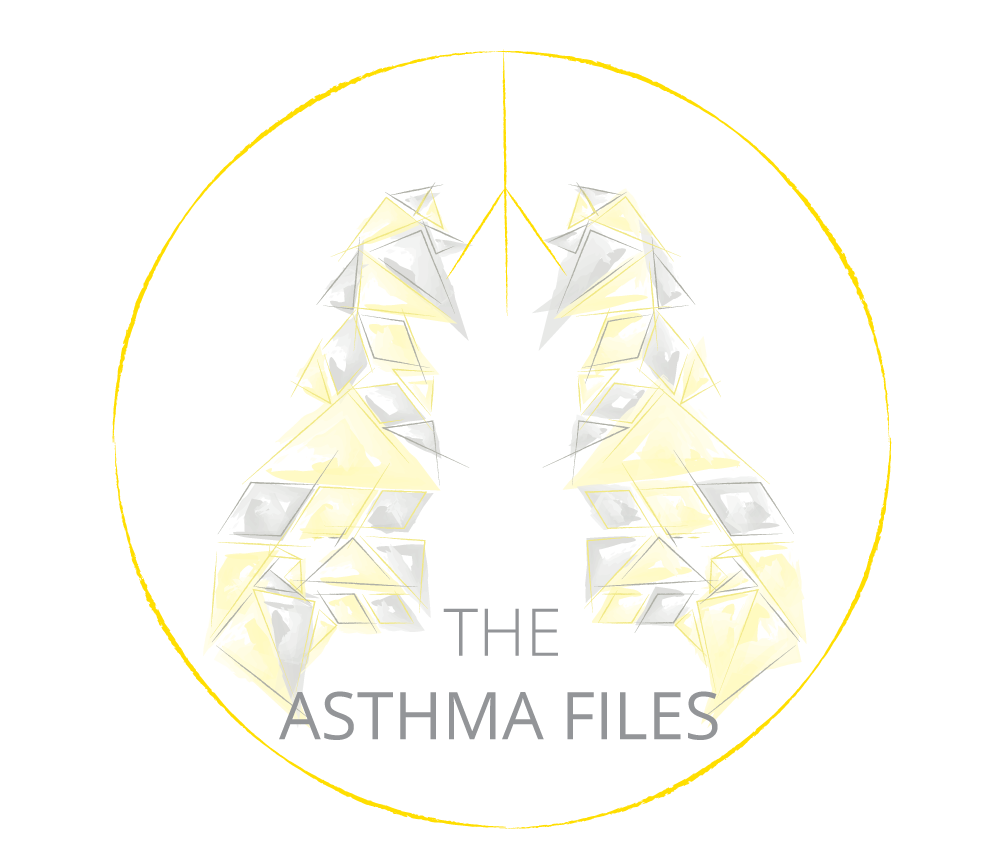
**THE ASTHMA FILES**

**a collective inquiry into complex conditions**

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**draft April 30, 2015**

**-CALL FOR COLLABORATION-**

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**The Asthma Files**

# Project Statement and Call-for-Collaboration

The Asthma Files (TAF)  is a collaborative ethnographic research project designed to advance understanding and efforts to address environmental public health challenges around the world.

 Focusing on dramatic global incidence of asthma and other respiratory illnesses as a starting point, the project spirals out to address growing concern about the health impacts of air pollution and associated need to build scientific, clinical and public health capacity to address environmental determinants of human health.  Through ethnographic interviews and analysis of scientific publications, policy debates, and media coverage, the project draws together many different ways of approaching environmental public health, aiming to enhance comparative and collaborative perspective.

A key aim is to develop comparative understanding of different styles of both environmental health research and environmental health governance, in different urban and national settings. The project will result in a theoretically robust, empirically grounded conception of (environmental health) research and governance styles, detailing and categorizing different ways of developing environmental health data, advancing the sciences of environment and health, and directing these toward governance of complex problems.  The project builds on work in the history and anthropology of science on how “thought styles” shape scientific research, and extends it to sociocultural analysis of “governance styles.” Project findings will support enhanced collaboration between environmental health research communities and governance regimes.

