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## EXPERIMENTAL ETHNOGRAPHY ONLINE

### The asthma files

*This essay describes The Asthma Files, an experimental, digital ethnography project structured to support a collaborative research process and new ways of presenting academic research. While examining ways in which asthma is understood, cared for and governed in varied settings, the project also examines how digital tools can be used to support new research practices, new ways of expressing ethnographic analyses and new ways of drawing readers to ethnographic work. The Asthma Files is an experiment in ethnography, and in science, health and environmental communication. The project responds to dramatic increases in asthma incidence in the USA and globally in recent decades, and to wide acknowledgement that new forms of asthma knowledges are needed. The project aims to advance understanding of the way asthma and other complex conditions can be productively engaged, leveraging ethnography, deep play with interdisciplinarity and deep respect for different kinds and forms of knowledges.*

**Keywords** medical anthropology; digital ethnography; environmental communication; experimental ethnography; interdisciplinarity; asthma

Asthma incidence has increased dramatically in recent decades, making asthma one of the most common chronic diseases in the world. Scientists, physicians and public health officials cannot explain these increasing rates. Indeed, much about asthma remains ambiguous, puzzling and resistant to scientific and clinical resolution. Asthma sufferers and caregivers also struggle daily to make sense of asthma, trying to understand the rhythms of incidence, triggers and effective modes of care and prevention. Researchers can connect asthma rates to social stratification, to increased pollen counts and ozone levels, to declining air quality, to the increased ‘hygiene’ of modern life – but all such connections are partial and

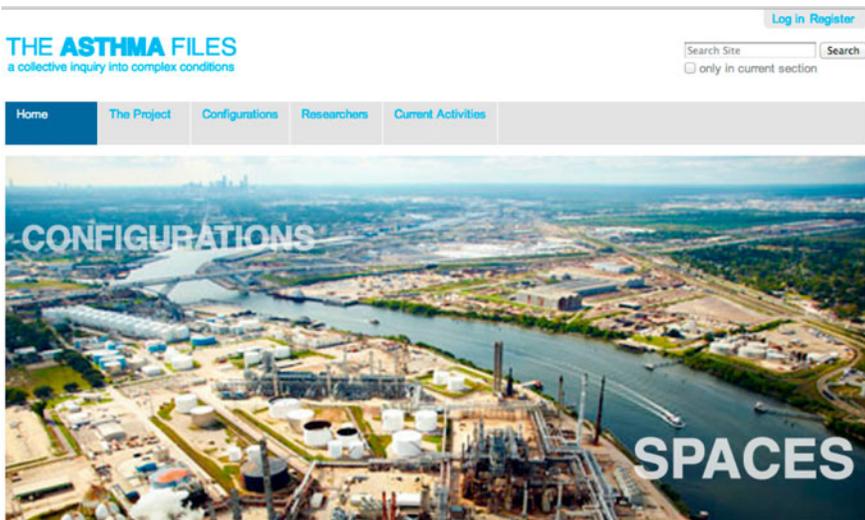
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inconsistent. Researchers from many different disciplines and perspectives, in many different geographic and organizational contexts, have tried to figure asthma out, but it remains elusive. *The Asthma Files*, an experimental, digital ethnography project, brings perspectives from these different groups together, cultivating synergism and comparative insight.

*The Asthma Files* leverages digital tools to animate the comparative cultural perspective that the humanities, and particularly anthropology, are known to offer. In this way, *The Asthma Files* are built around an early finding of the project: that asthma knowledges is fragmented, and there is little connection between people working on different factors in the complex matrix that produces asthma. Air pollution researchers describe themselves as unconnected to biomedical researchers, for example. Many epidemiologists are not familiar with the air quality data-sets that could be drawn into their studies. Geneticists have trouble collaborating with exposure scientists. Asthma parents describe themselves as insufficiently connected to asthma researchers. *The Asthma Files* responds to this disaggregation, aiming to animate new connections, conversations and collaborations.



*The Asthma Files (TAF)* project is structured to support both collaboration among distributed, diversely focused ethnographers and new ways of relating to the people ethnographers work with and write for. *The Asthma Files* is both an experiment in ethnography and in science, health and environmental communication. The project aims to advance understanding of how knowledges about asthma and other complex conditions can be produced and configured, leveraging digital tools to enable new modes of scholarly collaboration within the humanities – and between the humanities and the sciences – and news ways of presenting and disseminating humanities research.

