Community-based participatory health studies: Foundations and comparisons

Alison K. Cohen, PhD, MPH

University of California Berkeley & University of San Francisco

Divulgation de conflits d'intérêt potentiels

This presentation is done completely independently from the event organizer. I have no conflict of interest to declare with the topic presented

Agenda

- Introduction to community-based participatory research for health
- Comparisons
  - Community-based participatory health study in United States
  - Community-based participatory health study in France
- Conclusions

Community-based participatory research

- Community-based
  - Community key unit of identity
  - Build community capacity
  - Emphasize locally relevant health issues
  - Consider multiple determinants of health present
  - Publicly disseminate research findings
- Participatory
  - Collaborative, equitable research partnership
  - Promote co-learning among all partners
  - Empowers participants
  - Iterative research process
  - Integrates and achieves research-action balance for mutual benefit of all partners

Minkler & Wallerstein, 2008

Increase rigor, relevance, and reach

- Rigorous
  - Community engagement helps recruit research participants
- Relevance
  - Community engagement helps ensure connections to community and/or policy questions of interest
- Reach
  - Community engagement helps with broader dissemination to diverse audiences

Balazs & Morello-Frosch, 2013; Cashman et al., 2008; Cohen et al., 2012

CBPR overview

- Community-based participatory research: benefits for community partners
  - Deeper understanding of issues of interest
  - Increased access to monetary and personnel resources
  - Improved quality of research methods
  - Increased credibility of results for academic, political, and judicial audiences

Examples of CBPR in the US and France

- US: Richmond, California (Cohen et al., 2012)
  - Approach: CBPR
  - Method: Cross-sectional epidemiology study
  - Surveyors: community-based organization staff and trained residents in bilingual teams
  - Sample size: 198 respondents, 722 household members
- France: Fos-sur-Mer & Port-Saint-Louis-du-Rhône (Cohen et al., 2018)
  - Approach: CBPR
  - Method: Cross-sectional epidemiology study
  - Surveyors: university researchers
  - Sample size: 816 respondents, 2055 household members

Example: Richmond, CA

Aerial photograph of **Richmond, CA**, study community and neighboring industry and transportation.

