Development of a Knowledge-sharing Website for Hypersensitivity Pneumonitis Exposures

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ABSTRACT

Background: Identification of potential inciting antigens known to be associated with hypersensitivity pneumonitis (HP) is integral to achieving a confident diagnosis, its management, and prognostication. A barrier to achieving diagnostic confidence is that evidence for exposure assessment is not presented in an easily accessible or useful format.

Objective: To develop a freely available comprehensive living repository of contemporaneous exposures associated with HP.

Methods: Electronic searches were performed through Medline, Embase, and Web of Science from January 1, 2002, to December 31, 2019, using the following broad MeSH headings: *([allerg* or hypersensitiv*]*, and *adj [alveol* or pneumo*]).mp*. Articles were included if they described adults or children with a diagnosis of HP (as defined by authors) and a description of the causative exposure. Website development used a structured query language database and was powered by WordPress.

Results: HPLung.com is a freely available online searchable repository that lists all exposures and antigens associated with HP and links to their parent studies. Eighty-five unique exposures from 447 citations have been included thus far. The website continues to be updated iteratively. Since its launch in 2019, HPLung.com has been visited over 4,500 times by users from 75 different countries.

Conclusion: HPLung.com is a novel knowledge-sharing tool that addresses barriers of accessibility, contemporaneity, efficient evidence synthesis, and making the best use of technological platforms to improve the exposure assessment of those suspected of HP.

Keywords:
allergic extrinsic alveolitis; interstitial lung disease; farmer's lung; medical education

Exposure Assessment and Antigen Identification in Hypersensitivity Pneumonitis (HP): Identifying the Need

HP is an immune-mediated lung disease caused by inhaled exposure to an inciting antigen (1). HP can be inflammatory and/or fibrotic with a heterogeneous disease phenotype. Patients with nonfibrotic HP may have complete resolution of symptoms and lung function, whereas patients with fibrotic forms of HP may experience irreversible and/or progressive lung fibrosis. Identifying potential inciting antigens known to be associated with HP in the context of certain exposure settings is integral to achieving a confident diagnosis of HP (2, 3) and is also essential for clinical management and optimizing outcomes. The inability to identify a causative antigen is associated with worse outcomes in patients with HP, accelerating lung function decline and increasing the risk of death (4). Thus, antigen identification must be approached in a systematic, comprehensive fashion. Recent guidelines for the diagnosis of HP endorse taking a thorough history to identify exposures as potential causes of HP, recognizing that to date, there exist no validated exposure questionnaires for clinical application (2, 3).

It is frequently stated that there are over 200 different causes of HP (5). Yet a recent scoping review (6) identified a limited number of exposures associated with HP in the recently published literature, highlighting that a data-driven approach allows for the development of contemporaneous, evidence-based exposure assessment resources. A clinician cannot be expected to recall 200 causes of HP to inquire about on history, nor is such time available in most clinical settings. When asking patients about potential exposures and making the link between exposures and potential HP disease, clinicians may rely on memory, clinical questionnaires, patients volunteering information, or resources such as textbooks, websites, or published literature. Many tables of antigens or exposures are appended in HP review articles, but their length and lack of modern context limit their utility. In addition, many published articles require institutional access or are hidden behind a paywall, leading to inequitable access to the community clinician or those in low- and middle-income countries.

We identified a clinical need to provide a freely available comprehensive repository of contemporaneous exposures associated with HP. We thus developed www.HPLung.com with the goal of sharing our data with the broader community to facilitate potential antigen identification in cases of suspected HP. The intent was

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to improve information accessibility with an evidence-informed synthesis of published data. In this article, we describe our approach to developing and maintaining this knowledge-sharing tool, summarizing the data generation, synthesis, dissemination steps, and impact, while noting issues for consideration when creating such a resource. We hope that readers may be inspired by our approach and will gain insight from our lessons learned to develop their respective knowledge-sharing tools.

METHODS

Team Development and Inspiration

The team included members with expertise in systematic review, website development, digital knowledge dissemination, and clinical expertise in ILD, with a shared goal of developing clinically useful resources for HP exposure assessment. This work was inspired by and modeled after Pneumotox.com (7), a drug-related respiratory disease repository developed by Professor Philippe Camus from Dijon, France, who kindly provided tips, potential pitfalls, and ideas for HPLung.com. It was decided to keep the site free of advertising or sponsorship to avoid any potential or perceived conflicts of interest.