Found online at [theasthmafiles.org](http://theasthmafiles.org), the web platform includes a repository where ethnographers can share materials with each other, and with the varied people they work with, and a suite of tools that can be used to visualize archived material in different ways – in diachronic, timeline form, for example, or as a synchronic collage conveying heterogeneous thought styles and representational forms in a particular time. The web platform also includes a diverse set of asthma ‘files’. Each file is a brief, visually rich, hyperlinked digital presentation that conveys what a particular person, organization, methodology or technology says or has done about asthma. Files are short – what TAF researchers talk about as ‘staccato’ – but with depth. The mode of articulation is meant to allow different kinds of users to engage files and to facilitate movement across files. The file as a genre form and the file structure of *The Asthma Files* writ large are experiments with technology and textuality, working towards ways of configuring ethnographic analyses attuned to complex problems and shifting conditions of production.

While examining ways in which asthma is understood, cared for and governed in varied settings, *The Asthma Files* also examines how digital tools can be used to support new research practices, new ways of expressing ethnographic analyses and new ways of enrolling audiences in the process of ethnographic knowledges production. The project aims to advance understanding of how knowledges about asthma – and other complex conditions – can be produced and configured, leveraging ethnography, deep play with interdisciplinarity and deep respect for different forms of knowledges (Geertz 1973). A key goal is to involve people in the ethnographic research process, such that ethnography becomes an ever-evolving space for deliberation and collective evaluation of complex conditions. We are thus challenged to think about what *The Asthma Files* can become – for our asthma-focused research group, but also for others invested in new forms of scholarly work and publishing.

## Points of departure

*The Asthma Files* project is collaborative by design and in practice; our core group – what we call the ‘installation crew’ – includes Kim Fortun, Mike Fortun, Erik Bigras, Brandon Costelloe-Kuehn and Tahereh Saheb at Rensselaer Polytechnic Institute (RPI), Dan Price at the University of Houston, Jerome Crowder at the University of Texas Medical Branch at Galveston and Allison Kenner at Drexel University. Over the last few years, over 20 other researchers – many undergraduates and graduate students at RPI, but also a number of others – have contributed to the project; still others have voiced interest. *The Asthma Files* maintains an open call for new collaborators.

Researchers have come to *The Asthma Files* from many points of departure; the project is designed to be enriched by the diversity of perspective and experience among involved researchers. Kim Fortun’s point of departure, for

example, was recognition of the entangled scientific and political, informational and representational challenges of environmental health. Mike Fortun came to the project from long-standing study of the science and politics of genomics, interested in how scientists were thinking about complex conditions (such as asthma), and designing new protocols for understanding gene-environment interactions. Dan Price came to the project from philosophy, interested in fundamental problems of knowledges stemming from Hegelian constructs of truth and subjectivity. Jerome Crowder, a medical and visual anthropologist, represents the humanities in a biomedical research group focused on severe asthma. Erich Schienke, a Science and Technology Studies scholar focused on research ethics and informatics, has become the Plone developer for *The Asthma Files*.

Brandon Costelloe-Kuehn came to *The Asthma Files* with interest in experimental media and arts, which led to a dissertation focused on experimental environmental media systems. Erik Bigras came to the project with interest in ways digital technologies shape practices and subjectivity, and is writing a dissertation focused on different digital platforms (including the TAF platform) designed to address air quality issues. Tahereh Saheb came to the project interested in public health across national contexts. *The Asthma Files* thus provides a structure for collaboration without asking researchers to work in lock-step. There are many corners to occupy and angles to pursue.

As the etymology of collaboration [Latin, *con-* ('with') + *labōrō* ('work')] suggests, it can be laborious. Patience is required and can only be sustained through interest in the experiment and politics of it all. The politics of open-access publishing are embedded in the project, along with the politics of health and environmentalism, all laced with the politics of knowledges. Investment in the experiment extends from restless dissatisfaction with entrenched knowledges forms – particularly for addressing health disparities, environmental stressors and other phenomena resistant to simple, mechanical explanation. Investment in the experiment also extends from the concerns of *Writing Culture* (Clifford and Marcus 1986), which taught how the form of any articulation – ethnographic or otherwise – over determines what is said, what is sayable and what is not. Experiments with *The Asthma Files* can thus be conceived as experiments in textual form – in the manner experimental ethnographers are accustomed to, oriented by insight from literary, feminist, postcolonial and related theory, focused on the ways language works, subjects are formed and power is exercised.

