Google search data as a novel adjunct to patient and public involvement in rheumatology research

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Abstract

Patient and public involvement is essential in the design and implementation of research studies to ensure research remains relevant and in line with public priorities. Public views on a given area of research may be sought via platforms such as focus groups or surveys. Here, we present the use of an openly available Google search data query tool, which may be used alongside traditional forms of patient and public involvement in research to highlight public perceptions and priorities. We used an online search query tool (“AnswerThePublic.com”) to explore public Google searches relating to “arthritis,” and an exemplar rheumatic disease, “rheumatoid arthritis.” The most common searches relating to these diseases included quality of life, treatment, prognosis, as well as impacts on life, including work. However, they also reveal concerns that may be more difficult to elicit in face-to-face focus groups, such as questions on alcohol consumption in arthritis, and impacts on mental health. Using public search engine data in research, alongside the important traditional methods of patient and public involvement, is a cost-effective and time-efficient method of gauging public views and concerns on a given topic. It may facilitate broad scoping searches of public priorities and help to guide future research questions.

Keywords

Patient involvement · Rheumatology · Arthritis · Rheumatoid arthritis · Data visualisation · Google

Introduction

Patient and public involvement (PPI) is integral to the design and prioritisation of research studies. The National Institute for Health Research (NIHR) defines public involvement in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” [1]. PPI are typically conducted by funders and researchers to prioritise research questions, and offering advice as part of a project steering group. The term ‘public’ denotes a wide range of individuals, including patients, potential patients, carers, people using health and social care services, and those who represent them [1]. It is important to distinguish between the views of the public, and those with a professional role in health and social care, especially when considering research design and prioritisation. This facilitates optimal impact and improved enrolment to studies, especially if those with the condition under study are involved from the study’s inception [2]. In the rheumatic diseases, undertaking PPI ensures research remains patient-centred and clinically relevant, across a range of chronic and often debilitating conditions, treated with a wide range of drugs, including immunosuppressants and analgesics.

There is ample evidence demonstrating that PPI is necessary to optimise research design and output [2–4]. However, at the earliest stages of designing a study, it can be useful to gain a broad overview of public perceptions of a given topic, ensuring increased relevance and potential for wider benefit. Furthermore, it can be difficult to have access to focus groups, especially for junior researchers and clinicians. This has been made all the more difficult by social-distancing measures implemented worldwide due to the COVID-19 pandemic, which are likely to have lasting consequences for months to years. In outpatient specialties such as rheumatology, a quick and easy method of gauging public priorities for research can be through questionnaires...
Rheumatoid arthritis was selected as it is the most prevalent "rheumatoid arthritis," as an exemplar rheumatic disease. The most commonly-used terms in rheumatology, also used by to gauge a broad overview of public queries on one of the region in which it is accessed (e.g. UK); therefore, factors such as the user’s own Google search history are irrelevant. Google searches conducted per day through Google, summarising searches this way can provide an excellent overview of public concerns and queries on a given topic. They are already commonplace in marketing, to ensure content is relevant and up-to-date. An example of such a tool includes “AnswerThePublic.com” [6], which is able to fetch data on phrases and questions entered into Google, featuring certain keywords (as entered into the tool by the user). Results are presented in both a tabulated and infographic format, making it efficient to ascertain search patterns and popular phrases.

In healthcare, search query tools may not only serve to confirm prior knowledge from PPI and clinician perceptions, but also reveals searches on more sensitive topics, such as opioid dependence and psychological impact of rheumatic disease, which service-users may not necessarily wish to discuss face-to-face. We aimed to demonstrate the utility of a search query tool to complement PPI in the rheumatic diseases, using an exemplar rheumatic disease, rheumatoid arthritis.

**Methods**

We used an openly available search query tool to collate and map Google searches for two separate terms: “arthritis” and “rheumatoid arthritis.” We opted to use “AnswerThePublic.com”, due to ease of use and the resulting visual format of the results. Data on searches performed in Google are presented in real-time, so results are up-to-date at the time of using the search query tool. Since the results at any given time are identical regardless of the individual conducting the search, one author conducted the search for the chosen terms. Search queries are based on Google searches in the region in which it is accessed (e.g. UK); therefore, factors such as the user’s own Google search history are irrelevant.

