NCI Cohort Consortium

The NCI Cohort Consortium is an extramural-intramural partnership to pool the large quantity of data and biospecimens necessary to conduct a wide range of cancer studies. The Consortium, through its collaborative network of investigators, provides a coordinated, interdisciplinary approach to tackling important scientific questions, economies of scale, and opportunities to quicken the pace of research.

OUR MISSION IS TO: *foster communication among investigators leading cohort studies of cancer, promote collaborative research projects for topics not easily addressed in a single study, and identify and address common challenges in cohort research.*

2018-2021 STRATEGIC INITIATIVES: Advancing our Mission Together!

GOALS				
Communication	**Career Development**	**Research Facilitation**	**Leverage Cohorts to Fill Scientific Gaps**	**Address Common Challenges**
Increase the exchange of information and enhance member engagement	Provide networking and educational opportunities for early career investigators	Advance cohort consortia specific research	Promote collaborative research, particularly on cancer incidence and outcomes for rare cancers, cancer subtypes, and rare exposures, not easily addressed in a single cohort study	Identify and address common methodologic challenges in cohort research
STRATEGIES				
Increase the exchange of information at the annual meeting by including interactive sessions and more time for discussion during working group meetings.	Create opportunities for leadership roles within the steering committee and working groups for early career investigators.	Enhance technology infrastructure to support data sharing and harmonization, including CEDCD[1], CMR[2], controlled-access data repositories, and other options (e.g. cloud-based files that can be queried).	Identify and address specific research gaps across the cancer continuum.	Develop, validate and share linkage algorithms for a variety of exposures and outcomes from a variety of sources (e.g. electronic medical records, registries, geospatial databases).
Promote data sharing through CEDCD[1], CMR[2] and accessible controlled-access data repositories, via website, portal and at scientific meetings.		Assess feasibility (and implement if appropriate) of creating a centralized cohort tissue repository.		Develop and share algorithms for harmonization of commonly used data elements.
Provide regular updates in a monthly newsletter and a centralized portal about: • Governance, steering committee activities and decisions; members' roles; proposal review and approval; and working group expectations regarding timelines, data use, data sharing and completion and archiving of activities. • Information about new members, working group activities, best practices, lessons learned, guidelines, and available expertise in the Consortium.	Support opportunities for early career investigators to be invited speakers at the annual meeting.	Provide templates of standardized data sharing agreements (DTA[3], DUA[4], MTA[5]) and informed consent language regarding data sharing.	Identify and address research gaps for: • Rare cancers • Cancer subtypes • Cancer outcomes • Rare exposures • Diverse populations (*see appendix for examples of potential topic areas of interest)	Develop and validate new methodologies. Apply existing methodologies to study rare cancers, cancer subtypes, cancer outcomes and rare exposures.
	Develop a process for fostering collaboration between early career and senior investigators (i.e., matching them in working groups at the annual meeting).	Leverage cloud-based technology to provide comprehensive lists of data that have been harmonized including which working groups have harmonized data.		Develop procedures for validation of measurement instruments, including questionnaire and biomarker data.
	Develop and implement as appropriate, incentives to encourage involvement of early career investigators in working groups.	Assess feasibility (and implement if appropriate) of creating a centralized data repository.		Develop standard procedures for calibration in pooled analyses.
Evaluate the feasibility (and implement if appropriate) of developing a new cohort/member orientation video		Develop publication policy for acknowledgement of the NCI Cohort Consortium projects and working groups.		Identify and share best practices for participant engagement and retention.
Support webinars and other mechanisms to foster exchange of best practices (e.g., data, biospecimen and tissue collection, and data harmonization) and provide working group progress updates.		Support novel approaches and methods to support project managers, and data harmonization for new and existing work groups.		
		Incentivize data sharing.		

CEDCD[1] Cancer Epidemiology Descriptive Cohort Database
CMR[2] Cohort Metadata Repository
DTA[3] Data Transfer Agreement
DUA[4] Data Use Agreement
MTA[5] Material Transfer Agreement

Appendix – Examples of Topic Areas of Interest

a. Rare cancers, multiple primaries or cancers with changing incidence over time
b. Rare exposures or exposures that change over time
c. Health disparities
d. Molecular heterogeneity within cancer types and common molecular signatures across different types of cancer
e. Use of geospatial data in cohort study research
f. Gene-environment interactions, especially for rare cancers or cancer subtypes
g. Impact of co-morbidities (e.g., diabetes) and their treatment on cancer outcomes
h. Understanding the different dynamics of exposures - aging vs. change in exposure (e.g., early age weight gain vs. older age weight loss)
i. Accelerated aging among cancer survivors and the long-term effects of treatment
j. Other "omic" exposures (e.g., metabolome, microbiome, epigenome)
k. Potential use of cohorts for the study of early detection biomarkers
l. Long-term outcomes among cancer survivors

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