Disparities in National Institutes of Health Funding Between Gastrointestinal Disorders

The National Institutes of Health (NIH) is the major funder of research in gastrointestinal (GI) diseases. The National Institute for Diabetes and Digestive and Kidney Diseases' discretionary appropriation for fiscal 2016 is $1.818 billion of the overall NIH $32.31 billion.[1] As such, NIH support is essential for improving our understanding of health and disease from pathologic mechanisms to clinical trials. In theory, outside of specific request for funding applications the NIH distributes grants based on "meritorious science" as judged by peer reviewers, rather than favoring specific diseases. The National Institute for Diabetes and Digestive and Kidney Diseases states that it "supports clinical research, clinical trials, and epidemiology studies on GI inflammatory diseases, including, but not limited to, gluten-sensitive enteropathy, inflammatory bowel disease, and gastritis; malabsorption syndromes; diarrhea; gastric and duodenal ulcers."[2] This statement suggests an appropriate equipoise by the National Institute for Diabetes and Digestive and Kidney Diseases regarding areas most important to fund. If this were the case, it would be expected that grants awarded would be partially a function of disease prevalence as a surrogate for importance, partially related to the number of grants submitted within a disease area, and that that funding levels for different diseases would vary over time as meritorious applications arise from various groups and disciplines. Conversely, if funding levels are highly discrepant between diseases in a way that is not explained by disease prevalence and if these discrepancies are maintained over time, it would suggest an uneven playing field.

Because NIH funding is a major driver of scientific and medical progress, it is important to investigate whether or not disease funding is proportional to US disease burden and prevalence to ensure appropriate distribution of resources. Identifying any apparent disparities in funding may allow for improvement in the allocation of funds and could encourage increased research activity in underrepresented areas as this could also contribute to overall lower funding levels for specific diseases. We used the NIH online grant reporting system to investigate whether or not the NIH funding granted to 6 different GI diseases is proportional to U.S. disease burden and funding trends from 2011 through 2015. The GI diseases studied included celiac disease, irritable bowel syndrome (IBS), Crohn's disease, eosinophilic esophagitis (EoE), Barrett's esophagus, and non-alcoholic fatty liver disease (NAFLD).

We evaluated NIH funding for celiac disease, IBS, Crohn's disease, EoE, Barrett's esophagus, and NAFLD over the 5-year period from 2011 through 2015 using the NIH's Research Portfolio Online Reporting Tools (RePORT), which was launched in late 2009. In keeping with the NIH's goals for ample public accountability, RePORT "provides access to reports, data, and analyses of NIH research activities, including information on NIH expenditures and the results of NIH supported research"[3] (available from: https://report.nih.gov/index.aspx).

The name of each disease was searched in NIH RePORT under project title for each year, from 2011 to 2015. 'Celiac disease' and 'eosinophilic esophagitis' were the search terms used for these 2 diseases, respectively. For IBS, both 'IBS' and 'irritable bowel syndrome' were searched under project title, because the acronym for the disease is commonly used in place of its full name. Both 'Crohn' and 'Crohn's' were search terms for Crohn's disease. Similarly, both 'Barrett' and 'Barrett's' were search terms for Barrett's esophagus. To incorporate all funded projects focused on Crohn's disease, 'inflammatory bowel disease' was also searched under project title for each year, and projects focusing on Crohn's disease were selected. Any study that did not include the term 'Crohn' in its abstract, public health relevance statement, or project terms was excluded. NAFLD funding data were obtained by searching 'fatty liver disease' under project title, and then selecting the projects that focused on NAFLD. All projects that included 'alcoholic fatty liver disease' in their titles were excluded. In addition, we classified each study found through the NIH RePORT searches as clinical or basic/translational by carefully reading through the abstract of each project and assessing its methodology. Finally, we estimated the prevalence of each disease in the United States population using recent literature to assess for any association between NIH funding and disease prevalence for each disease over the 5-year period. Because raw data seemed to be adequate, a statistical analysis was not conducted.

Trends in NIH funding of the 6 different GI diseases remained relatively stable over the 5-year period. Crohn's disease was consistently awarded the highest amount of money, at approximately $16 million per year. Crohn's disease was followed by Barrett's esophagus at approximately $13 million per year, NAFLD at approximately $7 million per year, IBS at approximately $5 million per year, and EoE at approximately $4 million per year. Celiac disease consistently received the lowest amount of NIH funding over the 5-year period, at approximately $3 million per year. Looking at the number of grants awarded by the NIH per year rather than amount of money, revealed the same pattern over the five year period for the 6 diseases studied (Figure 1). Crohn's disease rose even further above the rest of the GI diseases, receiving an average of 40 grants per year. Crohn's disease was followed by Barrett's esophagus, NAFLD, IBS, EoE, and finally celiac disease. Celiac disease consistently received the lowest amount of NIH grants, at approximately eight grants per year. Celiac disease, IBS, EoE, Barrett's esophagus, and NAFLD all had a similar number of

