NCAB Subcommittee Presentation

Minority Health and Health Disparities Coding and Data Processing at the NCI: Challenges and Opportunities

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NIH NATIONAL CANCER INSTITUTE

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Outline of Presentation

- CRCHD's Mission within the NCI
- Background of Annual MHHD Reporting
- Pertinent Definitions (NIMHD, PL 106-525)
- NCI's MHHD Coding and Reporting Process
- NCI FY '18 Reportable Portfolio and Trends in Funding
- Potential Utilities of Annual MHHD Reportable Portfolio [Gap analysis, Advise on strategic priorities (CRCHD Mission), etc.]
- Current challenges in MHHD data collection and reporting
- Opportunities for improvement (NCI and NIH-wide)

NCI Center to Reduce Cancer Health Disparities (CRCHD)

Mission Statement:

- **Strengthens the NCI cancer research portfolio** in basic, clinical, translational, and population-based research to address cancer health disparities through collaborations with NCI Divisions, Offices, and Centers.

- **Advises** on strategic priorities, program direction, and scientific policy to strengthen cancer disparities research, diversity training, women's health, and sexual and gender minority opportunities.

- Leads NCI's efforts in **increasing workforce diversity** through the training of students and investigators from diverse backgrounds.

Annual MH / HD Coding -- Background

- Congressionally Mandated, PL 106-525 -- Minority Health and Health Disparities Research and Education Act of 2000' (Annual MH and HD $ Reporting)
- IOM Recommendations to NCI; NCI Response, 1999
- Guidelines:
  - 2004 Trans-NIH Working Group
  - 2015 Trans-NIH Working Group (NIMHD Revision of 2004 Guidelines; HD+/-MH)
- Processes:
  - Manual (OBF-CRCHD-DOC-CRCHD-OBF-NIH), 2004-2016
  - Automation (OEFIA/CRCHD-DOC-CRCHD-MCS/OBF), 2017+

Descriptions & Legislative Mandates

Biennial Report to Congress on Minority Health and Health Disparities
Section 10334 of the Patient Protection and Affordable Care Act of 2010 (P.L.111-148) requires the Secretary to submit, on a biennial basis, a report to Congress to describe the activities carried out by HHS during the preceding two fiscal years to address minority health and health disparities, and the outcome of these activities. NIH reports on selected MHHD activities at the program/initiative level and aligns those programs to the goals of the HHS Action Plan to Reduce Racial and Ethnic Health Disparities. Reports are/are not available online here. [Data Call – August/September Even Years (next in FY16)]

BRAIN
The Biomedical Research Advanced Information Network (BRAIN) is a database used to brief the NIH Director for Congressional Appropriations hearings each year. NIMHD leads the record on Health Disparities Research and many ICs are contributors. Required by NIH, but not legislatively mandated. Data are not available online. Reports are only available online to certain NIH staff. [Data Call – Late November/December; not all ICs are contributors]

Health Research Advisory Council (HRAC) Meeting Report
Established in 2006, managed by Office of Minority Health in HHS, HRAC is comprised of representatives from each IHS area. HRAC serves a formal avenue through which the HHS gathers tribal input on health research matters. NIH prepares a report for the annual HRAC meeting which lists selected research projects of relevance for American Indian and Alaska Native populations. NIH is asked for a report to be given at the annual meeting each June that lists selected major activities in support of AI/AN research and training, funding to Tribal entities, collaborations with Tribal entities, open FOAs that Tribal entities can apply for, and recently announced or upcoming calls for nominations for AI/AN grant reviewers. Reports are/are not available online here. [Data Call – August]

HHS Annual Tribal Budget Consultation
The HHS Annual Tribal Budget Consultation (ATBC) provides a forum for tribes to share their views with HHS officials on various cross-cutting issues important to Indian Country. These include national health and human services funding priorities and recommendations for the Department's next FY budget request. NIH provides briefing items for high level hot issues only. Reports are not available online. [Data Call – February; not always sent to ICs]

HHS Action Plan to Reduce Racial and Ethnic Disparities Progress Report
HHS collects data annually to assess progress toward the Action Steps listed in the HHS Disparities Action Plan. NIH reports on 7 Action Steps related to specific programs of 6 ICs (NIDA, NHLBI, NIDDK, NCI, NIA, NIMHD). *Need more info on mandate.* Reports are/are not available online here. [Data Call – June/July; was not received in FY 2015; only select ICs required to report]

Inclusion of Women and Minorities in Clinical Research (Biennial)
Need more information

MHHD Definition of Terms (NIMHD)

Frequently, the terms **minority health** and **health disparities** are used interchangeably. However, the two terms cover distinct areas of research with substantial overlap in areas where identification of or impact on a disparity is recognized.

- **Minority Health** refers to the distinctive health characteristics and attributes of a racial and/or ethnic group who is socially disadvantaged and/or subject to potential discriminatory acts.
- **Health Disparity** is defined as a health difference that adversely affects disadvantaged populations, based on one or more of the specified health outcomes:
  - Higher incidence and/or prevalence of disease and/or disorders;
  - Premature and/or excessive mortality in diseases where populations differ;
  - Greater burden of disease demonstrated with metrics such as reduced quality of life or disability-adjusted life years (DALYs); or
  - Poorer daily functioning.
- **Health Disparity Populations** include racial and ethnic minorities/ minority populations, rural residents, less privileged socioeconomic status (SES), and Others subject to discrimination [e.g., sexual and gender minorities (SGM)].