# Project Rationale

Staggering rates of asthma occur in very different settings around the world, exacerbated by an array of triggers, involving tangled natural, technical and social systems. Responding to asthma (and other complex conditions) requires extraordinary coordination of both intellectual and operational activities. Focusing our study on how people, communities and organizations have responded to asthma and environmental health more generally has thus been both methodologically challenging and promising. Through a focus on asthma, we have dealt with many different kinds of data (original recordings of interviews, found media, pharmaceutical advertising and educational material, historical documents, etc.) and have encountered real challenges in ethnographic collaboration: the need to share extremely heterogeneous primary material in a manner that makes sense to diverse researchers, the need for analytic annotation of material so that the archive can become meaningful in diverse ways; the need for genres of writing through which qualitative scholars can share their work as it progresses; the need to link jeweler’s eye level analyses (in varied settings) to systems levels analyses; the need for ways of describing a complex scholarly project and its findings to diverse audiences, which can be articulated by researchers in different contexts and at different career stages. *The Asthma Files* project has involved senior researchers across the United States, PhD students, undergraduates and high school interns. A key aim (and success) of *The Asthma Files* has been to create structures within which students at all levels can be involved in the research collaboration. Another key aim (and very preliminary success thus far) is to create structures and forms of representation that will draw diverse users to ethnographic scholarship.

# Project Structure

TAF includes an archive, space for online collaboration, and various forms for publication.

The TAF archive includes bibliographies, photographs, found documents, fieldnotes, recorded interviews, and other material collected by ethnographers – with options to share in delimited or fully open ways, with metadata that provides contextual information and guidelines for attribution. The archive also provides access to varied observation and interview templates that can be used to produce artifacts. See a list of currently available templates below. All materials original to The Asthma Files are licensed in the most open manner possible.

The Asthma Files also provides space where groups – large or small, private or public -- can collaborate, drawing on various evolving analytic structures developed to facilitate collaboration within the project. There are structures for annotating texts and interviews, for example, and structures for addressing shared questions about diverse asthmatic spaces and knowledge’s. There are also structures for addressing sub-themes; there are analytic structures to guide assessment of the many technologies and technology users related to asthma, for example. There are structures addressing questions central to a particular user’s project, and for addressing questions central to the larger collaborative project. The project is designed to support many different focused projects within a larger project structure, facilitating collaboration, project integration, and the capacity to read and think across cases without undermining the individual project specificity that is so important to ethnographers, and to their larger, cumulative body of research.

The Asthma Files encourages experimentation with a number of different genre forms. Timelines offer a temporally organized frame for images, video, and extended texts, with hyperlinks. Photo essays work with images – photos, data visualizations, drawings, etc. – to draw readers through a topic. The “PECE file” is a collage of artifacts, analytic text, and images, with links to other files, to material in the project archive, and to other Internet resources. The PECE file is an experimental genre form designed to leverage digital capabilities in ethnographic writing, supporting non-linear, expansive, but deep engagement with a topic. PECE files, timelines, and other publications become part of the project archive, and can be featured in online exhibits. All publications are open access, and designed to be reformulated in other genres (with attribution when material is shared among users).

## Research Threads, Questions and Substantive Logics

To advance its aims, The Asthma Files is designed around four interlaced research threads – focused on asthma knowledges, spaces, care, and governance – approaching the challenges of asthma and environmental public health from different angles, together generating complex perspective. The four research threads are shaped by overarching research questions for the project, which are bolstered by the array of sub-questions asked by different users and groups associated with the project.

These questions are overtly addressed by all interested users, through participation in groups focused on this level of analysis. The TAF spaces group, for example, strives to characterize environmental health challenges and their “governance styles” across different geographic spaces – drawing on analysis of environmental health conditions in different cities and regions around the world. A group focused on Beijing as an asthmatic space, for example, may in turn draw on the work of a group focused on innovative asthma and air quality visualization projects. Together, different groups both substantiate and animate new insight into the problems and potentials of environmental health governance.

Further grounding for The Asthma Files is provided by an ever growing and iterating set of what we call “substantive logics” – reasons why the project is important in our current historical moment. Dramatic increases in asthma rates in most areas of the world is one substantive logic, for example. The tendency to care for asthma with pharmaceuticals rather than through preventative measures is another substantive logic, pointing to the pressing challenge of integrating new understandings of the human health impacts of air pollution into public health programming. Our substantive logics are worked on by the TAF substantive logics group, and published as a photo essay on the TAF site.

