



A health study for oil spill clean-up workers and volunteers

Utility of a Participant Survey to Assess the Feasibility of a Follow-up Clinical Exam in the Gulf Long-Term Follow-up STUDY (GuLF STUDY)

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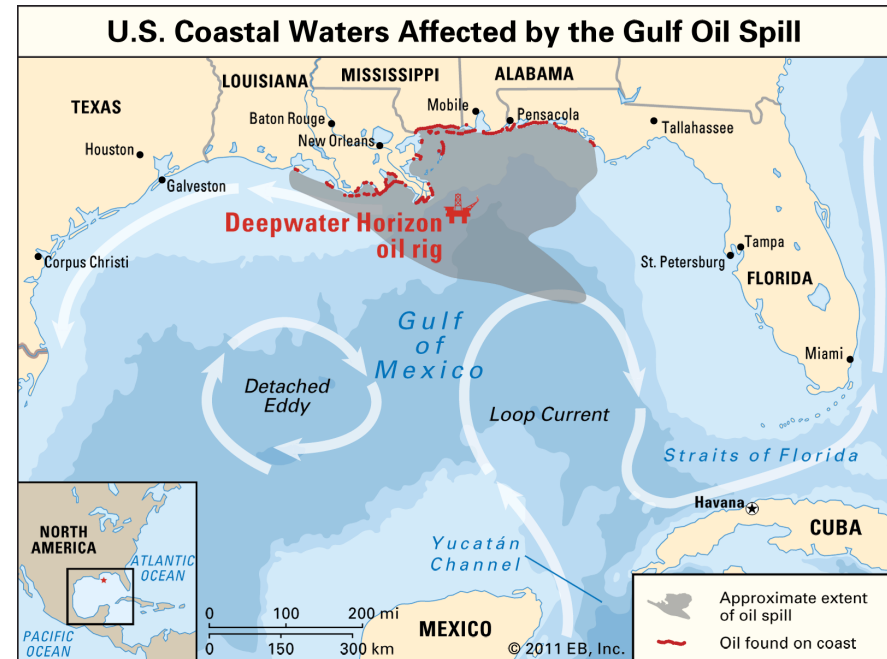
National Institutes of Health
U.S. Department of Health and Human Services

Background



2010 Deepwater Horizon Oil Spill

- Caused by drilling rig explosion
- Largest maritime oil spill to date
- >100,000 persons involved in clean-up
- Clean-up workers and residents exposed to crude oil and dispersants



