

# CFAR Supplement Activities

NW Health Department-CFAR  
Consortium Meeting  
November 4, 2013

# Agenda

- Review grant aims
- Discuss procedures for data collection & analysis
  - Data collection & form examples
  - Transmission of de-identified data
  - Oregon experience with out-of-care investigations
- Budget
  - Subcontract updates, Accurint access
- Timeline for grant activities
  - Anticipated abstracts, manuscripts and future grants

# Grant Summary

- Optimizing the HIV treatment Cascade: A Heath Department-CFAR Collaboration
- Funded 8/2013-7/2014
- Goal: *To implement region-wide HIV surveillance procedures to identify emerging research needs and lay the groundwork for collaborative research on key steps in the HIV treatment cascade*

# Grant Aims

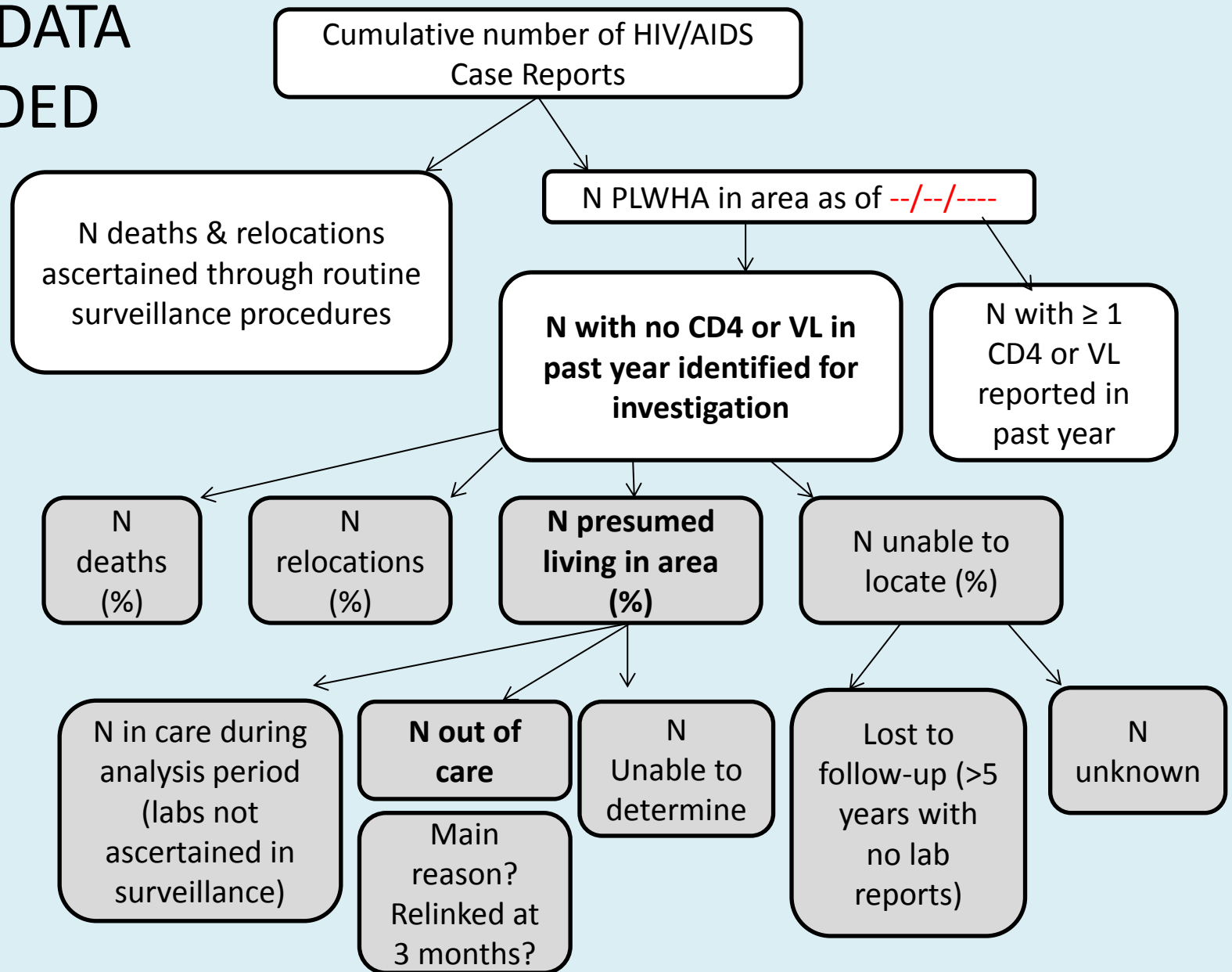
- **Aim 1. Enhance investigation of previously reported HIV cases to increase the accuracy of estimates of retention in care and viral suppression.**
  - Investigate cases with no lab results in past year and obtain comparable disposition data
- **Aim 2. Institute procedures for surveillance of new HIV cases to ascertain reason for HIV testing and time since last negative HIV test.**
  - Add/refine questions on the HIV Case Report to obtain comparable data