## Design Logics

The Asthma Files runs on the Platform for Experimental, Collaborative Ethnography (PECE), an open source (Drupal-based) platform customized for ethnographic research. PECE is designed to be used by an array of research groups, helping build out a rich ecology of interoperable digital projects that link researchers in different fields, and with diverse stakeholders. The Asthma Files was the original project from which the broader effort to build PECE emerged. PECE is thus shaped by the empirical demands and theoretical tenets of experimental ethnography. The platform design emerges from concrete ethnographic practices and (newly invented) collaborative work flows, inflected by poststructural understandings of language, meaning and knowledge. PECE’s “design logics” are meant to stay on the surface, open to debate and revision. This effort is sustained by the PECE design group, on PECE’s own platform. PECE’s design logics are thus built from and into The Asthma Files, and platform users are encouraged to continually help develop them.

## Governance

The Asthma Files is run by a design group with both permanent and rotating membership, led by Professors Mike Fortun and Kim Fortun at Rensselaer Polytechnic Institute, Troy, NY, USA.

In addition to The Asthma Files design group, the project enrolls lead curators across the project’s different threads of research.

The Asthma Files maintains an open call for collaborators interested in both existing and new lines of analysis. Interested researchers are asked to submit a short (200-400 word), informal proposal indicating the proposed focus of work, a timeframe, materials to be collected, publication goals, and interest in different forms of collaboration. A proposal template is available in the project archive. Proposals should be submitted to [TAFdesign@gmail.com](mailto:TAFdesign@gmail.com). Questions about the project and potential collaboration are also welcome.

# Research Questions

The Asthma Files project is driven by four guiding questions:

1. *What animates and delimits different forms of asthma knowledge?*
2. *What engenders and undercuts different forms of asthma care?*
3. *What raises and lowers asthma incidence in different spaces?*
4. *What forms of knowledge, care and governance best attend to the complex problem of asthma?*

# PECE Platform

The Asthma Files is one instance of the Platform for Experimental, Collaborative Ethnography (PECE).

PECE:

1. Is designed to be shared with other humanities and social science research groups once customized and stabilized, helping build out a rich ecology of interoperable digital projects, positioning humanities and social science scholars in the broad effort to leverage digital capabilities to support peer reviewed, open access scholarship.
2. Is built with Drupal, an object-oriented, open source database management system, which provides flexibility and the capacity to deal with the complex, open-ended data characteristic of ethnographic projects.
3. Functions as a portal to a suite of open source tools useful for humanities research, including tools developed in data science for other scientific communities.
4. Provides a place to archive and share primary data generated by humanities scholars, particularly ethnographers.
5. Provides a space for and facilitates analytic collaboration among humanities scholars, and experimentation with diverse analytic models.
6. Provides an opportunity to experiment with new forms of peer review for humanities research.
7. Provides opportunities to develop and evaluate new, digitally-enabled genres forms and ways of expressing humanities research.
8. Enables humanities scholars to experiment with and better understand digitally-mediated collaboration and interdisciplinarity.
9. Provides opportunities to involve students in humanities research as it progresses.
10. Is designed to quicken the public availability of humanities research, in an open access form

# Routes of Collaboration

The light structure of the project affords collaborators the opportunity to engage with any material at any point in the research. In order to bring experts and students from a wide variety of fields together, a group research structure was put in place to give space and shared resources to researchers studying similar phenomena within the world of asthma. After joining a group, collaborators may choose to Contribute Data, Analyze Data, or Compose Data.

Contributing data consists of uploading artefacts (news reports, studies, photographs, etc.), adding a bibliographic entry, conducting interviews or engaging in critical observation. Analyzing data takes place in many forms. After artefacts are shared, collaborators may use any of a variety of premade structured annotation templates to engage with the material and other researchers on the site. From there, users are encouraged to begin answering the shared analytics for spaces, knowledges, care, and governance. Shared writing is a critical utility in the analytics of the site. The shared writing space allows for researchers of varying backgrounds to converge over writing about the same topic. The site allows users to experiment with various methods for sharing their research. Timelines, photo essays, memos, and actual asthma files are all digital genres to allow for rich cross-disciplinary understanding for a particular research question.