We first explored public Google searches for “arthritis” to gauge a broad overview of public queries on one of the most commonly-used terms in rheumatology, also used by patients and public. We then assessed search suggestions for “rheumatoid arthritis,” as an exemplar rheumatic disease. Rheumatoid arthritis was selected as it is the most prevalent chronic inflammatory arthritis, and, therefore, likely to be a commonly-searched term in this field [7]. All searches were performed on 19 May 2020.

The output of results for each of the above two queries were delivered in the following categories: questions on the term; prepositions (i.e. searches incorporating additional terms such as “with” and “near”); comparisons (i.e. searches incorporating additional terms such as “and” and “versus”). Results were presented in lists as well as data visualisation images. Search query data for the UK, English language only, were interrogated.

**Results**

Figure 1 displays the results for search terms relating to questions on “arthritis,” with up to eight of the most common terms shown for each, as an example of output produced by the search query tool. Within each sub-category, the darker stems denote more popular search terms, while paler stems denote less popular search terms.

Subsequent searches are displayed in Tables 1, 2 and 3. Table 1 displays results for search terms relating to prepositions and comparisons to “arthritis”.

Tables 2 and 3 display the results for search terms relating to questions, prepositions, and comparisons to the term “rheumatoid arthritis,” in the same manner as for “arthritis.”

Public searches performed on these topics predominantly relate to impacts on quality of life, relief of debilitating features including pain, and prognosis. On review of questions asked on arthritis, approximately 30% referred to debilitating features or quality of life, while just over 20% were on treatment or prognosis. In the prepositions’ category, approximately 20% of searches were on debilitating features or quality of life, with a further 20% on treatment or prognosis.

For on “rheumatoid arthritis” searches, approximately 20% of search questions were on debilitating features or quality of life, with approximately 30% on treatment or prognosis. Looking at searches on rheumatoid arthritis, by prepositions, approximately 15% were on debilitating features or quality of life, with 30% on treatment or prognosis. The remainder of searches for both arthritis and rheumatoid arthritis covered topics including but not limited to anatomical sites of symptoms, possible associations with other rheumatological diseases (e.g. gout, systemic lupus erythematosus), investigations and diagnosis, and symptoms in animals.

**Discussion**

We used an openly available online tool to investigate Google searches for the terms “arthritis” and “rheumatoid arthritis,” conducted by the public. Our results reveal
striking patterns in search themes, with a focus on treatment, prognosis, quality of life, and debilitating features, including impact on work. While some results were novel, consistencies were seen with previous research in these areas, such as quality of life and patient-reported outcomes. These similarities with traditional methods of PPI suggest a role for a search query tool in this area.

One of the most common themes in searches for both arthritis and rheumatoid arthritis was on treatment. Specifically, some of the most frequently searched questions were “can arthritis be cured?”, “can arthritis be treated?”, “will arthritis go away?”, and “rheumatoid arthritis- can it be cured?”, as well as variations on these questions. This is consistent with previous studies on patient-reported health service needs. A recent scoping review identified that patients with inflammatory arthritis value discussions on treatment outside conventional medicine, such as alternative and complimentary therapies and dietary advice, as well as practical tools to help with daily activities [8]. Indeed, our review of Google searches revealed the following as some of

Fig. 1 Data visualisation of the 8 most common questions asked on “arthritis,” using the interrogative words: are, which, how, what, where, when, can, will, why, who. Darker green denotes an increased number of searches, while paler green denotes fewer searches
Another common theme in the searches centred on quality of life, and debilitating aspects of arthritis relating to this. Some specific frequently-searched examples include “when arthritis becomes debilitating”, “will rheumatoid arthritis cripple me?”, and “what rheumatoid arthritis feels like”. Quality of life outcomes have been explored increasingly in recent years in the rheumatic diseases. This has sought to increase clinical awareness of the burden of disease on mental health and daily living, with recommendations for factors such as health-related quality of life and fatigue to be routinely assessed in those with conditions including rheumatoid arthritis [11–13]. Our review of searches reveal that this remains an important priority in the public domain.