Objectives



Gulf Long-term Follow-up Study

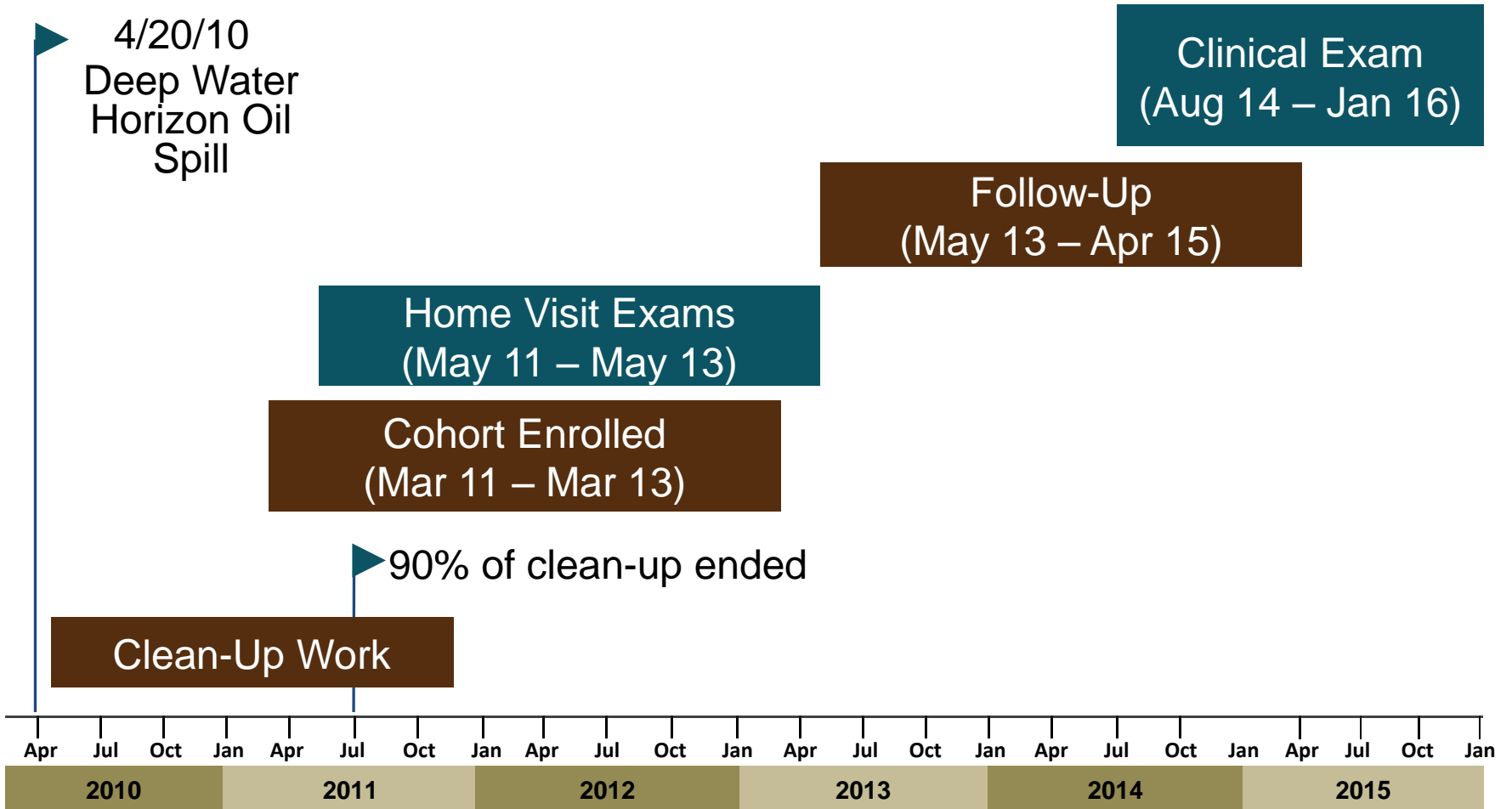
Examining health effects associated with the oil spill

Focused on oil spill clean-up workers, most exposed group

Largest, most comprehensive study of oil spill disaster

- 40 major spills worldwide
- Few studies of health effects
- No long-term studies
- Community concerns about a range of health effects

Study Timeline



Cohort Enrollment and Follow-up

32,608 adults enrolled between 2011 and 2013

- Worked at least one day in active oil spill clean-up, did support work, or took safety training but not hired
- Enrollment telephone interview collected information about demographics, socioeconomic factors, clean-up jobs, symptoms, medical history, and lifestyle
- Home visit included collection of anthropometric measurements, biological samples, environmental samples, and lung function testing with subgroup of 11,193 in the Gulf

Follow-up is currently underway

- 1st telephone follow-up nearly complete
- Multi-center follow-up clinical exam is ongoing

Clinical Exam Overview

Focused on neurological, pulmonary, and mental health outcomes

- 4 hour visit, not including drive time
- Carried out by clinical sites in New Orleans, LA and Mobile, AL

Initiated in August 2014

Inviting ~ 6,200 participants within 60 miles of clinics

Hoping for > 65% response; 4,000 completed exams

Survey to Gauge Participation

During planning phase, we were uncertain about -

- Distance participants would travel for an exam
- How long participants would stay for a visit
- What transportation barriers they might face
- What factors, beyond remuneration, would motivate participants

