Your Charge!

- Engage, participate, invigorate!
- Think provocatively and creatively about the future of cancer epidemiology and how the discipline needs to evolve with a changing landscape
- Engage online and tweet about the meeting
  - Email questions to nciepimatters@mail.nih.gov
  - Ask questions on Twitter (Follow @NCIEpi; #TrendsinEpi)
- Engage others and continue the conversation after you leave tomorrow
WHAT WE HAVE LEARNED FROM EPIDEMIOLOGY COHORTS AND WHERE SHOULD WE BE GOING NEXT?

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NCI Cohort Consortium

• NCI Cancer Consortium annual Symposium, October 2012.

• Took a hard look at ourselves, 12 years later.

• Formed by NCI’s intramural and extramural staff, with cohort PIs. Currently includes 46 cohorts, 15 countries, 4 million study participants, 2 million DNA samples.
NCI Cohort Consortium

• Mission:
  • Foster **communication** among investigators leading cohort studies of cancer
  • Promote collaborative research projects for topics **not easily addressed** in a single study
  • Identify **common challenges** in cohort research and search for solutions
NCI Cohort Consortium

• **Strengths and limitations** to accomplish mission?

• **Focus has been on etiology of cancer.** Should we **expand or extend** our activities over next decade?

• **Gaps in knowledge** we could best next address?

• **Obstacles?** How can we overcome?
Are Epidemiologic Studies Relevant?

- Increasingly so, as focus on complex interactions of genes and environment. Multi-level, systems, networks. Low level risks.

- Cohort studies unique strengths:
  - Prospective data, large sample sizes
  - Multi-ethnic composition
  - Extensive phenotyping, with serial measurements over time
  - Biobanks, genetic and biomarkers components
Expand or Extend Cohorts? Gaps in Knowledge

- For cancer....

- Detailed molecular characteristics of cancer subtypes; assess ability to obtain tumor tissue if not already obtained, with issue of time since diagnosis.

- Extend to recurrence, second cancers, survivorship; cancer treatment.

- Consider the lifecourse; inclusion of children and adolescents.

- Further methodology to validate, improve, adapt, extend exposure assessments (PA – actigraphy; use of social media).

Expand or Extend Cohorts? Gaps in Knowledge

- Beyond cancer...
- Compelling imperative to extend beyond cancer to multiple disease endpoints within cohorts.
- Mission (communication, collaborate, challenges) not unique to cancer.
- Value added; scientifically worthwhile; cost-effective.
- Achievable? We believe yes…
Multiple Outcomes

• Many major risk factors for cancer are major risk factors for multiple diseases.

• Many cohorts jointly funded.

• Multiple outcomes assessed same rigor as cancer. (WHS: cancer and CVD (MI, stroke, CV mortality); CHF, AF, PE/DVD, diabetes, cognitive function, vision, neuro, etc)

• Cancer cohort members also members of other non-cancer consortia.
Multiple Outcomes

- Proposed first step: proof-of-principle by cohorts validated non-cancer outcomes (eg. CVD).
- If feasible, extend communication (marketing) begun at October meeting to other Institutes: think of us, we can be part of solutions.
Obstacles to be Overcome

• Many – but can be overcome - and progress already being made.

• Cannot overstate: NIH is critical to assist with and accelerate the process.

• Some obstacles are structural:
  • For joint outcomes, need facilitating joint funding by multiple Institutes. Critical!
  • Need non-disease specific funding mechanisms, to deal with disease-specific study sections.
  • Integrated NIH management of cohorts.
Obstacles to be Overcome

- #1 concern of cohort leaders: need financial support for basic infrastructure: maintain data collection, blood repository, validation endpoints.
- Critical to continue to contribute to consortium. Cannot underestimate never-ending concern, time-consuming.
- Can’t be unfunded activities. Consider preparation of numbers events, consortium datasets, standardized defns, multiple requests concurrent. No sources for funds.
Obstacles to be Overcome

- Beyond maintaining, support to add new methodologies and technologies as needed to improve cohort.
- Central assistance for cross-cohort projects, such as harmonization.
Obstacles to be Overcome

• Some obstacles are methodologic:
  • NIH serving as liaison for cohorts to get low-cost opportunities to access record linkage, like Medicare/Medicaid (CMS).
  • Driver to overcome hurdles for new record linkage opportunities, such as for those under 65, or mechanisms (EMR).
  • Tracking cancer or mortality outcomes in accessible, cost-effective way.
  • One stop shopping. WHS: IRB applications for many states.
NCI New Initiatives

• Facilitated harmonization of data by outside group. It worked! Time and cost reasonable, trauma low.

• NCI Cancer Epidemiology Cohort Funding Opportunity Announcement.

• Interagency agreement re NDI; streamlining, improvement mortality assessment.

• Pilot of National Virtual Cancer Registry, not centralize storage of data, but centrally link all cohort registries.
Success of Consortium

• Bob Hoover said development and first successes of consortium was grass roots effort.

• True at first, but would not have been enough to continue, without active participation of NCI. True collaboration (R01), and progress on obstacles.

• Never forget how much cohorts want to be collaborating for scientific reasons – just need help.
Maintaining the Pipeline

- Some obstacles are human resources…
- Have to address career development of young investigators. Consortia are problematic.
- Promotion committees appreciate consortium scientific contributions, but don’t know how to recognize an individual’s contributions to consortial activities, especially if co-author 20 of 40.
  - Role of senior investigators to educate
  - Annotated CVs regarding middle authorship, contribution
Maintaining the Pipeline

- Renewal of grants – what is Progress Report?
- Data sharing with outside collaborators, broader public.
- Resource intensive to set up: data updated yearly, data definitions, policies, forms and procedures. Again, unfunded mandate – unless can include in infrastructure grant mechanism.
The Future Perfect

- Jointly funded so can cross multi-disciplinary lines, maximize impact.
- Have cohorts that in present have been harmonized centrally to the extent possible; new cohorts have anticipated need in design.
- Design/conduct of study not harmonized; distinctive reflecting population to be addressed.
- Have facilitated access to inexpensive common data sources to ascertain events/exposures.
- Leveraged innovative methods: digital age
The Future Perfect

- Have a reliable source of continued infrastructure funding.
- Focused on “better, faster, cheaper”. Conduct of studies as resources routine, business-like.
- Makes cohorts very flexible.
- Provides ability for us to concentrate on doing our scientific job, to be a cornerstone and push the field.
- Think ahead when beginning observational study or trial – can we piggy-back, how will use, can we embed, etc.
Use Synthetic vs. Form Mega Cohorts?

• Longstanding discussion – but one does not preclude the other.

• Leverage existing cohorts while developing new ones appropriate to fill identified gaps.

• Don’t need to wait.

• Won’t have everything needed, taking all cohorts together - but no perfect new cohort either. Do have **enough to establish rich research portfolio** on environmental, lifestyle and genetic factors on cancer and other diseases.