MHHD Definition of Terms (Cont'd)

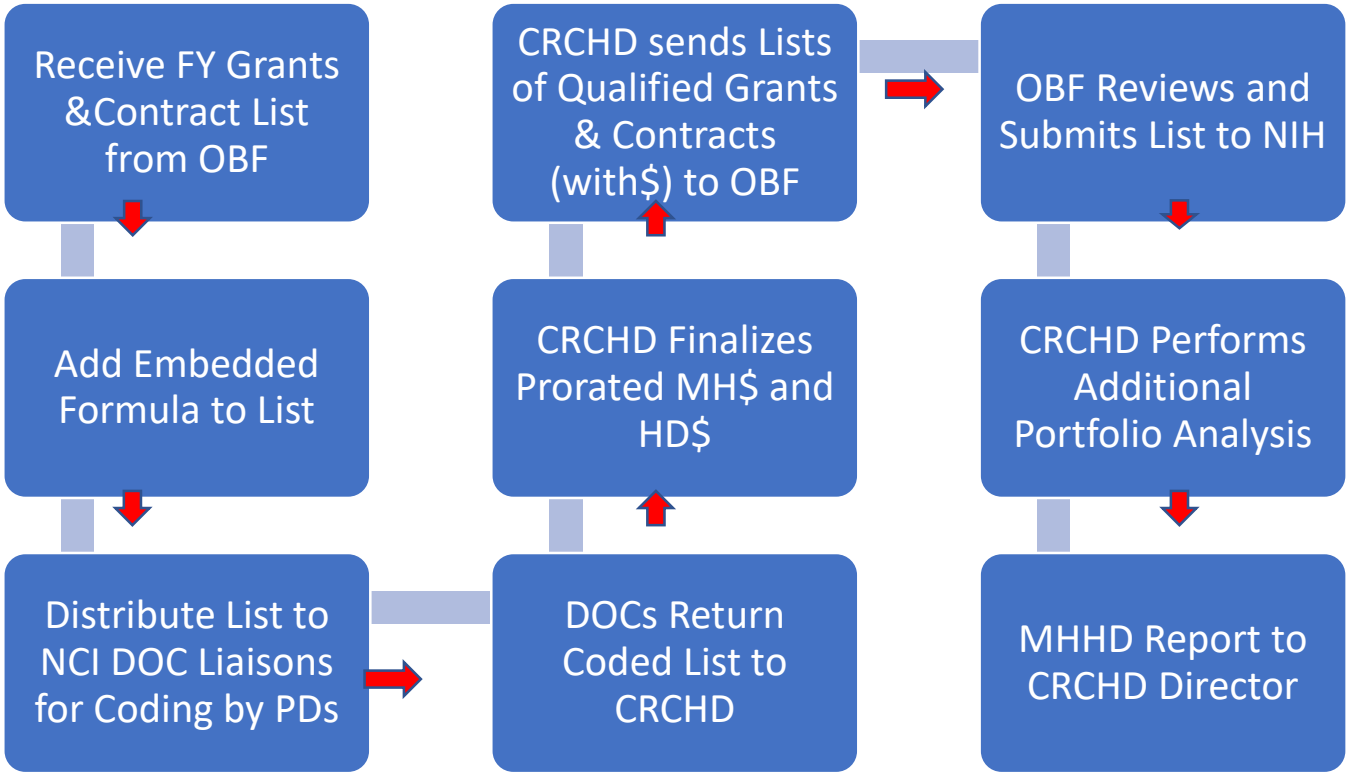
Minority health research is the scientific investigation of distinctive health characteristics and attributes of minority racial and/or ethnic groups who are usually underrepresented in biomedical research in order to understand population health outcomes. Racial and ethnic populations included in this definition are defined by the Office of Management and Budget Directive 15.

Health disparities research is a multi-disciplinary field of study devoted to gaining greater scientific knowledge about the influence of health determinants, understanding the role of different pathways leading to disparities, and determining how this knowledge is translated into interventions to reduce or eliminate health disparities.