Database Development

Electronic searches were developed in conjunction with an academic librarian and performed through Medline, Embase, and Web of Science from January 1, 2002 to December 31, 2019 (*see* data supplement). Articles were screened in duplicate and included if they described adults or children with a diagnosis of HP (as defined by authors), included original data, a description of the causative exposure, and did not overlap with another included study. All study designs

and languages were included. Conference abstracts were excluded. The data are stored in a structured query language database, and the website is powered by WordPress. The impact of the website was assessed by tracking site visits, capturing relevant Twitter hashtags, and performing a gray literature search (for research published outside academic or commercial publications) for the term "HPLung.com". This included screening all Google results relating to the term "hplung.com" and reviewing HP-related American Thoracic Society and Chest guidelines and position statements up to May 7, 2022.

RESULTS

A total of 23,402 citations were screened by two reviewers (H.B. and J.L.), and when consensus could not be met, the citations were arbitrated by a third reviewer (K.A.J.). A total of 338 citations met the prespecified inclusion criteria (up to May 8, 2018) and were included in the initial iteration of the website. An updated search was performed (December 31, 2019), and an additional 59 citations were added (Figure 1).

On the website, antigens and exposures are listed alphabetically and are searchable using the search function. For each antigen and exposure, the number of cases and citations are listed, and a link to the online citation is included (Figure 2).

Since its launch in 2019, HPLung.com has tracked over 4,500 visits by users from 75 different countries, has had over 1,200 Twitter impressions and retweets, and has been cited in Wikipedia, clinical practice guidelines, patient resources, and clinical studies. Contact details are provided on the site for visitors to contact the creators with questions or updated studies that could be considered for inclusion.
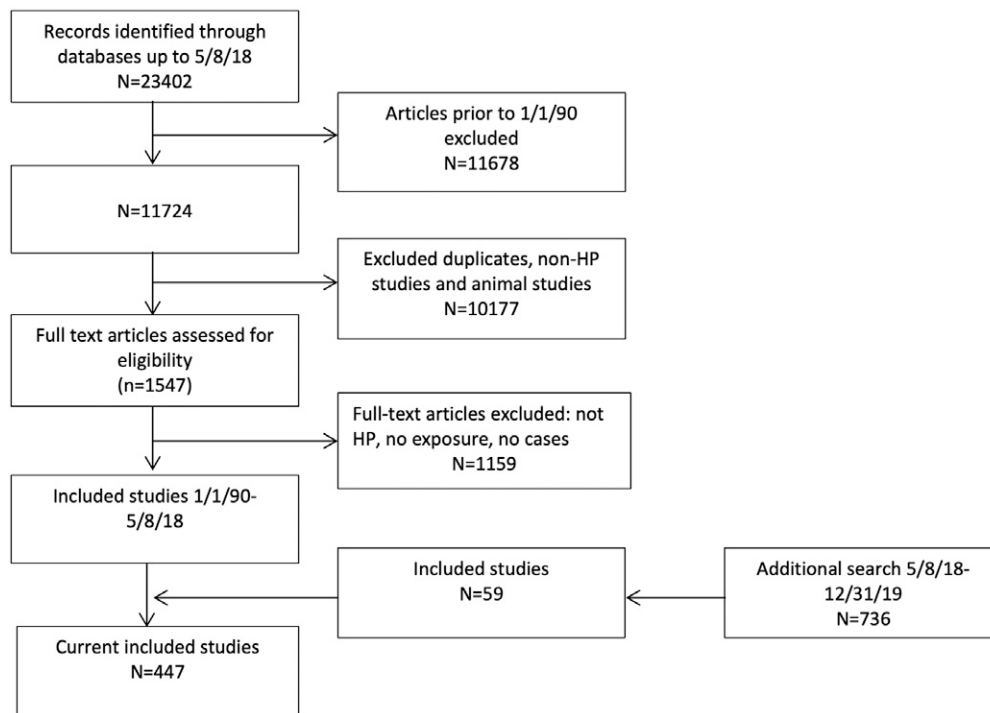
Figure 1. Prisma flow diagram. HP = hypersensitivity pneumonitis.

DISCUSSION

Knowledge Sharing and Accessibility

Effective knowledge translation is an essential but often overlooked component of research. Key barriers to the uptake of evidence in healthcare decision-making include inaccessibility, obsolescence, information overload, and inefficient evidence synthesis that does not make the best use of technological innovations (8). The dissemination of evidence through HPLung.com attempts to address these barriers. Many clinical resources are available only with payment or subscription, whether by an individual or their affiliated institution, limiting accessibility for many clinicians worldwide. This is true of most textbooks, journals, and other clinical resources. Textbooks are physically cumbersome, not readily available, and also require purchased access. As an alternative to a journal article or textbook summarizing the evidence, HPLung.com synthesizes the body of HP exposure literature into a searchable data repository responsive to the needs of clinicians, researchers, and patients.