# Aim 1. Case investigation

- Estimated case loads

	Estimated Number	Estimated % of all PLWHA	Notes
AK	212		70 thought to be in AK, others uncertain
ID/FMRI	46	8%	Clinic-based: no appointment in last 6 months
MT	79-144	27%	Based on # with no RW labs
OR	1080 (70% Multnomah)	19%	~ 270 will need investigation at the county level
WA	2897 (42% King)		Supported by another grant
WY	82	37%	Data from CDC Surveillance Report

# KEY DATA NEEDED



Gray box = individual case investigation required

# Aim 1. Case Investigation Protocol

Review Washington State protocol – will this work for other sites?

1. First stage investigations

- Cross-matching with all available databases

- Accurint

2. Second stage investigations

- Medical records, provider, patient

3. Disposition Definitions

# Disposition Definitions for Cases with No Labs a 12 Month Period

- In care – Documented lab OR completed visit during analysis period verified with provider
- Died
- Moved out of jurisdiction
  - Confirmed surveillance w another state
  - Patient or family member report
  - Medical record documentation or release of information
  - Accurint match with 2 identifiers indicates most recent address is out-of-jurisdiction
    - Name, DOB, SSN, past address match
- Out of care – including non-response, refusals
  - 2 calls/texts if allowed, letter, call (field visit per site)
- Unknown
  - Lost to follow-up (no labs >5 years)
  - No/bad contact info

# Aim 1. Data Collection

- Common data elements needed on each case
  - Demographic data (gender, race/ethnicity, risk factor)
  - Birth year
  - Year of HIV diagnosis
  - Jurisdiction of diagnosis (in or out of jurisdiction)
  - Source of care (Ryan White vs. non Ryan White)
  - Month and year of most recent lab report
  - Disposition of investigation
    - And supporting evidence
  - Primary reason for being out of care, if applicable
  - Relinked at 3 months (yes/no), if applicable



# Data forms and communication

- Proposal
  - Sites currently investigating cases will continue to use current data instruments
  - Site not currently investigating cases can use a simple Access database we will create
  - Notes fields to ensure we aren't missing big issues
  - Quarterly data transfer and calls?

# Reason for out-of-care

- Ideally, open-ended with common coding across sites
- *“Client’s main reason for not visiting a medical provider:*
  - *Felt good*
  - *CD4 and VL were good*
  - *Didn’t know where to go*
  - *Couldn’t find the right provider*
  - *Unable to get an earlier appointment*
  - *Had other responsibilities or things to take care of*
  - *Didn’t have enough money or insurance*
  - *Didn’t want to think about being HIV+*
  - *Forgot to go*
  - *Don’t know*
  - *Not applicable (in care, relocation or death)*
  - *Refused to answer*
  - *Other:”*

# Oregon Experience

Sean Schafer, MD

Ruth Helsley

Kim Toevs

## Aim 2. Data Collection

- 1. Date of last negative HIV test (month/year)
  - Feasible to confirm?
- 2. Where tested
- 3. Reason for testing

# King County HIV PS question

What was the main reason you went for a test when you were diagnosed with HIV (select one)?

- Partner contacted me and told me s/he has HIV\_\_\_\_\_
- Partner contacted men and told me s/he had an STD other than HIV\_\_\_\_\_
- Health department contacted me and said I was exposed to HIV\_\_\_\_\_
- Health department contacted me and said I was exposed to an STD other than HIV\_\_\_\_\_
- Starting new relationship or concerned about specific sexual exposure\_\_\_\_\_
- Symptoms of STD\_\_\_\_\_
- Symptoms of HIV seroconversion (fever, sore throat, rash, etc.)\_\_\_\_\_
- Other symptoms (specify symptoms)\_\_\_\_\_
- Regular testing\_\_\_\_\_
- HIV positive partner was not recently diagnosed\_\_\_\_\_
- Prenatal screening of mother\_\_\_\_\_
- Refused\_\_\_\_\_
- Other (specify)\_\_\_\_\_

# What our Consortium will do with the data

- 1. Use date of last negative HIV test as key information for estimating undiagnosed fraction
- 2. Monitor success of early diagnosis
- 3. Monitor success of routine testing in medical settings with implementation of ACA
- 3. Examine reasons for testing in order to identify intervention opportunities