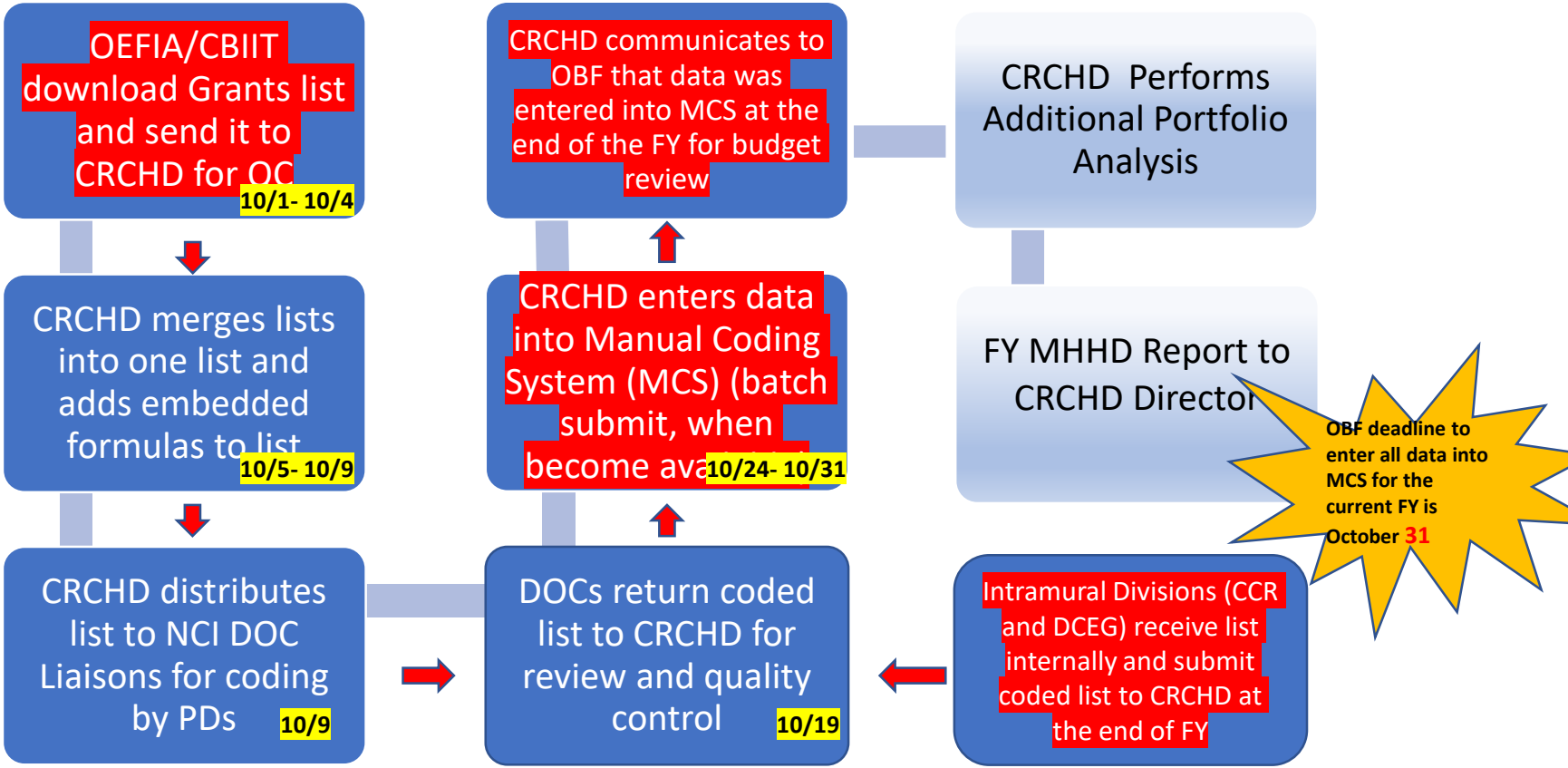
MHHD Definition of Terms (Cont'd) – PL 106-525

Term	Definition
Minority health research	Minority Health Research (MH) includes basic, clinical, and social sciences studies that focus on identifying, understanding, preventing diagnosing and treating such conditions as diseases and disorders, including mental health and substance abuse, that are unique to, more serious in, or more prevalent in racial and ethnic minorities (i.e., African Americans, Asian Americans, Hawaiian Islanders, Hispanic/Latino American, Native Americans/Alaska Natives, Pacific Islanders) for which the factors of medical risks or types of intervention may be different for such population groups.
Health disparities research	Basic, clinical and social sciences studies that focus on identifying, understanding, preventing, diagnosing and treating health conditions such as diseases, disorders, and such other conditions that are unique to, more serious, or more prevalent in subpopulations in socioeconomically disadvantaged (i.e., low education level, lives in poverty) and medically underserved, rural, and urban communities. Overall, **health disparities research includes three components:** 1) Minority health research and related activities, 2) Rural health research and related activities, and 3) Research and other activities related to the socioeconomically disadvantaged in the urban setting.
Basic research	Research on a disease, condition, biological process, behavior, or mechanism of disease or basic biological processes.
Targeted basic research - minority health	Research on a disease, condition, or biological process that affects exclusively or almost exclusively one or more minority populations. A behavior that is found exclusively or almost exclusively in one or more minority populations. Research on whether and/or how the mechanisms of disease or basic biological processes differ in minority populations; or how behaviors differ in minority populations.
Targeted basic research - health disparities	Research on a disease, condition, or biological process that affects exclusively or almost exclusively low SES or rural populations. Research on a behavior that is found exclusively or almost exclusively in low-SES or rural populations. Research on whether and/or how the mechanisms of disease or basic biological processes differ in low-SES or rural populations; or how behaviors differ in low-SES or rural populations.

Annual NCI MHHD Portfolio Analysis and Reporting Process (Pre-MCS, FY '17)



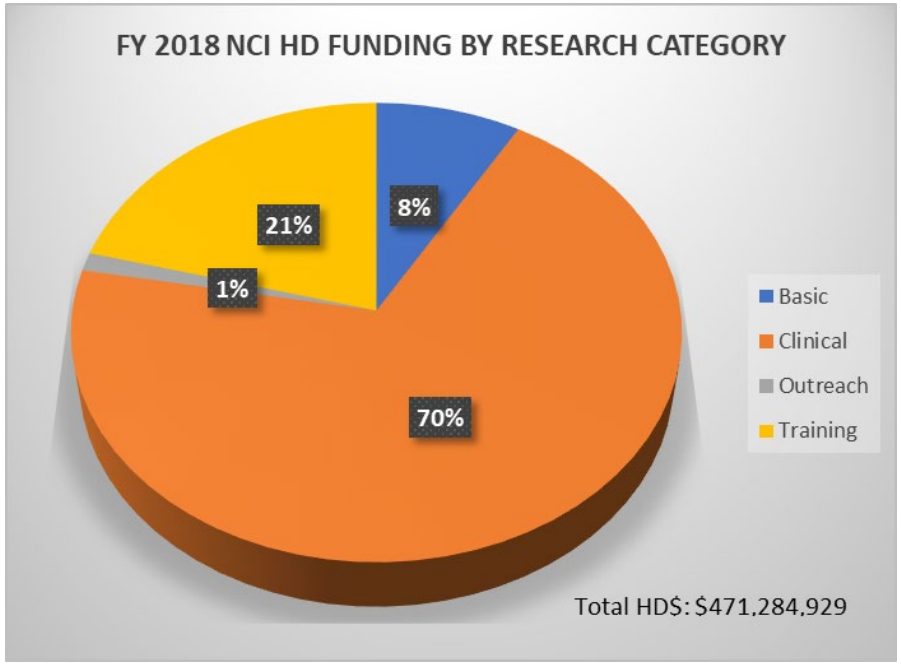
NCI/CRCHD MHHD Reporting Process and Timeline, FY 2017+