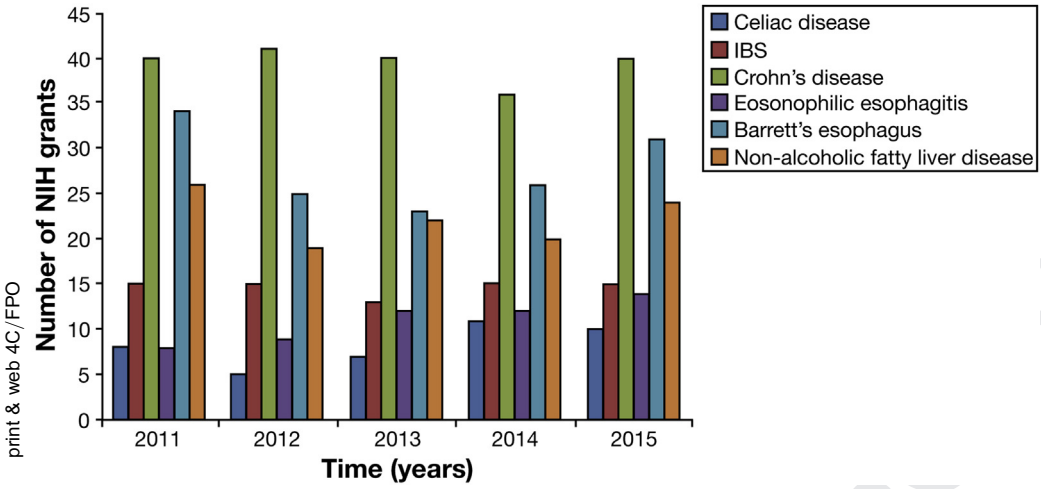

Figure 1. Number of National Institutes of Health (NIH) grants funded of different gastrointestinal disorders from 2011 to 2015. IBS, irritable bowel syndrome.

both clinical and basic/translational studies. Crohn's Disease, however, was awarded significantly more basic/translational than clinical grants.

There was no association between funding and estimated disease prevalence in the United States (Figure 2). EoE had the lowest prevalence at 0.04%, and received the second lowest amount of NIH funding over the 5-year period at $18.9 million.[4,5] Crohn's disease, with the second lowest prevalence of approximately 0.25%, received the highest amount of funding from 2011 to 2015 at $77.5 million.[6,7] Barrett's esophagus, with a prevalence of approximately 1%, received $64.1 million over the 5-year period.[8] Celiac disease, with prevalence very similar to that of Barrett's Esophagus at approximately 1%, received significantly less funding over the 5-year period at $15.4 million—the lowest amount of all the diseases studied.[9,10] IBS occurs in approximately 12.5% of the population and received a total of $24.6 million in NIH funding.[11] NAFLD, the most common disease studied, with a prevalence of approximately 18%, received a mid-range amount of funding at $33.9 million.[12] As a separate measure of disease burden, we used available data to assess estimated disease-specific normalized standardized mortality rates across the disorders studied (Crohn's 1.1,[13,14] celiac disease 1.3,[15,16] Barrett's esophagus 1.2,[17,18] EoE 1.0,[19] NAFLD 1.1,[20,21] IBS 1.0[22]) and again there was no relationship with funding level (Figure 3).