Disproportionate environmental health burden in Richmond, CA: the issue

Disproportionate environmental health burden in Richmond, CA

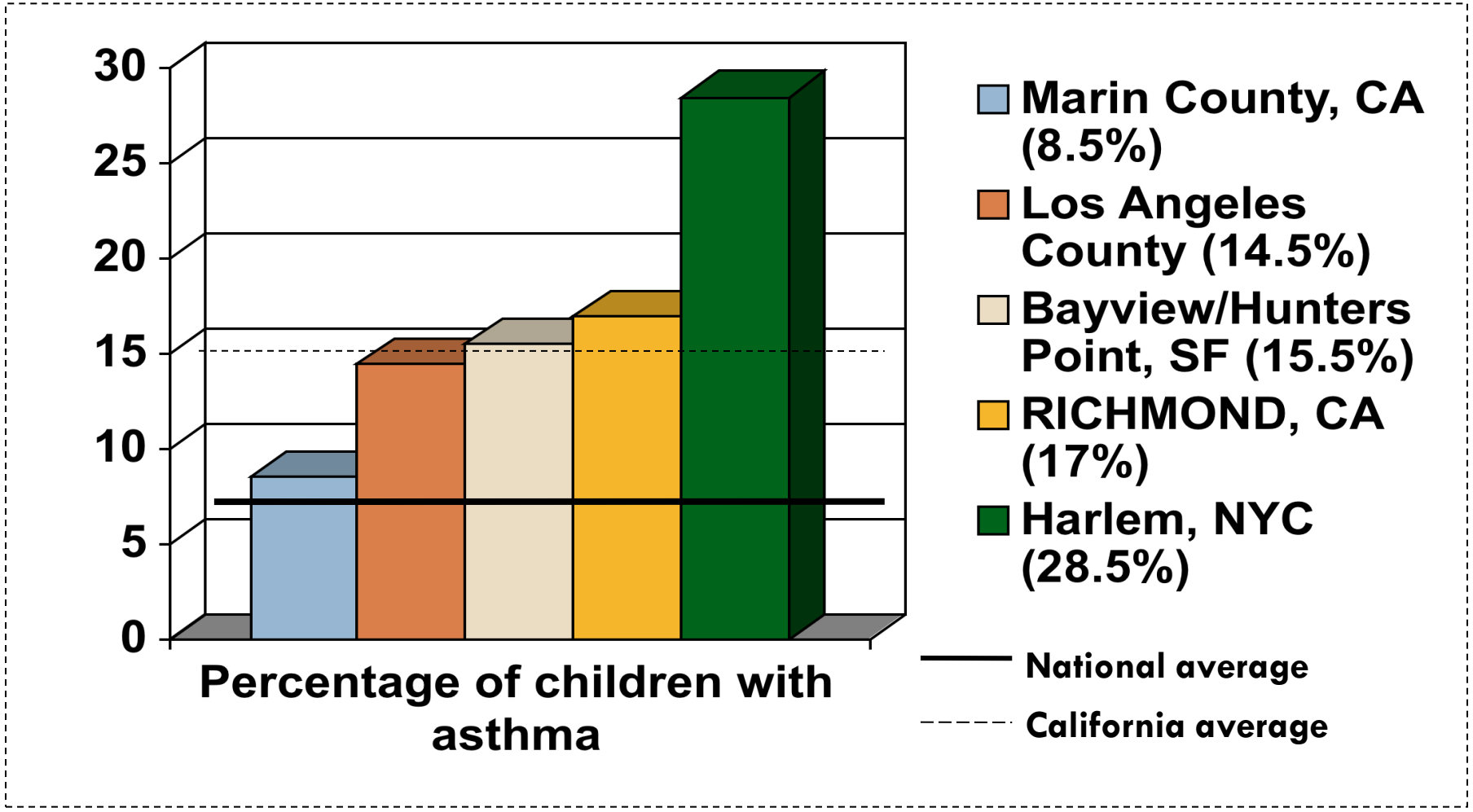
- The partners
  - Communities for a Better Environment
    - California-wide NGO combining grassroots organizing, science, and litigation to address environmental health justice
  - UC Berkeley
    - School of Public Health and Department of Environmental Science, Policy, and Management
  - Brown University
    - Department of Sociology
  - Silent Spring Institute
    - Non-profit research institute studying links between environment and women's health
  - West County Toxics Coalition
    - Richmond-based community organizing NGO