Figure 3. Time from last HIV negative test among MSM diagnosed with HIV, Seattle, 2008-10 (N=515) and U.S., 2010

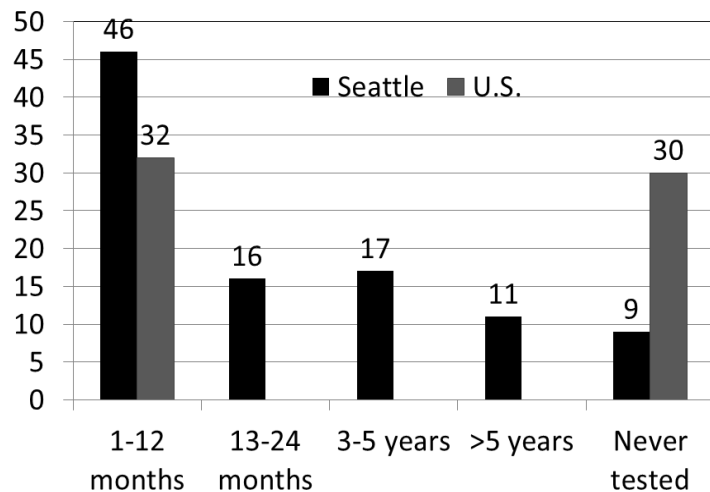
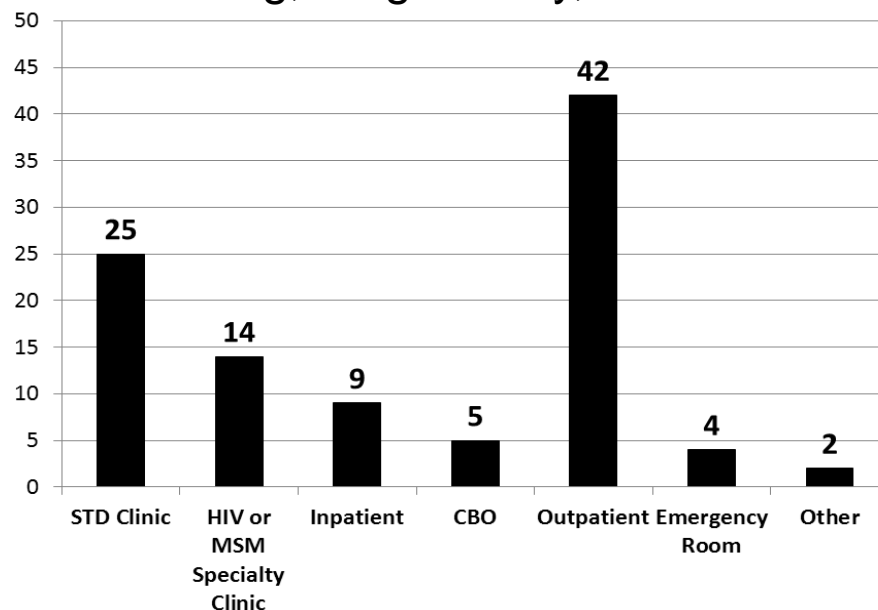


Figure 4. Percentage of new HIV cases diagnosed by type of setting, King County, 2011-12



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## Aim 2. Data Sharing

- Quarterly data transmission and calls

# Regulatory issues

- Justification for non-research determination
- IRB determination?
  - May vary by site

# Budget

- Status of subcontracts
  - Once in place, can bill back to Aug 2013
- Accurint access

# Proposed Timeline

- November
  - finalize data forms, subcontracts, apply for non-research determinations if needed
  - Accurint access
  - Generate list of cases with no labs in past 12 months
  - Add new case questions to HIV case report or interview form
- December
  - Submit numbers of total cases, # with no labs to CFAR
  - Begin Stage 1/internal investigations on cases with no labs
  - Finalize case report changes

# Proposed Timeline

- Jan-Mar: First quarter of case investigation
  - Monthly calls during Q1?
  - Submission of first data report to CFAR
- Apr-Jun
  - Ongoing case investigations and quarterly data reports
  - Next consortium meeting – location TBD
- July – Investigations complete in AK, ID, MT, WY
  - Analyze 6 month data
- Fall 2014
  - Conference abstract submission
  - Plan for next-step grant submission

# Additional Discussion Points

- Authorship and data ownership
  - Collaboration with shared authorship
    - All abstracts, manuscripts will have an author from each site
  - CFAR investigators will lead the proposed analyses of combined site data
  - Site investigators welcome to access combined data or lead additional analyses
    - Each site retains “ownership” of their own data
  - Communication with group about analysis plans involving multiple sites
- Ongoing communications – teleconferencing?
- Next meeting? Location?