Decided to ask participants about barriers and motives

- Surveyed participants during calls to update contact information
- Conducted survey prior to 1st follow-up interview and clinical exam

Survey Method

“Pilot within a pilot”

First tested methods to update contact information among full cohort:

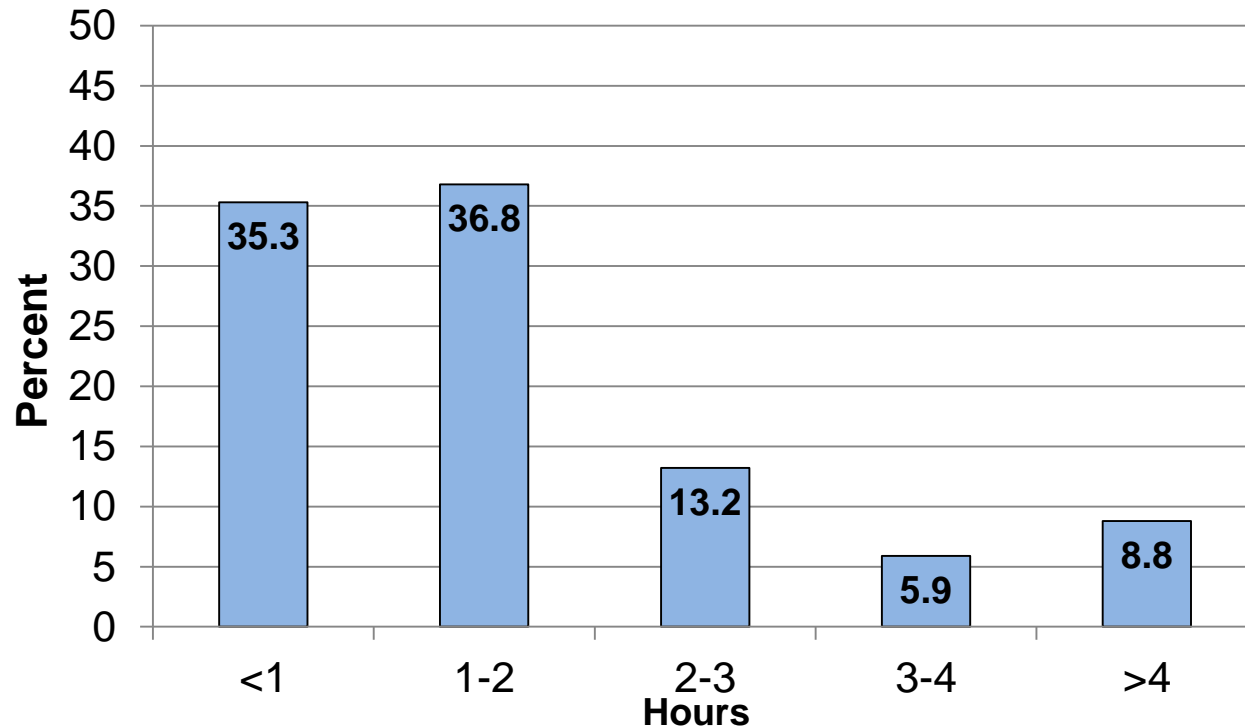
- Passive effort – 4 emails and 2 letters
- Active effort – 4 pre-notification approaches with calls to best number

Then attempted to survey exam eligible participants in active contact arm (N =348)

- 60% reached by phone
- 89% agreed to request for updates
- 89% completed survey
- 41% participation rate (n = 144)