Cohen et al., 2012

Our strategy: a health survey

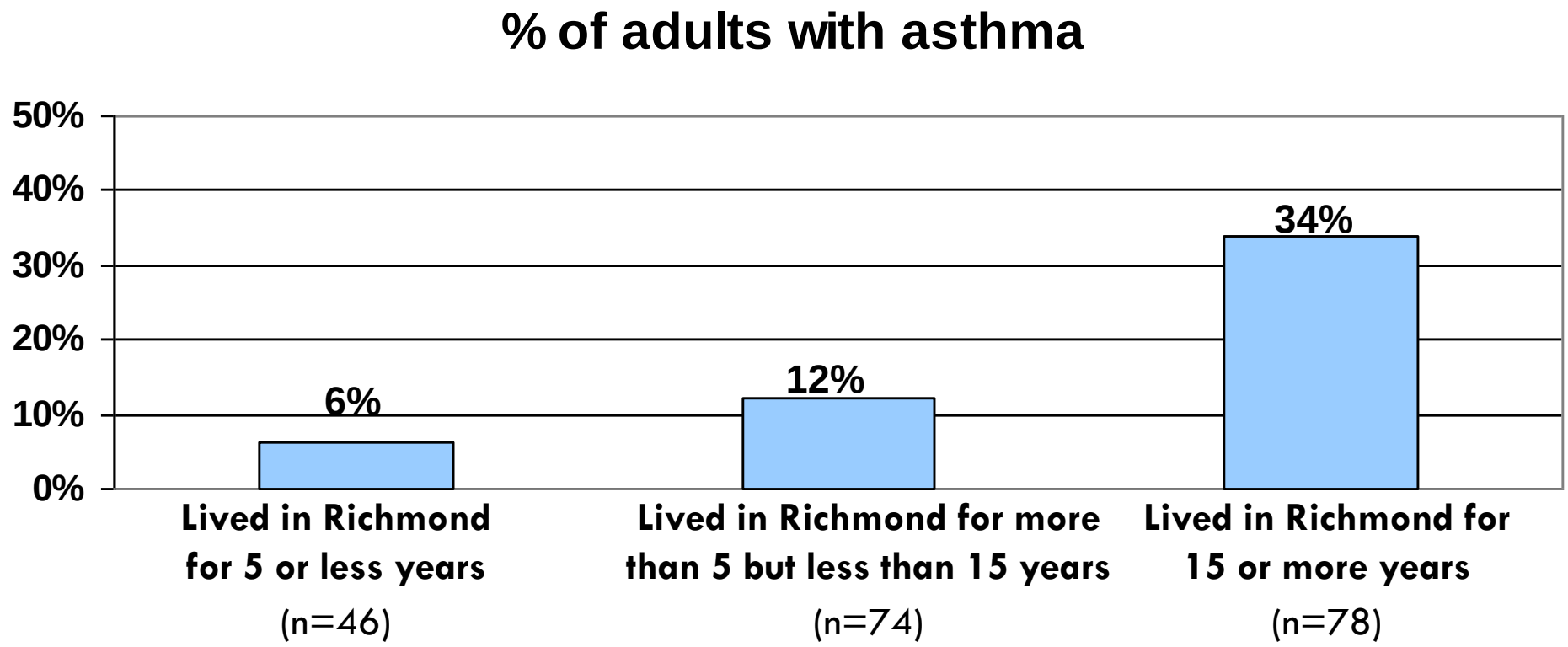
- Goals:
  - Document health experiences
  - Understand environmental factors that may affect health outcomes
  - Connect to and support advocacy and organizing efforts
- Reach:
  - Surveyed 198 residents in four neighborhoods
  - Collected health information on 722 household residents
- Impact:
  - Facilitated community unity around common concerns
  - Increased scientific and health literacy and numeracy in community
  - Informed local (neighborhood, city, county) policy critiques and revisions

Childhood Asthma



Sources: Center for Health Statistics, 2005; Mann, 2000; Nicholas et al, 2003.

Adult Asthma:
More common among longtime residents



Note: 45.0% of life-long residents (n=20) have asthma

Dissemination

Our Environment, Our Health: A Community-Based Participatory Environmental Health Survey in Richmond, California

Alison Cohen, BA[1], Andrea Lopez, BA[2], Nile Malloy, BA[2], and Rachel Morello-Frosch, PhD, MPH[3]

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Original Article

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DOI: 10.1089/env.2016.0008

Surveying for Environmental Health Justice:
Community Organizing Applications
of Community-Based Participatory Research

