritis conditions?	1	• (what is the) Interaction of gout with osteoarthritis
Nominal group 2 (1 Caucasian, 4 African-Americans); n=5)		
More research is needed into pain and swelling due to gout	23	• Research into pain associated with Gout • “Gout is very painful” • Can a cream reduce gout swelling? • ..find ways to reduce swelling • Why is it (gout pain) worse at night?
What is the role of food, supplements and vitamins in causing gout?	13	• What are you “supposed to eat” (Cherry, cherry juice) rather than not eat (soda, fish oil)? • Drink beer, eat barbeque pork, peanuts or protein and get a gout attack • Vitamin C & E are good. • Will too much “salt” cause it?
What medicines treat Gout? Which one works the best? What problems do they cause?	13	• Watch gout medications due to effect on kidneys • Coming off prednisone is very hard • (gout) Medicine constipates (me) • [Medicine] bad on kidneys • Allopurinol [began] rash
What causes uric acid to build up in your body?	9	• Is it diet? • Kidney not filtering well?
Why do some people get gout, why others don't?	7	• (is it) Hereditary? • You get it when you are “Older” • Diet has something to do with it
Why some people have gout arthritis associated with constant stiffness and pain and a sick feeling, not just a single joint pain?	4	

Nominal group 2 (1 Caucasian, 4 African-Americans); n=5)		
Why gout seems to effect joints that have been “stressed”?	3	• Pick up something “heavy” (and you get it) • Get it in my joints when I go “fishing”
What is the association of other illnesses with Gout?	2	• What other illnesses result from Gout? Or cause it? high blood pressure, diabetes? Are they related to prednisone affects? • (is it related to) “Shingles”?
Why does “cold temperature” affect Gout?	1	