We have taken care to design a digital platform and research process that reflect theory that has oriented critical cultural analysis in recent years – with hopes of research outcomes that move us towards new cultural insights, as well as towards new ways of thinking about, practicing and presenting ethnographic analyses. The aims are thus methodological as well as empirical and theoretical, and work towards new relationships between the methodological, empirical and

theoretical. The aims are also textual, technical and performative. A critical part of the experiment is with digitization – with what ethnographic texts can become online.

## Project design

In *The Asthma Files* experiment with collaborative research practice, a key dynamic turns audiences into users of the system, involving them in the ethnographic project; the difference between research practice and presentation has thus been continually blurred. What TAF researchers once thought of as ‘backstage’ has increasingly become a space where we invite ‘informants’ to join us, to look at and comment on found material, preliminary analyses and points of comparison. Carefully scripted texts remain centre stage – in the form of ‘files’, organized into file drawers – but these serve as portals to the continuing analysis behind. This structure is a way to remain invested in both the literary work of scholarship – a signature of experimental ethnography – and in categorically different ways of thinking about and staging ethnography.

*The Asthma Files*’ backstage includes a repository where users can store and share materials, and a suite of tools that can be used to compile, configure and visualize material in different ways. The repository contains materials found or produced by ethnographers and those they work with. There are images with analytic captions, video-recorded interviews, news articles and a large selection of scientific articles, many with ethnographic annotations. The repository also includes field notes, both individually and collectively produced. Our goal is to make it easy for ethnographers to share material and work through it collaboratively. As the project develops, we will test a range of digital tools for visualizing ethnographic material – some developed for natural science data, some for policy arenas, some for geographers and historians (often involving Geographic Information Systems), and some developed within *The Asthma Files* specifically for ethnographic analysis, oriented by critical theory as well as well-honed fieldwork techniques. Digitization allows ethnographers to easily build and overlap timelines, for example, and to work with images – a photograph, a table from a scientific paper, an advertisement – as windows into larger phenomena, hyperlinked to realize depth of perspective.

*The Asthma Files*’ front stage showcases asthma files, organized into thematic drawers, which create space for different kinds of analysis and framing. The aim is to leverage the capabilities of a digital platform to enrich cultural analysis – approaching phenomena from many different angles, enabling comparison and creating depth through links offsite. A digital platform supports this differently than printed text, film or museum installations.

An asthma ‘file’ is a genre experiment with what digitization enables. Each file is short – staccato or aphoristic in the Nietzschean sense – but multi-dimensional and porous, rich with links to supporting material and other analyses,

including other asthma files. File-to-file connections support what TAF researchers think about as a juxtapositional practice and logic. Insight is meant to intensify as different files are laid side-by-side – continually, kaleidoscopically.

Two ‘cabinets’ of files in *The Asthma Files* are methodological, providing framing for the project. Files that describe ‘substantive logics’ describe contemporary conditions that make the project intellectually and politically important, often describing what we have come to think of as ‘discursive risks’. Prevailing regimes of asthma care and education are oriented to produce a medically compliant, inhaler-ready patient, for example. While compliance with an asthma management plans can be a matter of life or death, this orientation is nonetheless limiting, discounting other ways of caring for asthma – through air quality regulation, for example. This ‘substantive logic’ is thus something *The Asthma Files* documents, and also seeks to displace.

Our substantive logics thus motivate us and allow ethnography to ‘loop’: what we learn in the project about the discursive tendencies, gaps and risks around asthma are fed back into the project, making it a representation of asthma as a complex problem and a critical response to the specific dynamics of the problem (Fortun 2012).

*The Asthma Files’* ‘design logics’ do a different kind of work. These logics are drawn from social, literary and aesthetic theory. Curating files of design logics allow theoretical ideas to animate without overdetermining *The Asthma Files*. One of our design logics is drawn from Derridean historian of biology Hans-Joerg Rheinberger’s conception of how experimental systems work in the sciences, as a play between limits and openness (Rheinberger 1988); another is drawn from James Clifford’s writing about how juxtaposition works in surrealist art and in ethnography (Clifford 1981). Yet another is drawn from Gregory Bateson’s description of what happens when different scales or orders of communication collide, sometimes producing pathology, sometimes creativity (1956/2000).

Centre stage in *The Asthma Files* are sets of files describing asthmatic spaces and asthma knowledges. Files describing asthmatic spaces focus on different countries, cities, neighbourhoods and communities. Houston and Manhattan have been key foci; plans are under way to develop analyses of Tehran and Los Angeles as ‘asthmatic spaces’. The ‘asthma knowledges’ cabinet includes files, organized into drawers, focused on how asthma has been accounted for, cared for, communicated and experienced and on different sciences of asthma – all returning to a set of questions that draw out genealogies of thought, language and practice.