**these actions may be carried out in any order using one’s own research material or material found on the site**

**jumpstart**

**collaborating with *The Asthma Files***

**join the site**

http://theasthmafiles.org/

username: firstnamelastname

initial password: test123

**The Asthma Files is one instance of the Platform for Experimental, Collaborative Ethnography (PECE)**

**contribute**

**download Zotero**

-Complete the tutorial

-Join *The Asthma Files* Group

https://www.zotero.org/groups/theasthmafiles/

Add a **bibliographic entry** to Zotero

*all artefacts may be tagged with key themes, people, or locations*

add an **artefact**

-Website

-Interview

-PDF

-JPEG Image

-Video

-Audio

-elicitation structure

**join or make a group**

**analyze**

current **elicitation structures** include:

-interview templates for asthma patients, physicians, scientists, etc.

-observation guides for asthma technology users

*A PECE file is a form of composition that leverages digital capabilities to draw readers into diverse content analysis*

group publication page

photo essay

**compose**

**explore**

**explore**

-groups

-tags

-artefacts

-bibliography

-timeline essays

-photo essays

-asthma files

-aggregated annotations

timeline essay

current **explication structures** include:

-basic structure for close reading

-*structures for explicating* asthma knowledges

-asthma spaces

-asthma care

PECE file

# Analytic Structures

## Analytic Structures *Basic Annotation*

*What artifact is being annotated, and who created it?*

*Why was the artifact added to the TAF archive?*

*What three quotes capture the critical import of the artifact?*

*What is the main argument?*

*Describe at least three ways that the main argument is supported.*

*Describe the main literatures or traditions of work that the artifact draws on and contributes to.*

*Describe practical initiatives described or called for by the artifact.*

*Explain how the argument and evidence of the artifact can contribute to TAF’s overarching research questions (about asthmatic spaces, knowledge, care and governance)?*

*List details or arguments that will help advance your particular thread of work in TAF.*

*Describe what the artifact prompts you to follow up on.*

## Analytic Structures *Asthmatic Spaces*

***Characterizing Asthmatic Spaces***

*What are signature characteristics of this area as an asthmatic space?*

*What are notable air pollution governance characteristics of this area?*

*Is there a record of environmental injustice? Is the area thought of as an asthma hotspot? Who are the stakeholders?*

*What spatial units (cities, counties, provinces, regulatory regions, etc.) are important in this area?*

*What examples illustrate the dynamics of environmental health governance in this space?*

*What other examples of governance in this space point to a signature governance style?*

***Accounting for Asthma***

*How prevalent is asthma, and who is tracking asthma prevalence?*

*What are the costs of asthma to families affected by asthma, to government, to businesses (in lost work days, for example)? Who is producing this information?*

*How has asthma been covered by local media? Where have causes of and responsibility for asthma incidence been placed? What interventions have been highlighted?*

*What kinds of civic organizations (environmental groups, caregivers groups) are involved in asthma surveillance and care?*

*What kind of research has been done on environmental health issues in this area, and what are the findings?*

*How have global concerns about environmental equity and health disparities shaped local research, and the use of research in governance?*

*How has science relevant to environmental public health moved into law and policy?*

*What has shaped scientific practices and culture in this space? Have scientific practices and culture shifted in recent decades?*

*What hierarchies have emerged between different research communities and the modes of evidence they produce, what accounts for these hierarchies, and how does it impact the use of science in governance?*

***Causes of Asthma***

*What cultural, social, political, economic, ecological and built features of the area may contribute to asthma patterns?*

*Are there notable occupational drivers of asthma in this area?*

*What is known about air quality and dynamics?*

*What information is available to assess cumulative community risk?*

***Experiencing Asthma***

*How do different people in this area experience asthma?*

*How have people integrated experiential knowledge with other kinds of knowledge?*

***Caring for Asthma***

*What forms of medical care are available (and not) to people suffering from asthma?*

*What forms of asthma education (in schools, for example) exist, and what is their orientation?*

*Who regulates environmental triggers of asthma, and what is their record and reputation?*

*What programs are in place to measure and mitigate asthma triggers in this area?*

