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Strategies and Opportunities to STOP Colon Cancer in Priority Populations: STOP CRC 4UH3CA188640-02 (NIH, NCI)

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## What is STOP?



- STOP is a pragmatic cluster randomized trial designed to test the effectiveness of an automated Electronic Health Record imbedded mailed fecal testing program.
- The primary outcome is completion of FOBT testing at one year.

# What Data Are We Collecting? - Eligibility Data -

- Adults ages 50-75, with at least one clinic visit in the prior in the prior year who become eligible for CRC screening in 2014:
  - No colonoscopy in 9 years, no flex sigmoidoscopy in 4 years, no FOBT in 11 months, no colonoscopy referral within 11 months (statuses are updated in real time)
  - Limited set of permanent ineligibility conditions
    - Colorectal cancer
    - Inflammatory bowel disease
    - End stage renal disease
- Research data sets will only include those whom are eligible for screening during the intervention and follow up year.

### **Research Data**

#### **Phenotype Characteristics (Table 1)**

	Control Clinics	Intervention Clinics
	N = approximately 15,000	N = approximately 15,000
Age		
Sex		
Race		
Ethnicity		
Language		
Income (Federal Poverty Level) <100% FPL, 100-150 FPL, 151-200 FPL, 200+ FPL		
Insurance Type		
Tobacco Use		
ВМІ		
Other Potential Moderators		
Comorbidity		
Utilization		
Prior Screening Behaviors		
Migrant status /Homeless status		

### **Research Outcome Data**

- Completion of FOBT testing (primary outcome)
- Completion of colonoscopy or flexible sigmoidoscopy
- Percent +FOBTs, percent +FOBT with a colonoscopy
- Process measures kits sent, reminder letters,

Additional outcome data

- Qualitative data
- Costs
- Possibly colonoscopy outcomes

## What can STOP share?

- OCHIN controls the data -
- The Center for Health Studies (CHR) Kaiser Northwest has a Data Use Agreement to receive specific OCHIN data as a de-identified data set (only identifier on the list of 17 identifiers is birthdate)
- CHR DUA states they cannot share data sets with external parties
- OCHIN will direct how the data is to be shared
  - Data that will not be shared records reviewed for eligibility
    - Birthdates
    - Clinics, networks, providers
  - Data that can be shared
    - Phenotype data (exclude those with larger amounts of missing data or small cells)
    - Outcome data (FOBT, colonoscopy, flex sig utilization, proportion + FOBT)

## **Next steps**

- OCHIN will need to be included in all public sharing of STOP data discussions
- OCHIN's membership in the PCORI CDRN may inform these discussions.
- Discussion points: sharing STOP data on PopMedNet
  Distributed Data Network with the level of sharing being similar to other OCHIN data sets