Aligned with this, HPLung.com is available free of charge, without association with a particular publisher or sponsor. This was a deliberate decision integral to the provision of equitable and unbiased access to clinicians, patients, and researchers who need it most. This, however, presents limitations, as there is a significant cost in time and resources to develop and sustain such a living resource. Unique to such resources is the ongoing cost required to maintain website platforms and update content. Funding bodies and philanthropic programs should consider both discrete project development and ongoing maintenance support of such novel knowledge dissemination resources, which may be accessed by both the clinician for improving diagnostic confidence and patients for exploring the causes of their
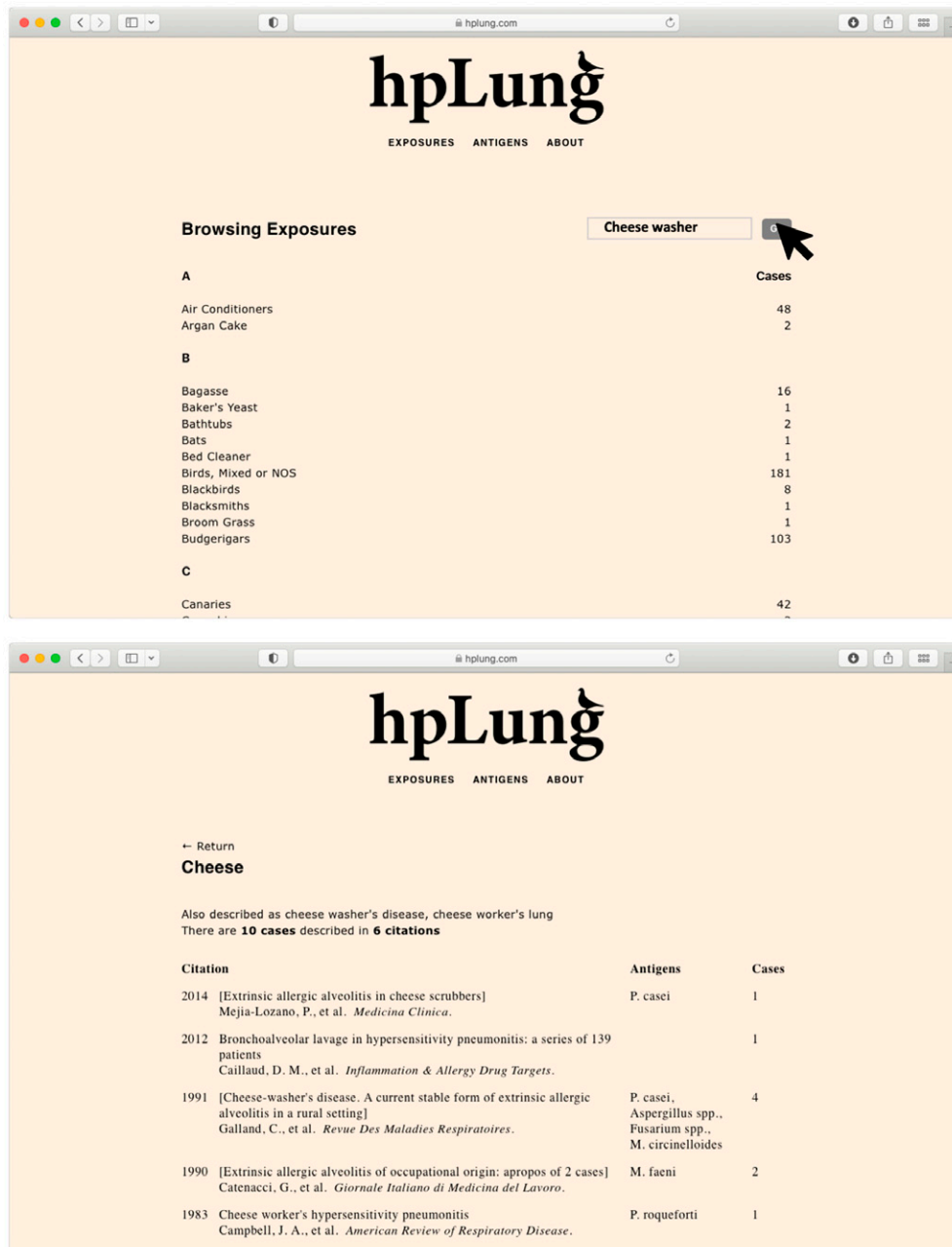
Figure 2. Screenshot from HPLung.com.

disease; otherwise, costs may be prohibitive to develop such resources.

In addition to cost, there may exist legal and/or liability considerations around an online resource providing information that may be incorporated into clinical care. Local and international laws may apply, and disclaimers should be considered when appropriate, with input from formal legal counsel if needed.