In addition, some specific frequent searches relating to quality of life, revealed public interest in aspects relating to work and arthritis. These included such examples as: “arthritis- can I claim PIP?”, “rheumatoid arthritis- can you work?”, and “is rheumatoid arthritis a disability?”. We know from previous studies and patient-reported interactions that public desire for information on these and similar issues remain consistent with previous findings.

### Table 1

**Searches on “arthritis”: prepositions**

| With Near Without Can To Is For |
|-------------------------------|----------------|----------------|----------------|-----------------|----------------|----------------|
| Arthritis with rash Arthritis near me Arthritis without swelling Arthritis can opener Arthritis to the knee Arthritis is an autoimmune disease Arthritis for dogs |
| Arthritis with ulcerative colitis Arthritis near ear Arthritis without pain Arthritis can opener UK Arthritis to the spine Arthritis is wrist Arthritis for cats |
| Arthritis without swelling Arthritis near heart Arthritis without medication Arthritis can be cured Arthritis to eat Arthritis is it hereditary Arthritis for dummies |
| Arthritis with psoriasis Arthritis near thumb Arthritis without joint pain Arthritis can you die Arthritis to fingers Arthritis is hands Arthritis for young adults |
| Arthritis without pain Arthritis near collar bone Arthritis without stiffness Arthritis can you die Arthritis to hands Arthritis is curable Arthritis for dogs medication |
| Arthritis with skin rash Arthritis in elbow Arthritis without fever Arthritis can you get disability Arthritis to avoid food Arthritis is thumb joint Arthritis for dogs treatment |
| Arthritis with Crohn’s Arthritis near groin Arthritis without treatment Arthritis can I claim disability allowance Arthritis to lower back Arthritis is killing me Arthritis for dogs home remedies |
| Arthritis with Crohn’s disease Arthritis in spine Arthritis without swelling or redness Arthritis can cause fever Arthritis to avoid Arthritis is disability Arthritis for cats natural remedies |

**Searches on “arthritis”: comparators**

Arthritis vs gout Arthritis and tomatoes Arthritis like conditions Arthritis or joint pain Arthritis versus arthritis Arthritis versus rheumatoid arthritis

Arthritis vs arthralgia Arthritis and alcohol Arthritis like pain that moves around Arthritis or gout Arthritis versus arthritis Arthritis versus osteoarthritis

Arthritis vs arthrosis Arthritis and diet Arthritis like symptoms but not arthritis Arthritis or RSI Arthritis versus arthritis Arthritis versus osteoarthritis

Arthritis vs MS Arthritis and COVID Arthritis like diseases Arthritis or bone cancer Arthritis versus fibromyalgia Arthritis versus gout

Arthritis vs rheumatism Arthritis and fatigue Arthritis like pain Arthritis or osteoarthritis Arthritis versus osteoarthritis

Arthritis vs tendinitis Arthritis and exercise Arthritis like pain in hands Arthritis or fibromyalgia Arthritis versus bursitis Arthritis versus osteoarthritis

Arthritis vs bursitis Arthritis and rheumatology Arthritis like pain in hands postpartum Arthritis or bursitis Arthritis versus tendonitis Arthritis versus osteoarthritis

Arthritis vs osteoarthritis Arthritis and turmeric Arthritis like pain in hands during pregnancy Arthritis or cancer Arthritis versus osteoarthritis Arthritis versus tendonitis

The commonest searches: “arthritis and diet” and “arthritis can opener”, consistent with the findings in this review and elsewhere in the literature [9, 10].

Another common theme in the searches centred on quality of life, and debilitating aspects of arthritis relating to this. Some specific frequently-searched examples include “when arthritis becomes debilitating”, “will rheumatoid arthritis cripple me?”, and “what rheumatoid arthritis feels like”. Quality of life outcomes have been explored increasingly in recent years in the rheumatic diseases. This has sought to increase clinical awareness of the burden of disease on mental health and daily living, with recommendations for factors such as health-related quality of life and fatigue to be routinely assessed in those with conditions including rheumatoid arthritis [11–13]. Our review of searches reveal that this remains an important priority in the public domain.

