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Methods and Strategies Working Groups (MSWGs)

Working Group III:

Chair: David Hunter, M.B.B.S, M.PH., Sc.D.
Co-Chair: Jill Barnholtz-Sloan, Ph.D.
Co-Chair / Writer: Sheri Schully, Ph.D.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Methodological challenges in rare cancers research

- Sample size – multicenter necessary, international may be necessary
- Biospecimens, standardization across centers necessary
- Multiple centers may have different selection criteria, different questionnaires etc
- Not adequate interactions between Epidemiologists, Geneticists, and Clinicians. Need to bring oncology disciplines together. Pharmacogenetics may be the key to bridging the gap between the disciplines (blend interests in etiology and prognosis).
- Researchers forced to reinvent infrastructure for each rare cancer – can we get economies of scale across sites?
- Institutional Collaborations (multiple PIs, authorship): How will younger investigators get noticed at their academic institution if I am a member of a large collaboration?
- Comprehensive Cancer Centers underinvested in population sciences in general

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Potential solutions to methodological challenges in rare cancers research

- Extension of existing infrastructures present for clinical trial and common cancers > query of existing cooperative groups and ADs for Population Sciences of CCCs]
- Utilizing clinical trial, patient advocacy, and professional groups for case ascertainment
- Consider Big Pharma as a resource (i.e. trials not run by cooperative groups but centrally from Pharma): how to get on the Pharma radar? > many have strong relationships with patient advocacy groups, C-Change, and private foundations

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Areas of potential improvements in existing consortia models to foster rare cancers research

- Rare cancer incidence is not common in any one particular place (geographic location) so working across institutions is a necessity.
- Linking prevalent studies model:

  Issues of heterogeneity of data/samples

  Lowest common denominator approach to data pooling

  Less expensive but funding issues related to viability of component studies on the 5yr RO1/10th percentile model

- Incentives for joining consortia
- Infrastructure funding mechanisms for component studies

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Areas of potential improvements in existing consortia models to foster rare cancers research

De novo common protocol model:

Standardization possible

Longer to put into the field

Reinvention of wheel for infrastructure?

- Common infrastructure for enrollment/interview/biomarkers across different rare cancers?
- CCC's the key? Augment capacity to enroll patients in etiologic studies as well as clinical trials (could be synergistic for some sites).
- Provide incentives for multiple CCC's to contribute across a list of priority cancer sites (needed – list of top 10 sites defined by logistical and scientific opportunity)

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Novel strategies in consortia coordination and implementation

- Recalibrate NCI Intramural role: Intramural has special advantages for rare cancers (convening meetings, setting up registries, more stable funding base).
- Rare Diseases network as possible collaboration point for rare cancers?

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Implementation of consortia coordination and implementation – some ideas

- Poll associate directors for population sciences at cancer centers to identify those with existing infrastructure for common cancer patient enrollment that could be extened to rare cancers
- NCI to incentivize cancer centers to collaborate on rare cancers.
- CCCs to designate an established and young investigator (so that new investigators are encouraged) (e.g. Minority and disparities mandates applied to rare cancer research).

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GWAS special funding opportunities for rare cancer studies – how to leverage the GWAS??

- GWAS a key new opportunity
- Obtaining scan and replication sample sizes a problem
- Use of in silico controls – probably adequate for most extreme hits, but a lost opportunity for lower RR's and other research
- Need to make the case for good epi study design in order to leverage the GWAS

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