The ‘accounting for asthma’ drawer, for example, focuses on how different organizations – international, state and local government agencies; pharmaceutical companies; patient advocacy groups – define asthma, track its prevalence, explain its occurrence or justify approaches to its care. There are also files about innovative asthma-accounting projects carried out by researchers

and artists affiliated with *The Asthma Files*. The ‘sciences of asthma’ drawer gathers different perspectives on the aetiology of asthma, examining what different people and organizations say are the causes, mechanisms and triggers of asthma. It includes files on scientists from numerous disciplines – geneticists, immunologists and epidemiologists, for example. In the future, we hope to create files that examine how asthma is understood in diverse traditions of medicine, such as ayurveda, homoeopathy, Chinese medicine and urani.

The ‘caring for asthma’ drawer includes files that describe diverse ways of caring for asthma, through different medical regimes, but also through efforts to understand and prevent asthma. Files profile how air pollution researchers are motivated by public health concerns, for example, and how community and parents groups mobilize to understand and address asthma. The ‘communicating asthma’ drawer examines a wide variety of educational and advertising media. Files examine television commercials funded by pharmaceutical companies, computer games designed to help children manage their asthma and scientific communication intended to shape public understand and policy. The ‘communicating asthma’ drawer also includes files about innovative asthma communications projects carried out by researchers and artists affiliated with *The Asthma Files*. The ‘experiencing asthma’ drawer includes files that describe what it is like to have an asthma attack, the challenges of keeping asthma ‘under control’ and what it feels like to be close to someone with asthma.

The structure of *The Asthma Files* thus provides space for many different kinds of work, aiming to draw ethnographers and other kinds of users together in new ways, experimenting with what ethnography can become online. This file drawer structure is also expandable, and it can stand, structurally, even without content. In other words: we have made space for collaborators we do not yet have. A collaborator that would develop files on China as an asthmatic space, for example, or one who would focus more on clinical engagements than any of us now in the group. The file drawer structure will allow the project to evolve and transform, without falling apart. We can add new themes – new drawers – and we can let drawers sit unattended, as our attention is directed to new issues.

*The Asthma Files* is thus an open source on many registers, including the technological. The web platform uses an open source Plone content management system; the suite of analytic tools is ever evolving and any tool can be taken up and reconfigured in ways that makes user-sense; and drawers can be re-thematized to match the interests of a new research group. The list of questions that shape files, and the digital objects that make them up, can be extended or displaced. The structure is designed to be stable, yet remain in play.

But the material will be archived, in a format that is easy to return to, to add new layers of analysis, to add links to new asthma files, etc. This archival sensibility – that admits the way analytic techniques change and the value of

re-analysis of old data – is something we have observed and learned from other scientific fields. *The Asthma Files* builds on their example.

## Results, use cases and performative effects

What I've been interested in are collective creations rather than representations. There's a whole order of movement in 'institutions' that's independent of both laws and contracts ... What interests me isn't the law or laws (the former being an empty notion, the latter uncritical notions), nor even law or rights, but jurisprudence. It's jurisprudence, ultimately, that creates law, and we mustn't go on leaving this to judges ... People are already thinking about establishing a system of law for modern biology; but everything in modern biology and the new situations it creates, the new courses of events it makes possible, is a matter for jurisprudence. We don't need an ethical committee of supposedly well-qualified wise men, but user-groups. This is where we move from law into politics. (Deleuze 1995)

*The Asthma Files* project has many dimensions and aspirations – empirical, analytic, theoretical, textual, performative and political. The 'results' of the project are both traditionally ethnographic and something different. While we have come to new *conclusions* about the ways in which asthma and other complex conditions become objects of concern, knowledges and action, we also have worked to animate an ongoing *process* for dealing with complex problems in new ways, leveraging ethnographic technique and insight, building out online possibilities.

An online platform allows *The Asthma Files* to pull together many different perspectives on asthma, facilitating movement between them. Asthma becomes a powerful site for understanding the differences within the sciences, among health care professionals, among different kinds of activists and among affected people. It is possible to see quite radically different constructions of causality, analytic precision and robust knowledges. Simple binaries – like those between 'experts' and others – are destabilized, even as we learn more about hierarchies of knowledges, not only between certified experts and others, but also between experts from different disciplines.