In addition, some specific frequent searches relating to quality of life, revealed public interest in aspects relating to work and arthritis. These included such examples as: “arthritis- can I claim PIP?”, “rheumatoid arthritis- can you work?”, and “is rheumatoid arthritis a disability?”. We know from previous studies and patient-reported interactions that public desire for information on these and similar issues remain consistent with previous findings.
**Table 2** The most common questions asked on “rheumatoid arthritis,” using the interrogative words: who, how, when, are, will, why, what, can, where, which. Searches are ordered in popularity vertically down each column, with the most popular at the top.

| How rheumatoid arthritis affects daily life | When rheumatoid arthritis turns deadly | Are rheumatoid arthritis patients immunosuppressed | Will rheumatoid arthritis show up on x-ray | Why rheumatoid arthritis occurs | What’s rheumatoid arthritis | Can rheumatoid arthritis affect your jaw | Where does rheumatoid arthritis start | Who rheumatoid arthritis which joints rheumatoid arthritis |
|-------------------------------------------|----------------------------------------|--------------------------------------------------|------------------------------------------|---------------------------------|-------------------------------|--------------------------------------|----------------------------------|------------------------------------------------ |
| How rheumatoid arthritis affects the body  | When rheumatoid arthritis is active    | Are rheumatoid arthritis and psoriasis related    | Will rheumatoid arthritis show up in a blood test | Why rheumatoid arthritis feels like | What rheumatoid arthritis affects your eyes | Can rheumatoid arthritis affect your eyes | Where does rheumatoid arthritis affect | Who gets rheumatoid arthritis |
| How rheumatoid arthritis starts           | When rheumatoid arthritis is fatal     | Are rheumatoid arthritis and polymyalgia rheumatica related | Will rheumatoid arthritis go away | Why rheumatoid arthritis causes anaemia | What rheumatoid arthritis affects your neck | Can rheumatoid arthritis affect the body | Where does rheumatoid arthritis affect | Who does rheumatoid arthritis affect |
| How rheumatoid arthritis is diagnosed     | When does rheumatoid arthritis start   | Are rheumatoid arthritis patients immunocompromised | Will rheumatoid arthritis kill me | Why rheumatoid arthritis is called autoimmune disease | What rheumatoid arthritis looks like | Can rheumatoid arthritis be cured | Where is rheumatoid arthritis | Who treat rheumatoid arthritis |
| How rheumatoid arthritis affects movement | When is rheumatoid arthritis diagnosed | Are rheumatoid arthritis patients candidates for dental implants | Will rheumatoid arthritis cripple me | Why rheumatoid arthritis common in females | What rheumatoid arthritis drugs are covered by medicare | Can rheumatoid arthritis kill | Where is rheumatoid arthritis | Who get rheumatoid arthritis |
| How rheumatoid arthritis can be cured     | When is rheumatoid arthritis           | Are rheumatoid arthritis and ankylosing spondylitis related | Will rheumatoid arthritis spread | Why rheumatoid arthritis causes fatigue | What’s rheumatoid arthritis | Can rheumatoid arthritis cause anaemia | Where is rheumatoid arthritis | Who treat rheumatoid arthritis |
| How rheumatoid arthritis affects the heart | When is rheumatoid arthritis considered a disability | Are rheumatoid arthritis and lupus related | Will rheumatoid arthritis cause hair loss | Why does rheumatoid arthritis cause fatigue | What rheumatoid arthritis risk factors | Can rheumatoid arthritis cause weight loss | Where do you get rheumatoid arthritis |
| How rheumatoid arthritis is caused        | When is rheumatoid arthritis caused    | Are rheumatoid arthritis and rheumatic fever related | Will rheumatoid arthritis cause weight loss | Why does rheumatoid arthritis make you tired | What rheumatoid arthritis symptoms | Can rheumatoid arthritis be inherited | Where to live with rheumatoid arthritis | Who treat rheumatoid arthritis |

