

National Cancer Institute

Group IV

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OF HEALTH AND  
HUMAN SERVICES

National Institutes  
of Health

## Group IV Members

- Shumin Zhang
- Herbert Yu
- Xifeng Wu
- Maria Worsham
- Mary Wolpert
- Sholom Wacholder
- Sara Strom
- Xiao Ou Shu
- Elaine Smith
- Katherine McGlynn
- Shannon Lemrow

## Working group IV demographics

- N = 11 participants
- 8 with experience in consortia
- 2 program staff
- 2 intramural

# Topics Covered

- Control Selection
  - Reusing controls already studied for common cancers as controls for rare cancers
- Affirmative action for rare cancers
  - Grant review
  - Manuscript publication
- Data Sharing / Informatics
  - Money set aside
  - Incentive for the bioinformatics expert
- Funding mechanisms
  - Linked R01s versus Multiple PI mechanism
- Central IRBs
- Conducting studies in other countries where US rare cancer rates are higher

## Affirmative action for rare cancers

Recognize the specific challenges of studying rare cancers by having...

- Special study section
  - Or at least ensure knowledgeable reviewers within the study section
  - Give 10 pts for cancer sites/ projects of interest (Clinical trials does this)
- Similar need for journals

# Data Sharing / Informatics

- Existing studies
  - Cost associated with pooling data upon specific request
  - Parent study ends up providing long-term support about data issues to the ancillary study
- Future studies
  - Importance of initially setting up clear data structures to facilitate data sharing in the future
    - Money set aside, from the beginning
  - Incentive for the bioinformatics expert
    - Recognition and financial support

## Funding mechanisms

- Uncertain how the Multiple PI system works versus Linked R01s
- Clarify rules about scientific versus administrative supplements for consortia

## Consortium management

- Secretariat needs to equitably monitor the progress of ongoing projects and publications
- Let “in gestation” consortia witness “established” consortia

## Immediate question -

- Should the Cohort Consortium provide numbers of rare cancer cases to investigators that are interested in collaborating?

## Lingering question

- How will the existing consortia carry the momentum forward into second generation studies to end?
  - Think now: this requires years of lead time and planning
  - Grow and diversify