FY 2016 DOC Subtotals		
DOC	$ MH	$ HD
CCR	$ 12,149,768	$ 13,824,251
CCT	$ -	$ -
CRCHD	$ 66,262,494	$ 72,305,369
CSSI	$ 113,541	$ 113,541
DCB	$ 6,961,912	$ 8,308,863
DCCPS	$ 74,987,455	$ 82,494,363
DCEG	$ 10,064,910	$ 10,064,910
DCP	$ 11,826,838	$ 11,982,080
DCTD	$ 48,812,272	$ 50,286,426
OHAM	$ 25,475,425	$ 25,527,960
SBIR	$ 12,663,556	$ 14,149,707
NCI Total	**$ 269,318,171**	**$ 289,057,470**

FY 2018 DOC Subtotals		
DOC	$ MH	$ HD
CCR	$ 11,808,484	$ 13,666,536
CCT	$ 23,617,208	$ 26,979,870
CRCHD	$ 87,738,416	$ 87,885,751
CSSI	$ 353,414	$ 353,414
DCB	$ 5,952,477	$ 7,142,863
DCCPS	$ 97,947,112	$141,688,761
DCEG	$ 15,799,194	$ 15,874,039
DCP	$ 12,701,017	$ 14,066,870
DCTD	$ 92,504,431	$123,556,612
OHAM	$ 22,260,832	$ 22,635,397
SBIR	$ 16,377,239	$ 17,566,757
NCI Total	**$ 387,059,824**	**$471,416,870**

FY 2018 HD Funding by DOC and Research Category (Intramural/ Extramural)					
DOC	Basic	Clinical	Outreach	Training	TOTAL
CCR	$12,226,449	$1,440,087	$ -	$ -	**$13,666,536**
DCEG	$ -	$15,874,039	$ -	$ -	**$15,874,039**
Intramural Sub-Total	**$12,226,449**	**$17,314,126**	**$0**	**$0**	**$29,540,575**
CCT	**$0**	**$0**	**$0**	**$26,979,870**	**$26,979,870**
CRCHD	$530,302	$10,303,671	$6,029,457	$70,890,379	**$87,753,809**
CSSI	$ -	$ -	$ -	$ 353,414	**$353,414**
DCB	$7,142,863	$ -	$ -	$ -	**$7,142,863**
DCCPS	$ -	$141,688,761	$ -	$ -	**$141,688,761**
DCP	$ -	$14,066,870	$ -	$ -	**$14,066,870**
DCTD	$ 5,946,574	$117,610,039	$ -	$ -	**$123,556,613**
OHAM	$ -	$22,635,397	$ -	$ -	**$22,635,397**
SBIRDC	$13,885,871	$3,680,886	$ -	$ -	**$17,566,757**
Extramural Sub-Total	**$27,505,610**	**$309,985,624**	**$6,029,457**	**$98,223,663**	**$441,744,354**
TOTAL	**$39,732,059**	**$327,299,750**	**$6,029,457**	**$98,223,663**	**$471,284,929**


FY 2018 NCI HD FUNDING BY RESEARCH CATEGORY
8%
70%
1%
21%
Basic
Clinical
Outreach
Training
Total HD$: $471,284,929

Trends in NCI Health Disparities (non-ARRA) Funding by DOC, FY '10 thru' FY '18

(Actual Amounts in Dollars)

	FY '10	FY '11	FY '12	FY '13	FY '14	FY '15	FY'16	FY'17 *	FY'18	% Change '16/'18	$ Change
CCR	11,169,446	13,889,383	13,933,059	11,621,748	13,678,314	13,141,043	13,824,251	N/A	13,666,536	-1%	$ (157,715
CRCHD	92,936,980	93,821,512	95,980,804	76,926,856	86,839,143	78,516,521	72,305,369	N/A	87,885,751	22%	$ 15,580,382
CSSI	2,666,635	3,591,506	0	176,319	1,853,378	0	113,541	N/A	353,414	211%	$ 239,873
DCB	706,244	3,981,393	6,431,775	5,739,852	5,143,137	4,795,579	8,308,863	N/A	7,142,863	-14%	$ (1,166,000
DCCPS	108,094,014	116,593,910	59,232,845	127,752,826	100,567,917	84,337,120	82,494,363	N/A	141,688,761	72%	$ 59,194,398
DCEG	1,679,234	1,743,624	13,977,834	1,333,960	3,656,338	5,542,282	10,064,910	N/A	15,874,039	58%	$ 5,809,129
DCP	11,349,237	0	20,244	9,800,769	14,507,841	19,573,627	11,982,080	N/A	14,066,870	17%	$ 2,084,790
DCTD	40,300,463	33,609,523	22,532,257	33,994,012	43,607,476	10,929,519	50,286,426	N/A	123,556,612	146%	$ 73,270,186
NCICB	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OD-CSD	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
ODDES*	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OD-OC/OCE	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OD-OESI	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OCTR-CMBB	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OCTR-CTB	0	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OCTR	200,000	0	0	0	0	0	0	N/A	0	#DIV/0!	$ -
CCT	16,623,382	14,042,911	0	0	0	0	0	N/A	26,979,870	#DIV/0!	$ 26,979,870
OHAM	9,336,150	5,096,737	0	9,244,718	2,164,379	7,435,800	25,527,960	N/A	22,635,397	-11%	$ (2,892,563)
OD/NCCCP		2,133,471	0	0	0	0	0	N/A	0	#DIV/0!	$ -
OOD/SBIR	10,913,187	4,673,435	0	6,884,449	2,899,397	13,472,790	14,149,707	N/A	17,566,757	5%	$ 3,417,050
Grand Total (FY)	**$305,974,972**	**$293,177,405**	**$212,108,817**	**$283,475,508**	**$274,917,319**	**$237,744,279**	**$289,057,470**	**$ 344,605,693**	**$471,416,870**	**22%**	**$ 182,359,400**
Annual NCI Budget	5,103,388,000	$5,058,577,213	$5,072,183,421	$4,779,000,000	$4,923,000,000	$4,950,000,000	$5,214,701,000	$5,689,329,000	$5,964,800,000	5%	**$ 750,099,000**
% of NCI Budget	**6.00%**	**5.80%**	**4.18%**	**5.93%**	**5.58%**	**4.80%**	**5.54%**	**6.06%**	**7.90%**	**2.36%**	