Travel Time

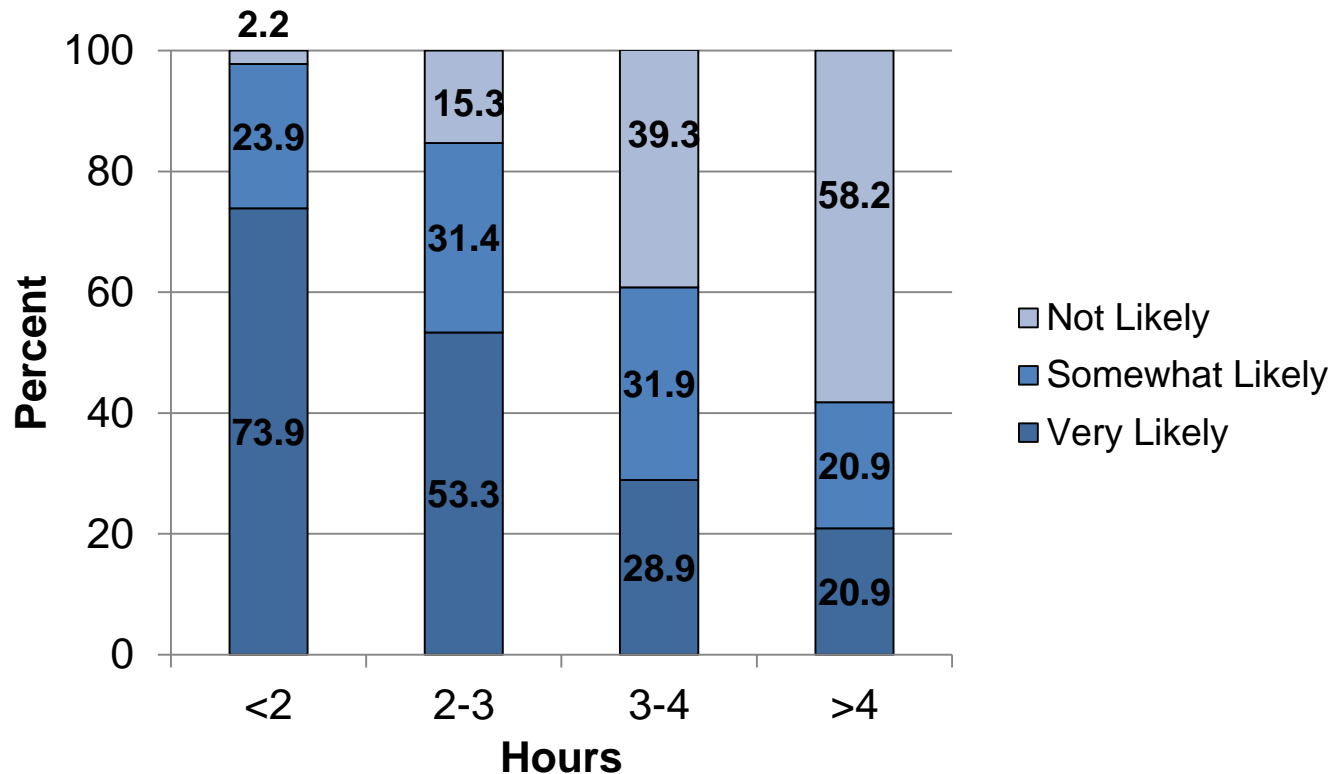
How much time would you be willing to spend traveling to the clinic and back?