It is also possible to see, map and visualize the myriad factors that make different places different as asthmatic spaces. Political structure and culture make a difference, of course, in specific ways. The political sway of the petrochemical industry is formative of Houston as an asthmatic space, for example, affecting data availability, the actors involved in the conduct and funding of research and the range of air quality interventions under consideration. Los Angeles is configured very differently, while continuing to compete with Houston as a smog capital, and as a city infamous for resolute car culture. An analytic challenge is to discern the

many entangled forces that make Houston and Los Angeles similar – and different – as asthmatic spaces.

Analytically, one also sees that the knowledges in play in efforts to understand asthma is not just substantively different, but also structurally different. They are ordered and oriented differently – attending to different scales of analysis, leveraging different types of comparisons and analogies, including different stages and variables. It thus does not make sense to simply compare and rank these knowledges, some as more true than others. They are not part of the same set, as Bateson would argue, creating communicative dissonance and double-bind (Bateson 1956/1999).

Theoretically, then, *The Asthma Files* illustrates how language and knowledges work in the context of complex problems, undercutting habits of thinking that assume and valorize shared understanding and consensus. Collaboration, *The Asthma Files* demonstrates, is far from straightforward, but nor is it impossible. People think, speak and generate data within particular discursive formations and genres, which often do not make sense to people operating elsewhere. But sense can nonetheless be made – created – through encounters that configure subjects differently. Our experiment is with ways in which digital platforms can stage such encounters.

The call, then, is for [research(er)] subjects capable of letting something really unexpected emerge, and for structured spaces – platforms – that give such subjects room to move. People, however situated, and even more so if certified experts, approach complex problems with particular discursive habits – habits that, by definition, are not up to the challenge of complex problems. Long-cultivated expertise is required, but also something beyond, something that a metaphysics of presence cannot produce or abide. People thus need to be pulled into deep play with a problem, beyond what makes entrenched sense. Encounters with asthma and other complex problems can then be aleatory, underdetermined by established hierarchies of sense and sensibility. Space for collaboration also opens up – a way of relating that does not require a shared metaphysics.

*The Asthma Files* thus demonstrates the need for structures that let objects of concern emerge, underdetermined by already-knowing subjects. Knowledges of asthma and other complex conditions, *The Asthma Files* suggests, must and can emerge discursively, in a way a carefully designed digital media system can support.

We have designed *The Asthma Files* to study, embody and animate these ideas about how knowledges can work – queerly, leveraging rather than seeking to resolve difference, systematically open to new connections. There is, in our view, a critical political need for this kind of experiment, which promises a different kind of knowledges, built on different modes of collectivity, than what we have become accustomed to. ‘Collective creations’ produced by and re-constitutive of ‘user groups’ instead of ‘ethical committee[s] of supposedly well-qualified men’,

argues Deleuze, will help jurisprudence flourish and better jurisprudence – deliberate and deliberative creation of new knowledges and practice – is what asthma and other complex conditions need.

## Towards kaleidoscopic reflexivity

We pursue *The Asthma Files* aware of long-standing effort, often experimental in tenor, to integrate new technologies and media into the work and expression of cultural analysis. Gregory Bateson and Margaret Mead's stunning work with photography – as both a research tool and means of conveying their analysis – comes immediately to mind (Bateson and Mead 1942, Jacknis 1988). The history of filmmaking in the conduct and expression of cultural analysis has also laid important ground, generating impressive methodological debates and innovation, and a body of work that literally provides different angles on matters of interest and concern to cultural analysts. Films do not and cannot provide the same kind of analysis that a written text provides, and this is why they are important. So, too, with acoustic recordings and material collections. They make different kinds of sense and each has critical value; however, medium matters.

Digital tools and modes of presentation add still other possibilities for getting at and sharing understanding of how 'culture' works – in historical, geographic, political economic and media context – always in need of deeper or alternative ways of understanding. Bateson's *Naven* is thus also a key reference, demonstrating what is gained through parallel processing of particular phenomena through different analytic frameworks (Bateson 1936/1958). Technologies also frame phenomena differently. Employing different technologies in the work of cultural analysis also enables insight through comparison of different ways of seeing and understanding 'the same thing'. Such multiplication of techniques also stimulates the reflexivity so critical to the health of all communities of practices, – including those involved with cultural analysis. Taken together, it is easier to see how a particular cultural frame or technology foregrounds some dimensions of a phenomenon while foreclosing others and are historically sedimented – carrying habitual ways of thinking and doing things, laced with methodological and representational norms. The goal could be described as kaleidoscopic, both within *The Asthma Files* and within the broader effort to enrich cultural analysis through use of an ever-evolving array of techniques and technologies – which, together, multiply perspective, give texture to insight and animate reflexivity.

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