Alison Klebanoff Cohen, Andrea Lopez, Nile Malloy, and Rachel Morello-Frosch

CBE

CONTRA COSTA HEALTH SERVICES

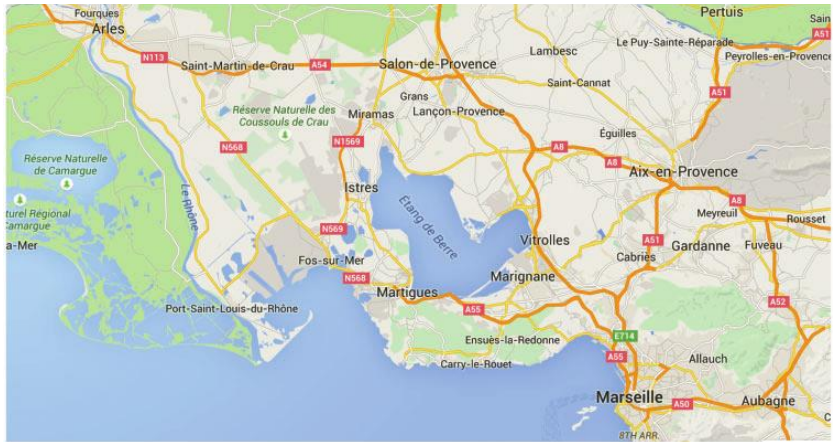
Home

CONTRA COSTA COUNTY HAZARDOUS MATERIALS COMMISSION

Example: EPSEAL study

Industrial corridor of Marseille: Fos-sur-Mer & Port-Saint-Louis

Fos epseal
Etude Participative en Santé Environnement Ancrée Localement



Multidisciplinary research team

anthropologist

Centre Norbert Elias UMR 8562

epidemiologist

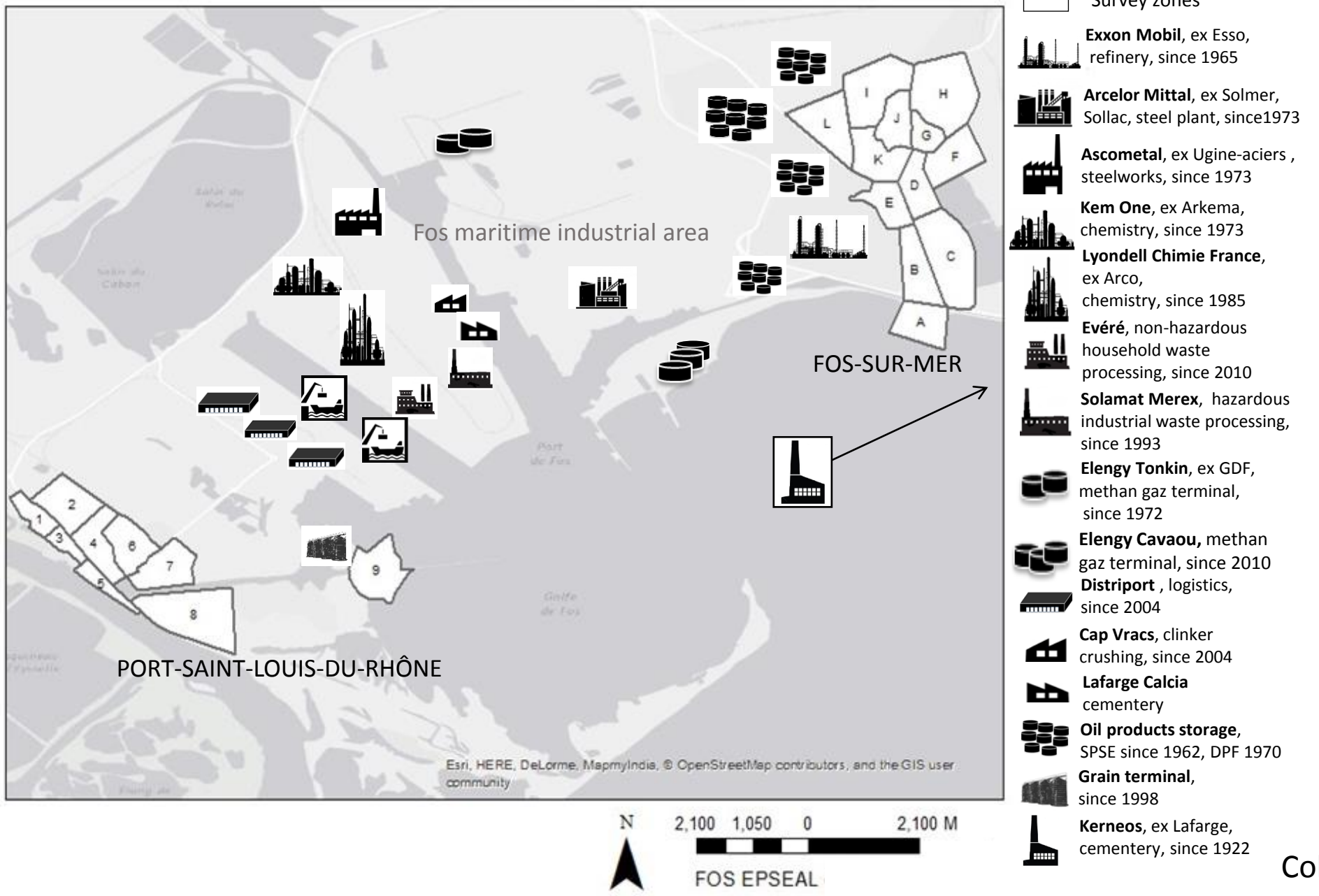
anthropologist

Centre Norbert Elias UMR 8562

Virginia Tech

sociologist

urban planner & epidemiologist



Cohen et al., 2018

Context and Objectives of Community-Based Participatory Environmental Health Study

- To synthesize lay and expert knowledge, with goal of co-producing a snapshot of health in two industrial fence-line locales : Fos-sur-mer and Port St. Louis du Rhone.