***Histories of Asthma***

*How have asthma rates in this area changed since 1985? Since 1945?*

*Are there new treatments for asthma? How, over the last decades, has medical care for asthma changed? Have traditional medical practices been overtaken by modernized practices?*

*Have government agencies changed the way they conceive and respond to asthma?*

*Are there new civic organizations working on asthma?*

*Has concern about climate change shaped the way asthma is understood and addressed?*

***Changing Asthmatic Spaces***

*What kinds of policies and enforcement could change asthma incidence?*

*What would improve asthma care and education, and how could this build on existing infrastructure?*

*How could The Asthma Files project help mobilize positive change in this area?*

## Analytic Structures *Asthma Knowledges*

***Identifying Asthma Knowledges***

*What person, group or organization is being profiled, and why are they of interest to The Asthma Files?*

*What have they done – through research, or a particular way of documenting or caring for asthma, for example-- that illustrates how they conceive of the causes, triggers and management of asthma?*

*What timeline of events illustrates how this way of thinking about asthma has developed?*

***Characterizing Asthma Knowledges***

*What causes, mechanisms, triggers and dynamics of asthma are identified or presumed by this way of thinking about asthma?*

*Does this person, group or organization claim to have a new or unique way of thinking about asthma? Does this approach point to or suggest problems with other approaches?*

*What studies have they done to further their understanding of asthma? How were their studies designed?*

*What data (including experiential data) was collected or used to support or explore their way of thinking about asthma? What visualizations of this data have been created?*

*What relationships and types of causation are drawn out in this way of thinking about asthma?*

*What kinds of technology and infrastructure enabled this ways of producing asthma knowledge?*

*What kinds of social collectivity have shaped or enabled this way of thinking about asthma?*

*How does this person, group or organization make use of data and findings generated by others – in other scientific disciplines, in other municipal or national contexts, etc.?*

*Has this person, group or organization devised ways of testing their asthma knowledge, or ways to pursue new asthma knowledge?*

*How can the thought style of this person, group or organization be described?*

## Analytic Structures *Caring for Asthma and Environmental Public Health*

*What person, group or organization is being profiled, and why are they of interest to The Asthma Files?*

*What have they done – through research, or a public health program or education forum, for example-- that illustrates how they have worked to improve environmental public health?*

*What timeline of events illustrates how this way of addressing environmental public health has developed?*

*Does this person, group or organization claim to have a new or unique way of addressing environmental public health? Does this approach point to or suggest problems with other approaches?*

*What data have they collected or used to support their approach to environmental public health? What visualizations of this data have been created?*

*What kinds of technology and infrastructure do they rely on in the production of environmental health care?*

*What social ecology does this person, group or organization work within, and how did it shaped their way of conceiving and engaging asthma?*

*What events or data seem to have motivated their ways of thinking about and engaging asthma?*

*What funding enables their work and possibly shapes their way of thinking about asthma?*

*What in the history of this person, group or organization likely shaped the way they conceived or and engage asthma?*

*What does this person, group or organization seem to find methodologically challenging or concerning in dealing with asthma?*

*What kinds of governance are (implicitly or explicitly) called for in the way they think about asthma?*

*How can The Asthma Files enable or supplement this way of thinking about asthma, and the work of this person, group or organization?*

## Analytic Structures *Asthma Technologies*

*What technology is the focus of this analysis, what functionality does it have, and what problem does it address?*

*What organizational setting and dynamic was the technology developed in, and who was involved in its development?  What kind of expertise did participants bring to the project?  What participants were notably absent in the design and development of the project?*

*What motivated design and development of the technology, and how do project designers and developers articulate its "design logic"?*

*How has the project been funded, and how has this shaped the project?*

*What stakeholders have been enrolled in project development? What stakeholders have been ignored?*

*How has involvement with development of the technology e/affected project participants?*

*What was the technology originally designed to accomplish, and how has the design evolved over time?*

*What is the development history of the technology? What previous technologies were used by those involved?*

*What data is produced by or associated with the technology, and how has this implicated its development?*

*Is the data produced available to the public? If so, what is the license attributed to it? Is there an API available for users and developers? If so, is it documented? What are the skills necessary to make use of the data?*

*How has the organizational context and express purpose of the technology evolved over time?*

*What significant setbacks have impacted development of the technology?*

*How has the technology been used, and what do users say about the technology? Who has had access to and used the technology?*