Note: ODDES included OCTR in FY '03 and FY '04*

** FY'17 Data Incomplete, there Not Appropriate for Inclusion here (See MCS); Grand Total and NCI Budget from RePORTER*

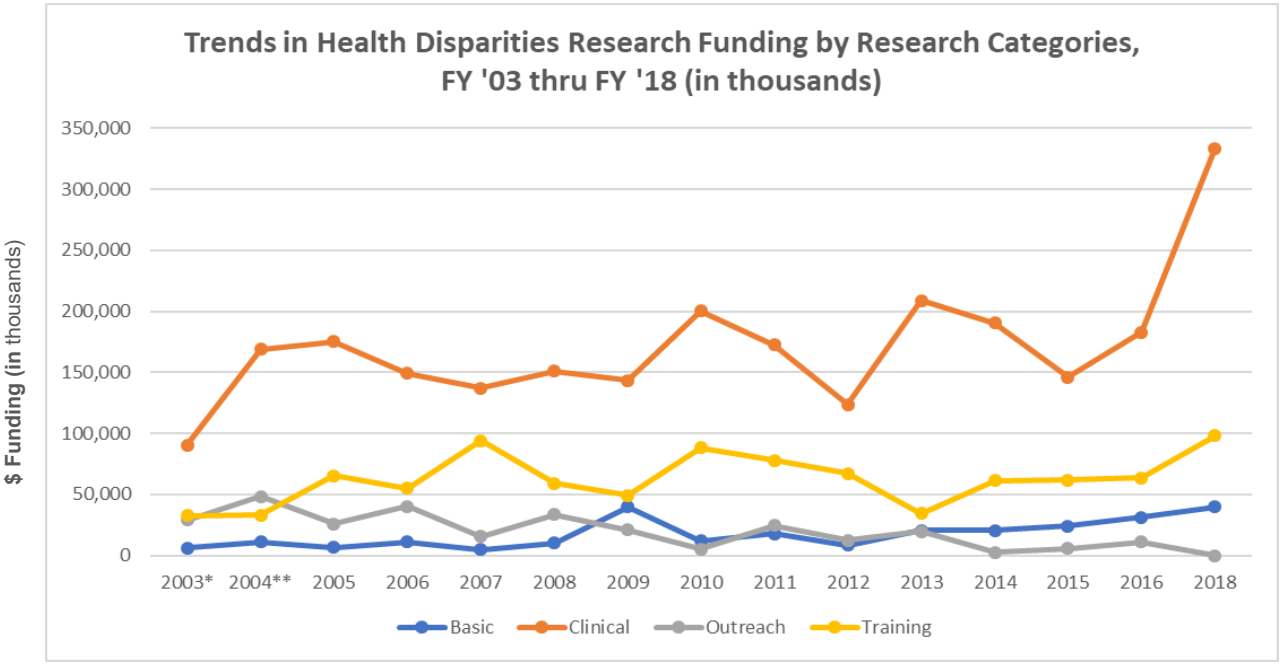
Source: NCI budget from NCI Annual Factbooks and Appropriations History

Trends in NCI MH & HD Funding, FY ‘16 – ‘18

	2016	2017*	2018*	Change ('18-'17)	%Change
MH	$ 263,749,672	$ 306,871,406	$ 405,227,791	$ 96,043,627	31.29
HD	$ 289,057,470	$ 344,605,693	$ 487,138,724	$142,533,031	41.36
NCI Budget	$ 5,214,701,000	$ 5,689,329,000	$ 5,964,800,000		
%NCI Budget (MH)	5.06	5.39	6.75	1.36	
%NCI Budget (HD)	5.54	6.06	7.90	1.84	

* Data Entry into Manual Categorization System (MCS)

Trends Analysis



DCCPS Health Disparities Portfolio

Health disparities are differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups.

Continued growth in the Health Disparities and Medically Underserved Research Grants

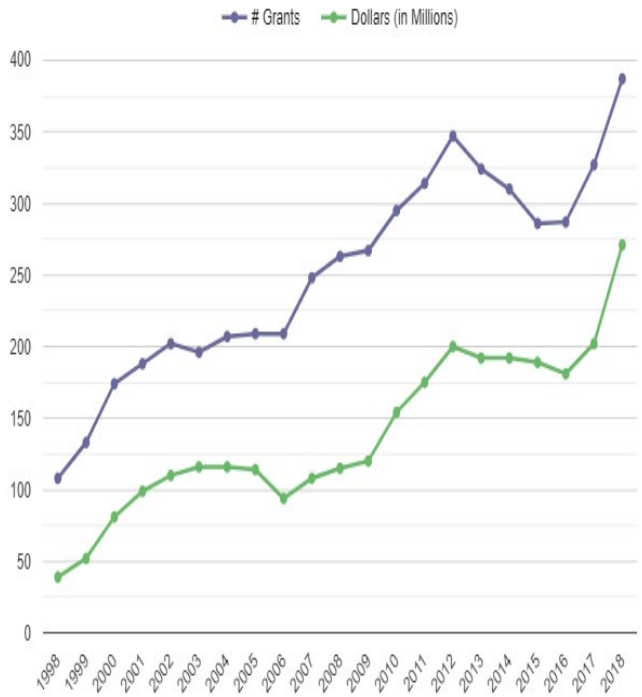


Figure 3b: Distribution of CCT Trainees by Race and Ethnicity (from FY 2011 MHHD Report)