- Develop survey questionnaire based on feedback of residents and other local experts that can be used to quantitatively and qualitatively describe health issues in Fos-sur-Mer and Port-Saint-Louis-du-Rhone
- Systematically document health experiences in these two communities using a random sample of residents and volunteers
- Health survey will capture localized data, help make science more relevant, and open a space for participation in the production of knowledge by residents affected by environmental exposures.
- Conducted with funding support from ANSES

Overview of EPSEAL activities

- Design study
- Identify topics to study
- Design questionnaire
- Develop sampling strategy
- Recruit participants
- Analyze data
- Make sense of findings through resident focus groups
- Disseminate findings

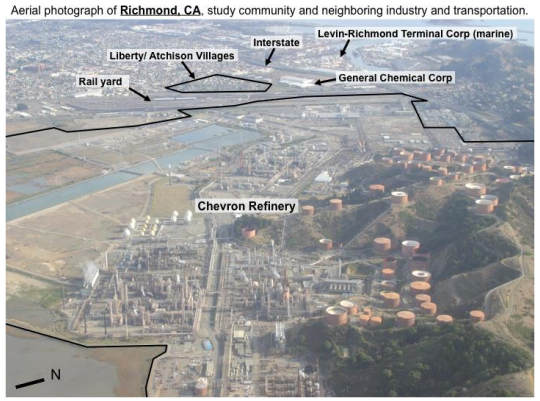
Study design

- Community-based participatory research
- Previous science and technology studies research elucidated how residents and stakeholders had made meaning of previous studies in the region