*What will create the most significant barriers to further development and dissemination of this technology?*

*What broad social, political, economic and cultural trends have and will likely continue to affect the development, use and impact of the technology?*

*Who is implicated or dependent on the use of the technology?*

*What is the current reach of the technology, and is it scalable in the future? Is there a sustainability plan?*

*How has the technology been received by various stakeholders?*

*How are tasks defined and distributed within the project? Who gets to define and assign tasks? Are there distinct roles and attributions related to the tasks? If so, what are they?*

*What, from your (the analyst's) perspective, are the "design logics" and implications of the project?  In other words: what kind of knowledge, care and governance does the technology engender, and undercut?*

*Has this technology produced data that contributed to environmental health knowledge and governance?*

*What additional questions should be asked about this (and other) technologies implicated in environmental health knowledge and governance?*

## Analytic Structures *Technology Users*

*What technology is being observed?*

*Who uses the technology, and how did they access it? What costs are associated with use?*

*What do users do with the technology, with what frequency and in what kinds of instances and spaces?*

*What motivates use of the technology by different kinds of users? What promotes confidence in the technology?*

*What are the e/affects of use of the technology by different users? Does the technology change user behaviour or perceptions? What kinds of social or political interactions result from use of the technology?*

*What adaptions have users made to the technology, and why?*

*Are there users who are actively experimenting with the technology to push its development and possible application?*

*Who and how is use of the technology being tracked and evaluated?*

*What is your (the analyst’s) evaluation of the technology? What is your reading of the design logics of the technology? What is your reading of the design effects of the technology?*

*Additional questions that should be asked about technology users?*

# Sample Group Activity: Asthma Technologies

The Asthma Files is organized around groups of activity. Groups can be small or large, and private and public, and can work on very specific themes – that of a dissertation project, for example – or on open themes – like “asthmatic spaces.” The group-based architecture of the project supports the nesting of many separate projects within a larger project structure, facilitating collaboration and cross-talk without undermining the individual project specificity that is so important to ethnographers. Below we outline the kinds of activity that a group can undertake, using a group focused on asthma technologies as an example.

The Asthma Technologies Group was organized to explore the array of technologies – from inhalers to citizen air monitoring devices to real-time ozone maps -- developed to understand and respond to asthma and poor air quality.

* Build a Zotero bibliography to support the group’s work.
* Annotate academic and news articles about asthma technologies, using TAF’s annotation template:
* Build a timeline that functions as a scan of relevant technologies, indicating when they emerged and became available for use. See (growing) list of relevant technologies below.
* Produce structured observations of relevant technologies, using TAF’s structure for this:
* Produce structured observations of technology users, using TAF’s structure for this:
* Produce a digital survey that explores how people (on a particular college campus, for example) use different asthma technologies. A TAF survey instrument for this is under development.
* Contribute to shared analysis of asthmatic spaces, using TAF’s structure for this:
* Contribute to shared analysis of asthma knowledges, using TAF’s structure for this:
* Contribute to shared analysis of different modes of asthma care. A TAF structure for this is under development.

**ASTHMA TECHNOLOGIES**

SUTD O-Lab Environmental Monitor Air Quality Egg

<http://olabsutd.wordpress.com/> <http://airqualityegg.com/>

<http://airqualityegg.wikispaces.com/AirQualityEgg>  
Houston Clean Air Network Air.Air!  
<http://houstoncleanairnetwork.com/> [https://www.kickstarter.com/projects/1886143677/airair- portable-air-quality-detector](https://www.kickstarter.com/projects/1886143677/airair-%09%09%09%09%09%09%09portable-air-quality-detector)

Global Community Monitor Citoyenscapteurs -- Citizenair:  
([call-in tutorial](http://org.salsalabs.com/o/852/p/salsa/event/common/public/?event_KEY=82638) Tuesday, Oct 21, noon EST) <http://www.citoyenscapteurs.net/>

<http://www.gcmonitor.org/> <http://www.citizenair.io/>

Louisana Bucket Brigade Citoyenscapteurs -- Citizenair:  
<http://www.labucketbrigade.org/> <http://www.citoyenscapteurs.net/>  
 <http://www.citizenair.io/>