**Searches on “rheumatoid arthritis”: questions**

| How rheumatoid arthritis affects daily life | When rheumatoid arthritis turns deadly | Are rheumatoid arthritis patients immunosuppressed | Will rheumatoid arthritis show up on x-ray | Why rheumatoid arthritis occurs | What’s rheumatoid arthritis | Can rheumatoid arthritis affect your jaw | Where does rheumatoid arthritis start | Who rheumatoid arthritis which joints rheumatoid arthritis |
|-------------------------------------------|----------------------------------------|--------------------------------------------------|------------------------------------------|---------------------------------|-------------------------------|--------------------------------------|----------------------------------|------------------------------------------------ |
| How rheumatoid arthritis affects the body  | When rheumatoid arthritis is active    | Are rheumatoid arthritis and psoriasis related    | Will rheumatoid arthritis show up in a blood test | Why rheumatoid arthritis feels like | What rheumatoid arthritis affects your eyes | Can rheumatoid arthritis affect your eyes | Where does rheumatoid arthritis affect | Who gets rheumatoid arthritis |
| How rheumatoid arthritis starts           | When rheumatoid arthritis is fatal     | Are rheumatoid arthritis and polymyalgia rheumatica related | Will rheumatoid arthritis go away | Why rheumatoid arthritis causes anaemia | What rheumatoid arthritis affects your neck | Can rheumatoid arthritis affect the body | Where does rheumatoid arthritis affect | Who does rheumatoid arthritis affect |
| How rheumatoid arthritis is diagnosed     | When does rheumatoid arthritis start   | Are rheumatoid arthritis patients immunocompromised | Will rheumatoid arthritis kill me | Why rheumatoid arthritis is called autoimmune disease | What rheumatoid arthritis looks like | Can rheumatoid arthritis be cured | Where is rheumatoid arthritis | Who treat rheumatoid arthritis |
| How rheumatoid arthritis affects movement | When is rheumatoid arthritis diagnosed | Are rheumatoid arthritis patients candidates for dental implants | Will rheumatoid arthritis cripple me | Why rheumatoid arthritis common in females | What rheumatoid arthritis drugs are covered by medicare | Can rheumatoid arthritis kill | Where is rheumatoid arthritis | Who get rheumatoid arthritis |
| How rheumatoid arthritis can be cured     | When is rheumatoid arthritis           | Are rheumatoid arthritis and ankylosing spondylitis related | Will rheumatoid arthritis spread | Why rheumatoid arthritis causes fatigue | What’s rheumatoid arthritis | Can rheumatoid arthritis cause anaemia | Where is rheumatoid arthritis | Who treat rheumatoid arthritis |
| How rheumatoid arthritis affects the heart | When is rheumatoid arthritis considered a disability | Are rheumatoid arthritis and lupus related | Will rheumatoid arthritis cause hair loss | Why does rheumatoid arthritis cause fatigue | What rheumatoid arthritis risk factors | Can rheumatoid arthritis cause weight loss | Where do you get rheumatoid arthritis |
| How rheumatoid arthritis is caused        | When is rheumatoid arthritis caused    | Are rheumatoid arthritis and rheumatic fever related | Will rheumatoid arthritis cause weight loss | Why does rheumatoid arthritis make you tired | What rheumatoid arthritis symptoms | Can rheumatoid arthritis be inherited | Where to live with rheumatoid arthritis | Who treat rheumatoid arthritis |
### Table 3: Top: the most common search terms on “rheumatoid arthritis,” using the prepositions: with, without, can, to, is, for, near, bottom: the eight most common search terms on “rheumatoid arthritis,” using the comparators: vs, and, like, or, versus