Although there is no global metric for disease importance, it is difficult to

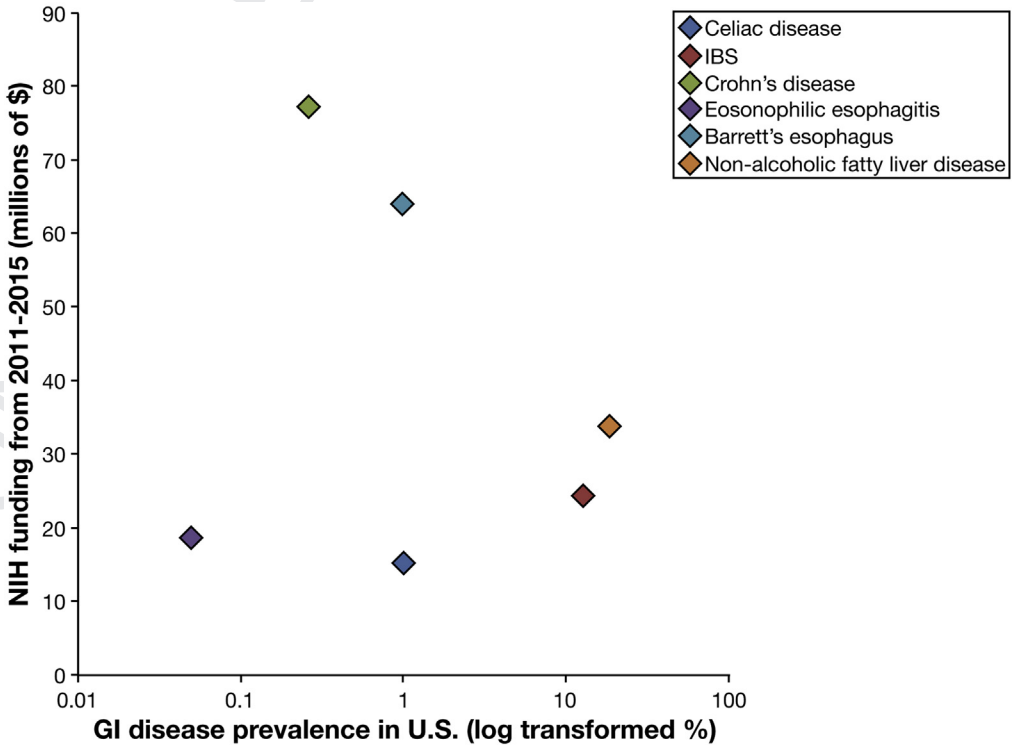

Figure 2. Number of clinical versus basic/translational studies on gastrointestinal (GI) diseases funded by the National Institutes of Health (NIH) from 2011 to 2015. IBS, irritable bowel syndrome.

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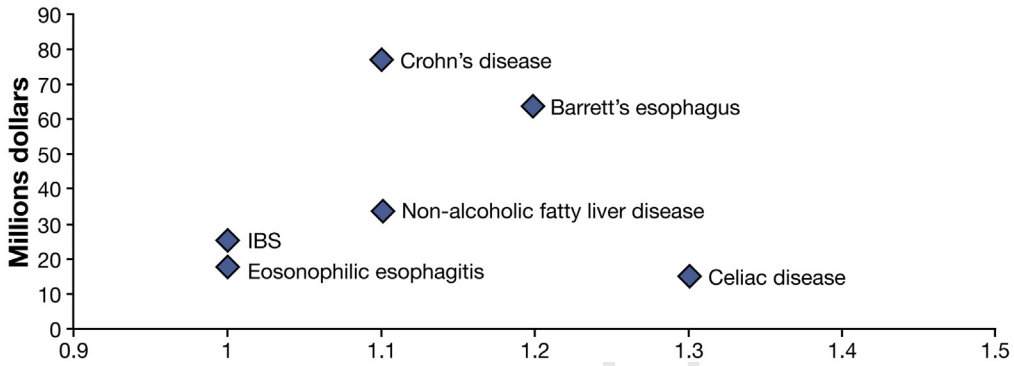

Figure 3. National Institutes of Health (NIH) funding of different gastrointestinal diseases from 2011 to 2015 versus gastrointestinal disease prevalence in the United States. IBS, irritable bowel syndrome.

justify on medical and scientific bases a reason for such large and persistent funding differences. Although Crohn's disease has many available and emerging treatment options, celiac disease, for example, is more prevalent and has no current treatment available to patients beyond the burdensome gluten-free diet; however, celiac disease received only a small fraction of the funding that Crohn's disease received from the NIH over the 5-year period.

Although funding for most diseases was stable over time, there was an upward trend in funding for EoE, possibly owing to the presence of program announcements and requests for applications put out by the NIH for EoE, in comparison with the last request for funding application for celiac disease in 1999 (available: https://grants.nih.gov/grants/guide/rfa-files/RFA-AI-14-003.html; https://grants.nih.gov/grants/guide/pa-files/PA-15-027.html), suggesting that the NIH has the power to encourage research in desired areas.

We did not look at every GI disease funded by the NIH, and it did not capture all other funding sources of research. Moreover, it was not possible to determine the total number of grants submitted for a particular disease to assess whether there could be a deficit in research activity contributing to lower funding levels, because this information is not available in RePORT or otherwise made public by the NIH. However, if differential research activity was a major factor in NIH funding rates, one would expect that diseases with lower funding levels to have fewer PubMed citations. This does not seem to be the case, however; Barrett's esophagus had and average of 444 citations per year from 2011 to 2015, compared with 906 per year for celiac disease. Additionally, disease prevalence alone is not a holistic measure of disease importance and we do not suggest that any one disease is more important than another. However, inequity in funding is still apparent when mortality rates for the GI diseases studied are considered. Studies have shown that diseases such as IBS and NAFLD are not associated with increased mortality, whereas celiac disease has a reported mortality rate of approximately 1.3; however, both IBS and NAFLD still received significantly more NIH funding than celiac disease.[16]

In conclusion, NIH funding of GI diseases is not proportional to disease prevalence or mortality. These data further suggest that a few diseases, including IBS and celiac disease, are underfunded in comparison with other diseases, especially when the prevalence, burden, and available treatment options are considered. Plausible reasons for this disparity include varying numbers of established research programs to recruit young investigators, fewer grants submitted because of a lack of investigators in the field owing to poor funding, and narrow expertise of peer reviewers on NIH review committees. In contrast with disorders with low funding levels, ample public and private funding of Crohn's disease allows for excellent research, which in turn, favors more awards of research funding. This may seem circuitous; however, funding of Crohn's disease research provides an example of the way in which success breeds success.

Ultimately, the data presented herein argue that intervention is necessary to improve the existent disparities in disease funding. National authorities should take notice and address this inequity to improve progress across all GI diseases to improve quality of life for patients and their families.

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Conflicts of interest
The authors disclose no conflicts. Q1

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