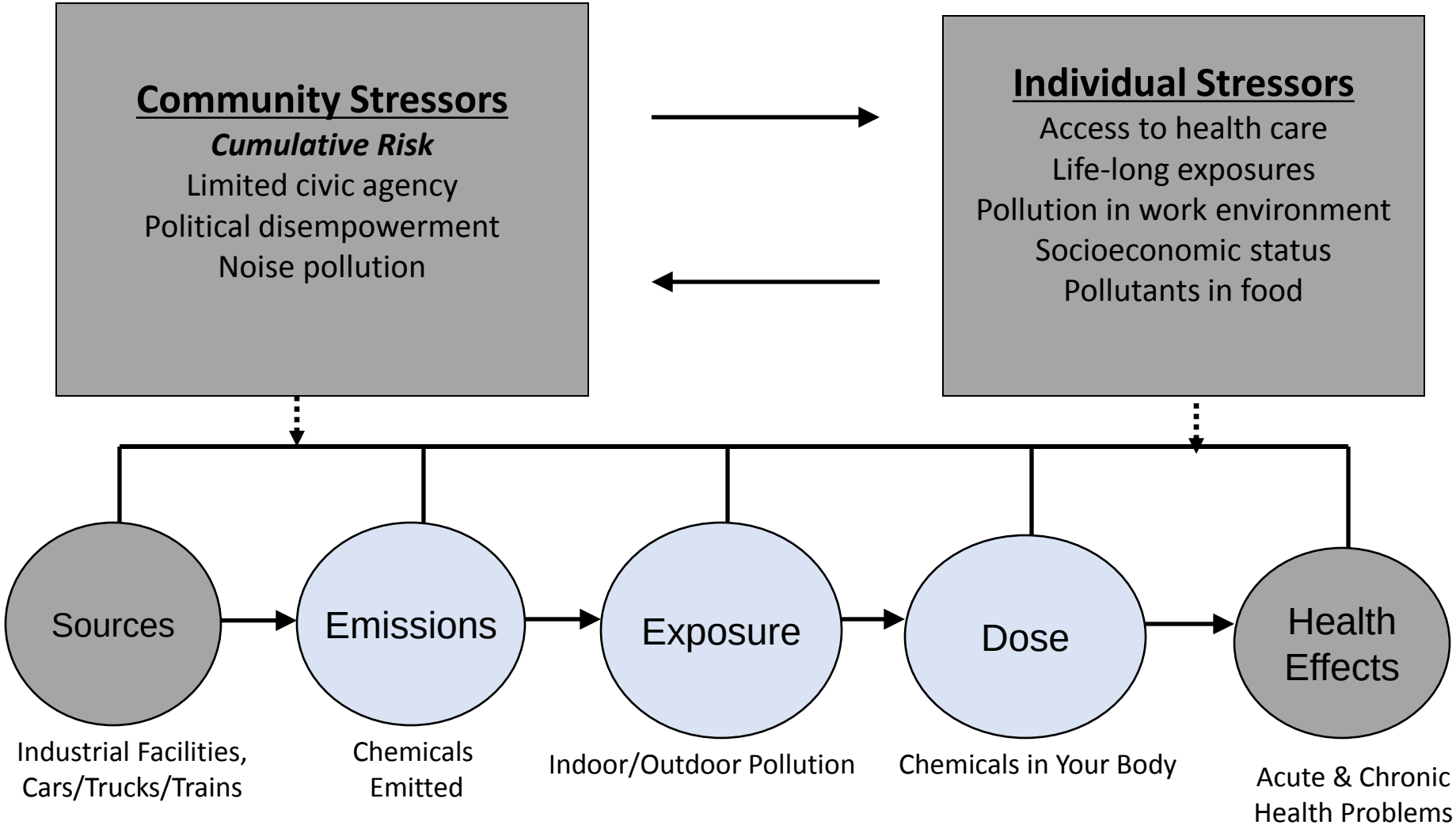
Identifying topics to study

- In-depth socio-anthropologic interviews conducted locally

- Environmental epidemiology studies from elsewhere



The Big Picture: Understanding Health in Fos-sur-Mer & Port-Saint-Louis



Adapted from: Morello-Frosch, 2007 & Cohen et al., 2012

Designing questionnaire

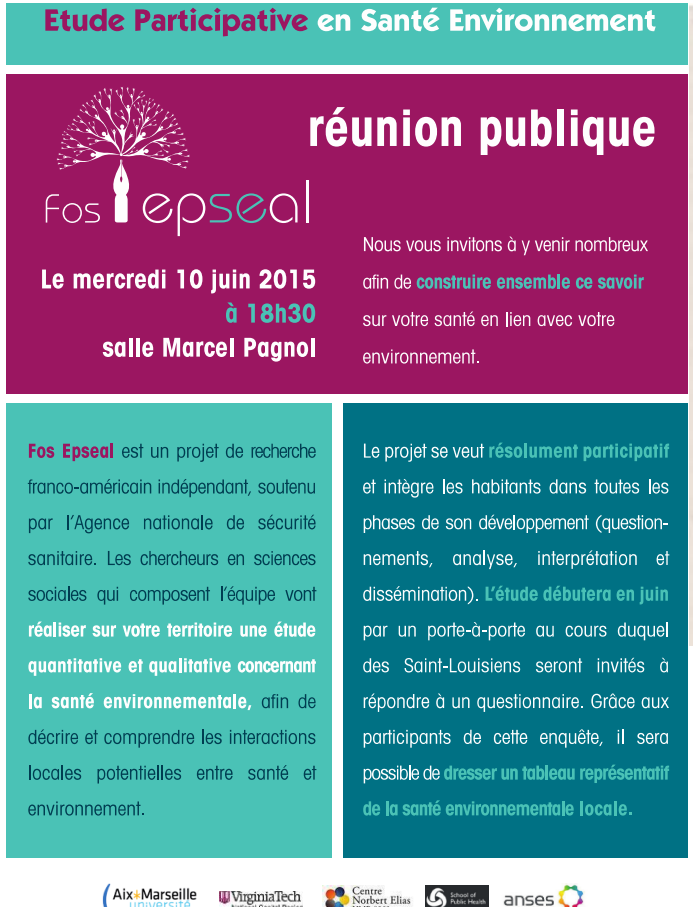
- Identified questions to measure each of the topics identified
  - Used question text from other sources when possible to use well-tested questions and to allow for additional comparison groups as relevant
    - Un médecin ou un professionel de santé vous a-t-il déjà dit que vous avez l'asthme?
  - Ask questions about participant and all household members
    - Est-ce qu'un médecin ou un autre professionel de santé a déjà dit à une autre member de votre foyer qu'il/elle avait de l'asthme?

Sampling strategy

Random door-to-door sampling

Online volunteer sample

Recruiting and engaging participants




La Provence 22/6/2015 p.7 (Arles)
Crau - Camargue
PORT-SAINT-LOUIS
Comment allez-vous Port-Saint-Louisiens ?

Analyzing data

- Community-based: analyzing data to respond to community members' hypotheses and questions
- Multidisciplinary:
  - Epidemiologic analysis of quantitative data
  - Sociologic and anthropologic analysis of qualitative data