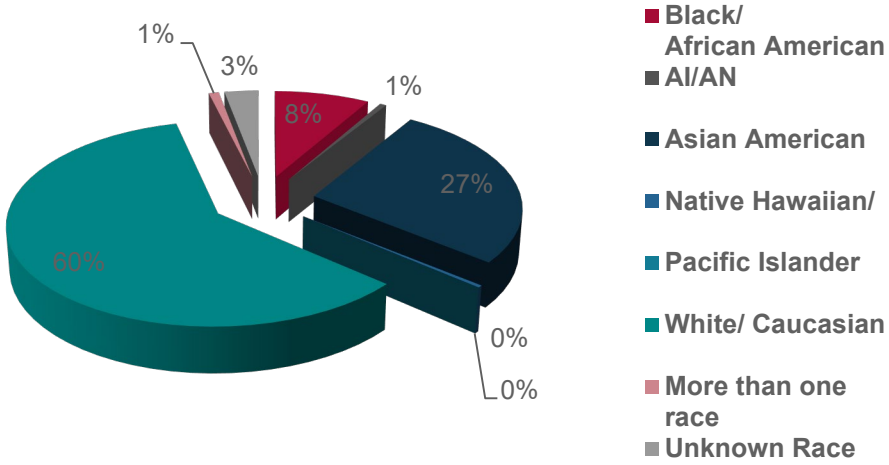
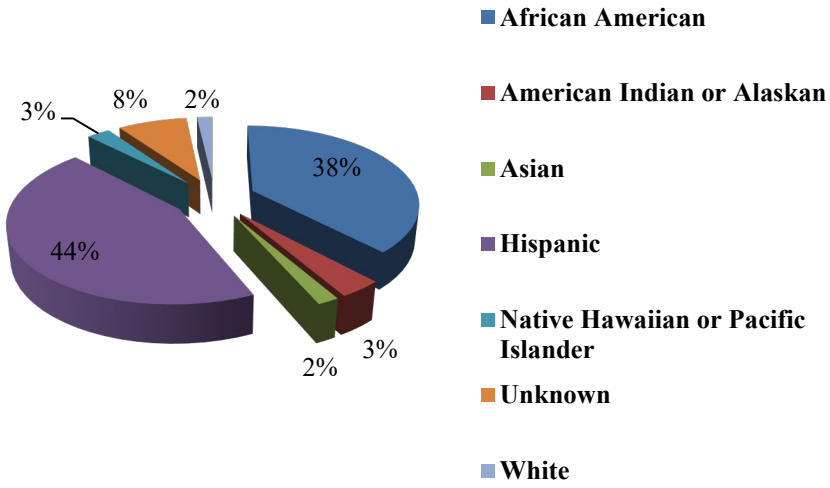


Figure 3a: Distribution of CRCHD Trainees by Race and Ethnicity, FY 2018



Sample NCI MHHD Projects

NCI's Efforts/ Research Initiatives to Address Cancer Health Disparities

- Multiple fronts (basic research, clinical, community-level, surveillance and portfolio analysis to identify areas for further studies)
- Multiple cancer sites (lung, prostate, breast, colorectal, brain, etc.)
- Basic Research – CCR/ Clinical Center

  (genetic and biological basis of health disparities; risk factors identification and pathways/mechanisms of cancer initiation/development and progression; molecular biology/ genomics; epidemiological and translational research strategies, etc.)
- Community-based Clinical trials and cancer care research – DCP and DCTD: National Clinical Trials Network (NTCN) and NCI Community Oncology Research Program (NCORP) to increase participation of R/E minority pops. and other underserved populations in clinical trials, test interventions/ protocol accrual, and biospecimen collection in community-based clinical settings;

NCI's Efforts/ Research Initiatives to Address Cancer Health Disparities

- Surveillance and Population-level Research – DCCPS

  (SEER/CDC/CMS national tumor registries and research partnerships; steady improvement in breast cancer survival rates…however, R/E disparities remain/ benefits not shared equally; increasing incidence and prevalence of liver cancer among all population groups);

- Genetic factors in Breast cancer etiology and outcomes

  (Breast Cancer Genetic Study in African-Ancestry Populations; African American Breast Cancer Consortium; African American Breast Cancer Epidemiology and Risk Consortium, and the NCI Cohort Consortium; biospecimen repositories, resources and data sharing; studies in entire cancer control continuum, biology to prevention, access to treatment, and survival care);

- Population Sciences: Health disparities component in nearly half of DCCPS grants portfolio, including Rural health; increase in rural health disparities research, and implementation science to increase cancer screening rates;

- Physical activity and risk reduction interventions in overweight African American and Hispanic/ Latina women.