20% of participants have no transportation

Exam Duration

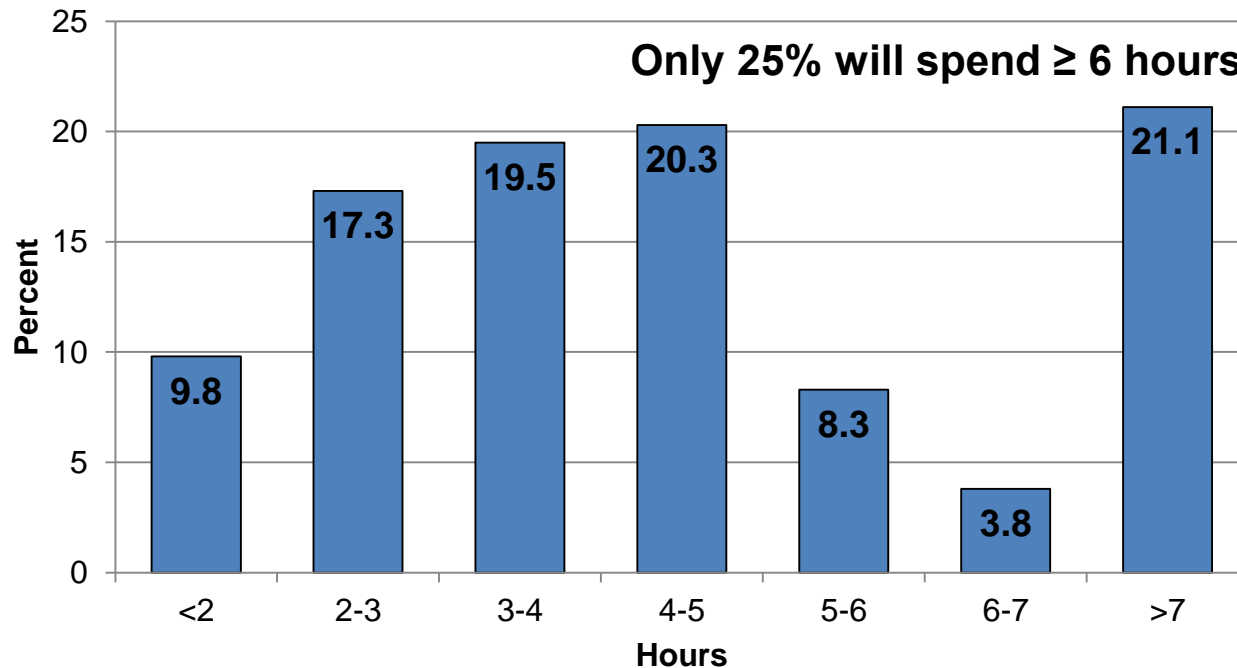
How likely are you to participate if the exam takes...



Among those who said “not likely” to any of the proposed exam lengths, 80% would consent to a longer exam if compensated

Total Effort

Assuming you will be compensated for travel / time, what is the total amount of time that you would be willing to spend participating, including your travel time and the exam time?



69% would be willing to spend more time if they did not have to travel to and from the clinic on the same day

Other Findings (%)

Factors	Very Important	Moderately Important	Not Important
Receiving results of medical screening tests	89.4	8.5	2.1
Helping my community	85.0	12.9	2.1
Being able to help others like you	82.1	12.9	5.0
Reimbursement for your travel costs	68.8	18.4	12.8
Financial compensation for your time and effort	66.0	24.1	9.9
Receiving referrals for free/reduced cost health care	65.0	24.3	10.7

Other Findings (%)

Factors	Very Important	Moderately Important	Not Important
Evening appointments available	48.9	39.0	12.1
Weekend appointments available	47.4	35.8	16.8
Free cab or shuttle to the exam site	33.3	23.4	43.3
Free child care at the clinic	33.1	11.5	55.4

Decisions Based on Survey

Planned for on-the-ground locating, due to low contact rate

Added screening exams and shared more results

Offered medical referrals

Continue to emphasize “helping” messaging

Offered evening and weekend appointments

Set catchment area at 60 mile radius around clinics

Overnight hotel stays available, as needed

Increased plan reimbursement for time, effort, and travel

Maintained plan for 4 hour visit for scientific reasons

Conclusions

Participant input can help shape decisions about study design and methods

Altruism is an important motive in studies of health effects of environmental contamination

Results sharing and referrals are forms of reciprocity that may motivate participants in studies of health effects of environmental contamination

Importance of reimbursement for time, effort, and travel and other convenience factors should not be overlooked during study planning



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