  - Mixed methods synthesis of knowledge from both qualitative and quantitative data

Key findings

- Disproportionate health burden in these towns in comparison to a variety of other data sources, even after doing direct standardization (to account for any differences in age and gender distributions)
  - Chronic skin problems, asthma, cancer, diabetes all elevated
  - Also high prevalence of acute symptoms that affect daily life

Table 2 Health issues in our study sample and relevant comparison populations

Health outcome	Respondents (n = 818)	Region	France
Self-rated health	Excellent: 15% Good: 57% Poor: 19% Very poor: 7%		Very good: 25% Good: 43% Somewhat good: 23% Bad: 7% Very bad: 1%
Chronic conditions			
At least one chronic disease	63%		37%
Chronic skin problems	26.8%		9.4% 15–20%
Asthma	All: 15.1% Only non-smokers: 12.3%	Marseille: 5.2% Region: 6%	10.2%
Cancer	11.8%		4.1% 6%
Endocrine disease other than diabetes	13.4%		5–10%
Diabetes	12.9% (11.5% type I, 76.9% type II, 11.5% unknown)		5% (5.6% type I, 91.9% type II, 2.5% unknown)
Sought fertility advice (women only)	10.3%		
Acute conditions			
At least one acute symptom non-hay fever related	63%		
Eye irritation	43.4%		
Nose and throat problems	39.0%		
Frequent headaches	37.2%		
Frequent nosebleeds	7.5%		
Health risk factor			
Smoking	30.1%	33%	34%

Table 3 Standardized prevalences, using the entire French population as the standard population