NCI's Efforts/ Research Initiatives to Address Cancer Health Disparities

- Community-based Participatory Research (CBPR) – CRCHD

  (in ***and*** with communities experiencing cancer health disparities; all minority population groups and underserved communities; national and regional Centers; Cooperative Agreement – academia, communities/ community-based clinicians/ FQCHCs, and NCI; focused on reducing cancer health disparities – risk factors/ behavioral, screening, and access to care);

- Partnerships to Advance Cancer Health Equity (PACHE)

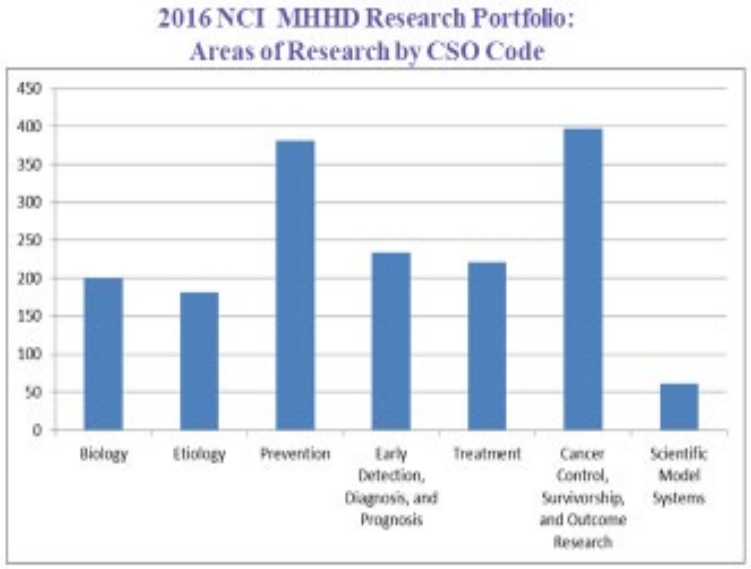
  (Partnerships and collaborations among investigators at institutions that serve communities with cancer health disparities, including communities served by NCI-Designated Cancer Centers; factors/ causes underlying cancer health disparities; outreach, research training and education of underrepresented students and investigators across the cancer research continuum, including CHD.

NCI's Efforts/Research Initiatives to Address Cancer Health Disparities

- Diversity Training/ Career Development – CRCHD
- Training of Individuals from backgrounds typically underrepresented in cancer research and cancer health disparities research;
- Continuing Umbrella of Research Experience (CURE)
  - (holistic approach toward independence in a career in cancer research; supports these individuals across the academic continuum, from middle/ high school students through early-stage investigators; has increased the participation and competitiveness of under-represented individuals in biomedical, behavioral and clinical research.)
  - iCURE: CRCHD & CCR collaborations to increase representation of underrepresented scholars and scientists in NIH/NCI intramural research
- Partnerships and Collaborations to Develop a blueprint for prioritizing areas of focus for disparities research

(Disparities-focused Think Tanks: NCI CDAC, ASCO, ACS, AACR)

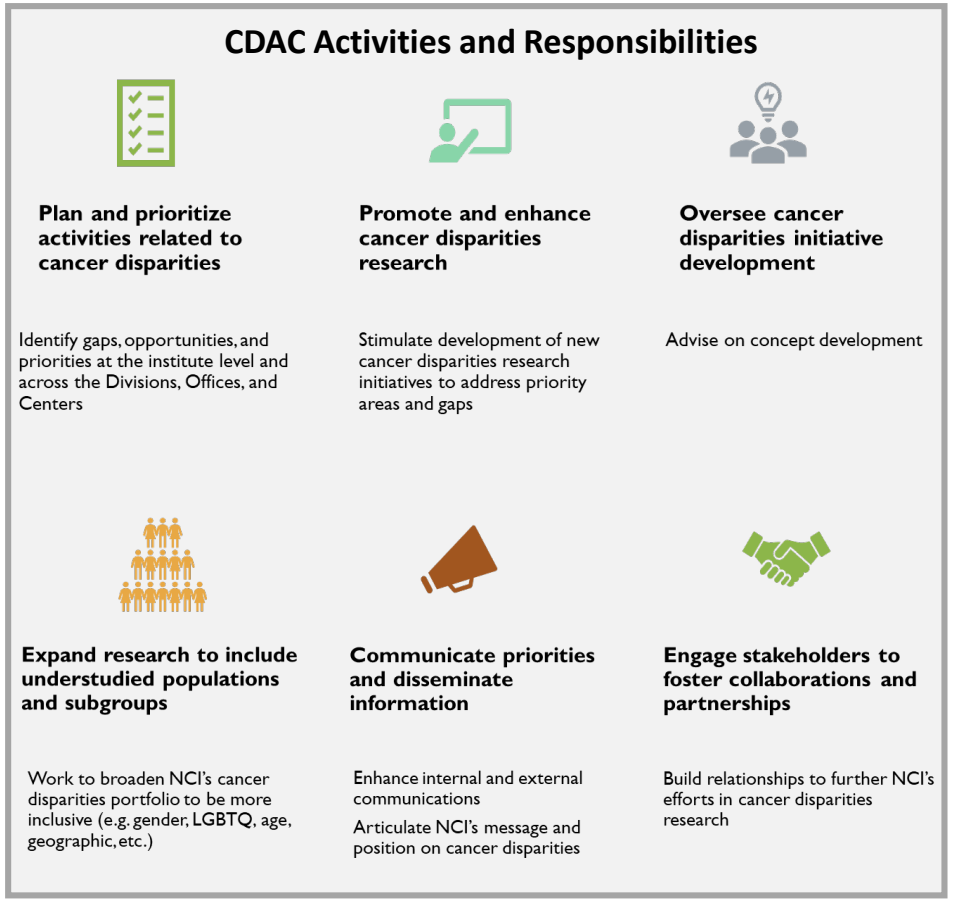
Potential Utilities of MHHD Reportable Portfolio:
Gap Analysis, Priority Setting and Resource Allocation



NOTE: CSO codes not yet available for FY 2017 grants and contracts

Trans-NCI Cancer Disparities Activities Committee (CDAC)

- Initiated in March 2019
- Co-Chaired by Center to Reduce Cancer Health Disparities (CRCHD) and Center for Research Strategy (CRS)
- Purpose:
  - Serve as a hub of cancer disparities activities across the institute leveraging the passion and expertise of staff from all the divisions, offices, and centers.
  - Support research and initiatives that mitigate both the biological and nonbiological factors that contribute to cancer disparities.