Searches on “rheumatoid arthritis”: prepositions

| With                                      | Without                                      | Can                           | To                            | Is                            | For                           | Near                           |
|-------------------------------------------|----------------------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|---------------------------------|
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it  | Rheumatoid arthritis to       | Rheumatoid arthritis is it    | Rheumatoid arthritis for       | Rheumatoid arthritis near me    |
| coronavirus                              | swelling                                     | kill you                     | lupus                         | hereditary                    | dummies                       |                                 |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it   | Rheumatoid arthritis to       | Rheumatoid arthritis is an    | Rheumatoid arthritis for        | Rheumatoid arthritis doctors    |
| fibromyalgia                             | rheumatoid factor                           | be cured                     | hands                         | autoimmune disease            | child                          | near me                         |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it   | Rheumatoid arthritis to       | Rheumatoid arthritis is it    | Rheumatoid arthritis for dogs  | Rheumatoid arthritis near me    |
| COVID-19                                  | medication                                   | you die                      | lungs                         | dangerous                     | nurses                         |                                 |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it   | Rheumatoid arthritis to       | Rheumatoid arthritis is it    | Rheumatoid arthritis for nurses| Rheumatoid arthritis doctor     |
| negative rheumatoid factor               | joint pain                                   | go away                      | ankle                         | inherited                     | for nurses                     | near me                         |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it   | Rheumatoid arthritis to       | Rheumatoid arthritis is it    | Rheumatoid arthritis for       | Rheumatoid arthritis specialist |
| psoriasis                                | inflammation                                | affect the lungs             | Chinese                       | serious                       | young adults                   | near me                         |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can I    | Rheumatoid arthritis to neck  | Rheumatoid arthritis is there | Rheumatoid arthritis for       | Rheumatoid arthritis support    |
| normal rheumatoid factor                 | pain                                         | still work                   | with neck                     | a cure                        | medical students               | group near me                   |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis can it   | Rheumatoid arthritis to       | Rheumatoid arthritis is it    | Rheumatoid arthritis for       | Best doctor for rheumatoid      |
| normal ESR and CRP                       | fever                                        | affect eyes                  | ankle                         | genetic                       | nurses                         | arthritis near me               |
| Rheumatoid arthritis with                | Rheumatoid arthritis without                | Rheumatoid arthritis you can | Rheumatoid arthritis in       | Rheumatoid arthritis is this a| Rheumatoid arthritis for       |                                 |
| Crohn’s disease                          | inflammatory markers                         | get disability               | Hindi                         | disability                    | exercises                      |                                 |

Searches on “rheumatoid arthritis”: comparators

| Vs                                        | And                                      | Like                           | Or                              | Versus                         |
|-------------------------------------------|------------------------------------------|---------------------------------|---------------------------------|--------------------------------|
| Rheumatoid arthritis vs gout              | Rheumatoid arthritis and COVID           | Rheumatoid arthritis like       | Rheumatoid arthritis or         | Rheumatoid arthritis versus    |
| Rheumatoid arthritis vs lupus              | Rheumatoid arthritis and osteoarthritis  | diseases                       | lupus                           | arthritis                      |
| Rheumatoid arthritis vs osteoarthritis    | Rheumatoid arthritis and shielding       | Rheumatoid arthritis like       | syndrome                        | Rheumatoid arthritis versus    |
| Rheumatoid arthritis vs osteoarthritis X-  | Rheumatoid arthritis and eyes             | symptomatics                    | syndrome                        | osteoarthritis                 |
| ray                                       | Rheumatoid arthritis and alcohol         | Rheumatoid arthritis           | Rheumatoid arthritis or         | Rheumatoid arthritis versus    |
| Rheumatoid arthritis vs other arthritis   | Rheumatoid arthritis and exercise        | feels like                     | ankylosing spondylitis         | psoriatic arthritis            |
| hands                                     | Rheumatoid arthritis vs reactive arthritis| and pip                        | Rheumatoid arthritis or         | Rheumatoid arthritis versus    |
| Rheumatoid arthritis vs psoriatic arthritis| Rheumatoid arthritis and fatigue         | flu symptoms                   | psoriatic arthritis            | MS                             |
|                                            |                                         | feels like                     | Rheumatoid arthritis or         | Rheumatoid arthritis versus    |

Searches are ordered in popularity vertically down each column, with the most popular at the top.
outcomes that productivity at work, as well as presenteeism and absenteeism, are affected by all forms of arthritis [14–16]. However, these searches demonstrate more sensitive topics, such as eligibility for benefits, that patients may not feel able or comfortable to discuss during appointments. This highlights the need for clinicians to facilitate conversations regarding work and disability during clinic appointments, and the importance of the multi-disciplinary team, including psychologists and occupational therapists, and patient support services.

Patient and public involvement, in rheumatology and elsewhere, has repeatedly highlighted the value placed on their relationship with health professionals, including ease of communication and approachability [8, 17]. Consistent with this, some common Google searches included “rheumatoid arthritis doctors near me” and “rheumatoid arthritis support group near me”. This again demonstrates the importance of access to patient, as well as clinician, support.