Similar evidence synthesis resources that make use of technological innovations have been developed, the most widely known likely being Pneumotox.com, a data repository of drug-induced respiratory diseases. These resources are

beneficial in providing critical information within shorter time frames compared with conventional literature searching (9). In addition to websites, some clinical resources have developed digital applications (apps) to ensure that data are available at the fingertips of anyone with a smartphone, which further increases accessibility.

Beyond clinical resources in respiratory medicine, there is an emerging trend to make research-based data open source, with a key example being the idiopathic pulmonary fibrosis and chronic obstructive pulmonary disease Cell Atlas (10). Open sharing of data has been called for transparency, accessibility, and fostering collaboration in science. This is not yet the norm but may be an expectation in the near future.

A Living Resource

An additional advantage of data dissemination through a resource such as HPLung.com is the opportunity to maintain an up-to-date evidence base. Living evidence (such as living systematic reviews or clinical practice guidelines) not only aims to incorporate new evidence into clinical practice recommendations as soon as it becomes available but also broadens the type of research data able to be included (e.g., real-world registry data) and publish evidence in multimodal digital formats that are readily and easily accessible (11). The site creators will assume responsibility for providing site updates every 2 years to maintain a living evidence base, ensuring its usefulness and contemporaneity. This iterative intention raises important questions about the durability of such resources, recognizing the need for long-term upkeep, commitment, and quality.

Digital Scholarship: Dissemination and Impact

The development of such resources requires consideration of the most appropriate means of dissemination. Journal publications are the traditional means of publicizing new research and impact measured in citation-based bibliometrics. Digital scholarship and digital dissemination use newer digital platforms to search for, synthesize, and disseminate data, representing a paradigm shift away from traditional means. Dissemination of data by social media has been shown to increase citations and societal impact (12). HPLung.com has been disseminated through a range of platforms, such as Facebook and Twitter. In turn, metrics complementary to traditional bibliometrics should be considered a measure of performance and research impact. Altmetrics (alternative metrics) include Wikipedia citations, public policy documents, media coverage, and social media mentions (metrics such as tweetations and twimpact factor) to provide a more comprehensive measure of research influence and impact (13). A challenge in ascribing value to such resources is that they fall outside of traditional metrics and may not be considered as or equated to academic scholarship, given their lack of formal citation. There are evolving metrics in academia to appreciate online content such as Twitter tutorials ("tweetorials"), educational video content, and other nontraditional means of generating and translating knowledge. Recognition of such tools and resources would likely foster interest and motivation to pursue such creative endeavors, and additional consideration should be made by academic institutions as to how to best measure nontraditional academic productivity. In turn, measuring the impact of nontraditional resources can be difficult. We tracked website visits and performed gray literature searches to determine where HPLung.com had been

incorporated into clinical practice guidelines and articles. Further digital health intervention assessment may include surveys of pulmonologists to determine their frequency of use and suggestions for further improvement (14).

Limitations and Future Directions

HPLung.com is of greatest use when the clinician suspects a specific exposure or antigen. It is not a substitute for clinical history taking and does not provide a resource to broadly screen exposures; complementary use of validated questionnaires may be more appropriate in this setting. Clinician discretion is still required to determine if the suspected antigen is causative in the individual patient. Although we used a broad range of search terms, it is possible some relevant citations were missed. We included all studies which met our search criteria and allowed the user to determine the quality and relevance of the study with respect to their particular patient. Future iterations of the website could include quality assessments for each study or groups of studies relating to specific exposures.

Conclusions

HPLung.com is a novel knowledge translation tool using technological platforms for evidence provision. We encourage further discourse on the methods, benefits, and pitfalls of knowledge dissemination and implementation science to encourage

Table 1. Key considerations in knowledge translation resource development

Domain	Key Considerations
Content	Identify the clinical and research gaps, identify and assess currently available related resources, and identify the intended audience
Delivery	Consider the most appropriate platform for content delivery, technological innovations (websites, apps, videos, etc.), consider the end user
Accessibility	Consider platforms most accessible for the intended user, barriers to access, the cost to the user, login requirements, institutional versus single–user access
Responsibility	Consider who is responsible for the integrity of content, legal implications, and required disclaimers (worldwide)
Quality	Included data should be accurate, contemporaneous, and free from actual and perceived conflicts of interest
Maintenance	Consider how to maintain knowledge as an updated, living resource, maintain technology platform functionality
Cost	Initial costs for resource development, ongoing costs for technology platform maintenance, content updates
Impact	Consider how impact and utility will be measured, alternative metrics
Dissemination	Consider alternative means of dissemination appropriate to the intended audience, content, platform, etc.

better dissemination of evidence in respiratory medicine (Table 1). Addressing key barriers of equitability, accessibility, information overload, efficient evidence synthesis, and novel uses of technological innovations should be supported.

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