All of France	Respondents	All adults	All children (< 18 years)	Everyone
Asthma	15.8 (13.9, 17.8)	11.6 (10.0, 13.2)	11.1 (8.2, 14.0)	11.5 (10.3, 12.8)
Autoimmune diseases	6.8 (5.4, 8.2)	6.1 (4.8, 7.3)	2.0 (0.7, 3.3)	5.2 (4.2, 6.1)
Breast cancer	2.3 (1.4, 3.3)			
Among women	4.5 (2.6, 6.3)			
All cancers	10.5 (8.9, 12.1)	8.2 (6.8, 9.5)		6.4 (5.3, 7.4)
All diabetes	11.6 (10.1, 13.1)	9.8 (8.3, 11.2)	0.2 (0.0, 0.7)	7.6 (6.5, 8.8)
Type 1 diabetes	1.1 (0.6, 1.7)	1.6 (1.0, 2.2)	0.2 (0.0, 0.7)	1.3 (0.8, 1.8)
Type 2 diabetes	9.0 (7.7, 10.3)	7.2 (6.0, 8.5)	0.0	5.6 (4.7, 6.6)
Endocrine disease(s) other than diabetes	11.3 (9.5, 13.1)	10.2 (8.7, 11.7)	0.4 (0.0, 0.9)	8.0 (6.9, 9.2)
Fertility problems	9.6 (8.0, 11.1)			
Among women	10.9 (8.0, 13.8)			
Hay fever	42.3 (39.9, 44.8)	34.9 (32.5, 37.3)	20.0 (16.3, 23.7)	31.6 (29.7, 33.5)
Other respiratory illnesses	13.8 (12.1, 15.4)	10.7 (9.2, 12.2)	6.2 (4.0, 8.4)	9.7 (8.5, 10.9)
Other respiratory allergies	25.9 (23.7, 28.2)	19.0 (17.0, 21.0)	12.3 (9.3, 15.3)	17.5 (16.0, 19.1)
Chronic skin conditions	26.7 (24.5, 29.0)	20.9 (18.8, 23.0)	21.0 (17.2, 24.8)	20.9 (19.3, 22.5)
Smoking	33.7 (31.5, 35.8)	32.3 (30.1, 34.6)	1.9 (0.6, 3.2)	25.6 (23.8, 27.3)

Fos epseal
Etude Participative en Santé Environnement Ancrée Localement

Cohen et al., 2018

Dissemination

Redesigning a Participatory Health Study for a French Industrial Context

Barbara L. Allen[1], Alison K. Cohen[2], Yolaine Ferrier[3], Johanna Lees[3,5], and Travis Richards[2,4]

L'ÉTUDE FOS EPSEAL
QUELQUE CHOSE D'ERIN BROCKOVICH

FOS EPSEAL *
Etude participative en santé environnement ancrée localement sur le front industriel de Fos-sur-Mer et Port-Saint-Louis-du-Rhône

Rapport final

Janvier 2017

Barbara L. ALLEN, Alison K. COHEN, Yolaine FERRIER, Johanna LEES

SANTÉ – SCIENCES

À Fos-sur-Mer, une population malade de son industrie ?

Par Marion Bargiacchi, France Bleu Provence et France Bleu

Mardi 14 février 2017 à 21:58 | Mis à jour le mercredi 15 février 2017 à 8:15

Cancers à Fos : "L'ampleur des chiffres nous surprend"

Mercredi 01/03/2017 à 10H03

1.8K Partages | Partager | Tweeter | Partager | 8 réactions

L'étude Epséal a révélé des taux de maladie très élevés. L'ARS reste prudente

Conclusions

- Community-based participatory studies are increasingly common in the US but remain relatively rare in Europe (including in France)
- Understanding and working within local customs, local practices, and local culture is essential when adapting principles of community-based participatory research to a particular study location
  - How can the study answer questions that residents want answered?
  - What approach will lead participants to have the highest trust in the findings?
- Such studies can increase research's relevance to local populations and be used to inform interventions to improve public health
- For more information: akcohen@gmail.com