The co-existence of fibromyalgia with other rheumatic diseases has become more apparent in recent years, associated with poorer clinical outcomes in inflammatory arthritis [18, 19]. Some of the most common public searches seek to explore this relationship e.g. “arthritis versus fibromyalgia” and “are arthritis and fibromyalgia connected?”. These searches may also represent questions asked by patients during the diagnostic process for inflammatory arthritis or fibromyalgia, as they seek to explore the overlapping symptoms and relationship between the two diseases. This is also consistent with studies demonstrating a sense of ‘invalidation’ experienced by those with fibromyalgia, due to the invisibility and medically-unexplained nature of the syndrome, and the subsequent impact on quality of life outcomes in these patients [20, 21].

Some searches did not follow a theme, or revealed unexpected patterns of search behaviour. One of the commonest phrases was “rheumatoid arthritis and COVID”, consistent with the time at which we conducted this study (i.e. during the UK lockdown and shielding period for those at high-risk of complications of COVID-19, including some patients with rheumatoid arthritis). Other common searches were on the genetics of rheumatoid arthritis (“is rheumatoid arthritis hereditary?” and “rheumatoid arthritis—is it genetic?”). This perhaps demonstrates a sensitive area which clinicians may not routinely address in clinic, but of importance to the patient. On a similar theme, searches such as “arthritis and alcohol” and “arthritis and sex” reveal similar sensitive topics which may prove potentially embarrassing for the patient to ask, leading them to seek answers on the Internet and online forums.

**Future directions**

Our use of a search query tool to explore searches conducted on “arthritis” and “rheumatoid arthritis” reveal known concerns from patients and the public, but also demonstrate areas of concern which may not be immediately apparent to researchers and clinicians. There is, therefore, scope to apply this tool as an adjunct to traditional methods of PPI, for example, when planning research in sensitive fields, such as opioid addiction and medication side-effects, for example, corticosteroids. It may also enhance and encourage research in areas including the impact of rheumatic disease on mental health. In the era of COVID-19 and telemedicine, such a tool provides a quick method of ascertaining public concerns and questions on its use, not only in rheumatology, but also other fields. Finally, as our internet and social media habits change, search query tools which are able to capture phrases used on social media may provide additional information on patient perceptions on healthcare-related topics. This has already been done through applications which are able to capture increased social media activity in relation to disease activity, including pain, but there is scope to extend further to incorporate use of specific phrases [22].

**Limitations**

A key limitation of such a tool is the inability to attribute all searches to a patient body. However, the tool can provide broad indications of public perceptions of a topic, within a given geographical region, e.g. UK. Furthermore, while searches on a topic such as arthritis may not change significantly from one day to another, searches conducted in Google on current and fast-changing situations may do so, which will affect the output from search query tools if conducted at two separate times. A prime example of this is search terms relating to COVID-19. In addition, as described above, search query tools are currently limited in number and can only capture data from the most commonly-used search engine, Google. Search query tools are complimentary, but not identical, to online platforms such as Google Trends which is able to display volumes and patterns of searches on a given topic, but no granularity on the nature of these searches. It is this additional information on extended phrases and questions entered into search engines which may enable their use as an adjunct to traditional PPI. As their utility grows in areas outside marketing, including in healthcare, possibly so too will their scope, including in areas such as social media.
Conclusion

PPI is, and must continue to be, an essential part of research, from inception, to implementation, and dissemination of results. However, we have demonstrated the utility of a search query tool to complement traditional methods of PPI, for example, to conduct scoping searches at a project’s inception, or in addition to PPI, particularly at present, when focus groups may be difficult to convene due to social distancing regulations. Not only are the searches revealed by this tool consistent with known priorities of patients and the public, but they also demonstrate areas which benefit from user anonymity, such as concerns regarding the impact of arthritis on relationships, lifestyle, and work. This has the potential to guide future research questions, increasing the alignment of research priorities with those of the public.

Author contributions All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest or funding to declare.

Informed consent Patient or public involvement was not required for this work.

Ethical approval Ethical approval was not required for this work.

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