Trans-NIH MH&HD Reporting Working Group

CHARGE OF THE GROUP

The charge of the MH&HD Reporting Working Group is to examine how NIH can reliably identify and prepare informative reports on:

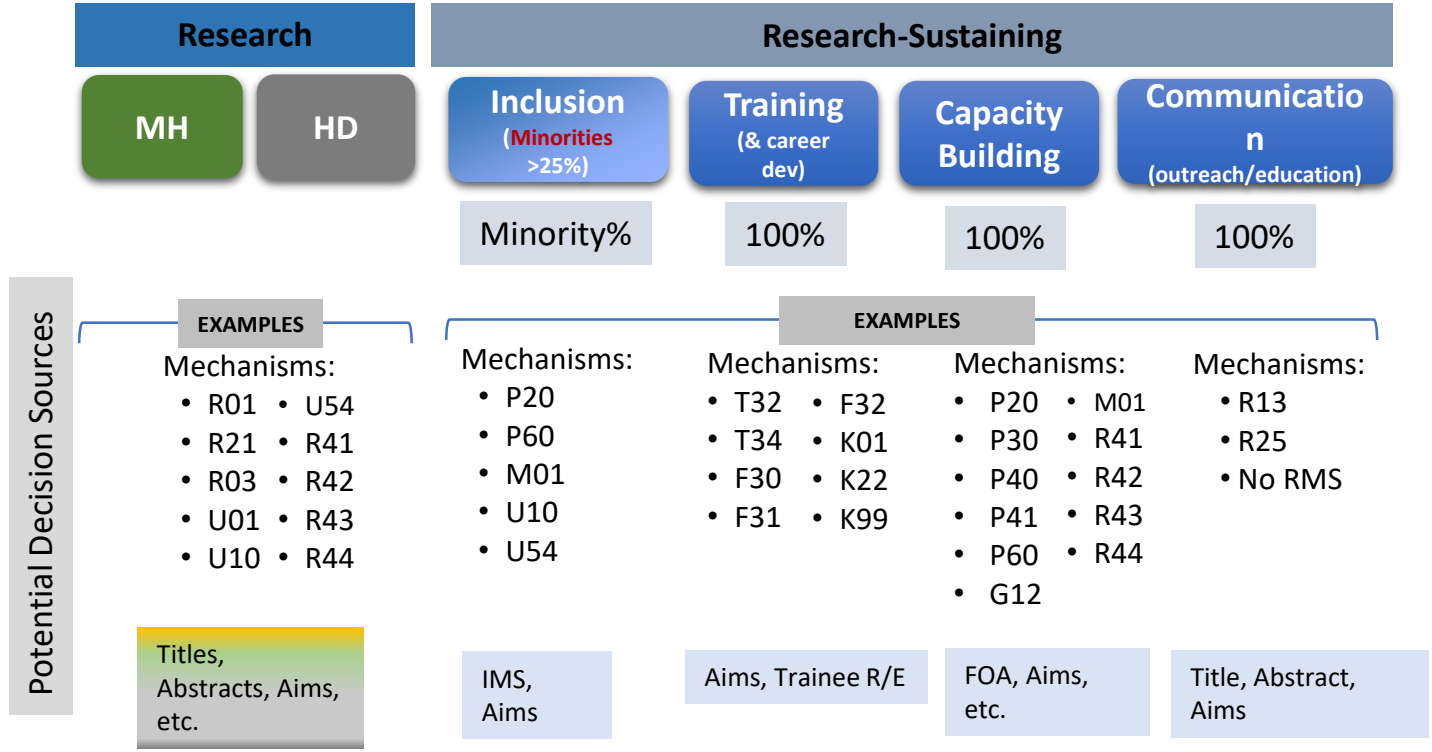
- Minority health and health disparities scientific research, career development/training, and related activities as well as ascertain how to provide these data separately and/or synergistically.
- Research that has achieved reductions in health disparities.

More generally, the group is charged **with examining the purpose of and current procedures used for MH&HD reporting at NIH and determining whether improvements can be made.**

OVERVIEW - DRAFT CODING STRATEGY (NIMHD)

- ❑ External Reporting:
  - Minority Health
  - Health Disparities
- ❑ Internal Reporting
  - Targeted Research
    - Minority Health
    - Health Disparities
  - ○ Research-Sustaining
    - Inclusion
    - Training
    - Capacity Building
    - Communication / Education / Outreach

Internal Initial Coding Decision – Intent of Award at Onset



**Relevant contracts should be included*
**Intramural research program counts as MH/HD research*
**Relevant international research counts as MH/HD research*
**For clinical trials and networks, ICs have the opportunity to revise their coding annually for MH and HD research*

Challenges

- Large number of grants (and contracts) to be coded each year – even though only approx. 33% (~ 2,000 of over 6,000) of NCI grants meet reportable threshold;
- Intramural projects/ sub-projects coding;
- Reportable threshold changed from 25% to 30% starting with FY ‘17 reports (MH and HD) – reflected in formulae;
- Who in NCI should do the coding, PDs / RAEB? CRCHD will continue to consolidate coded projects into a single NCI report;
- Data coding and validation/ QA – deleted formulae and obvious projects not coded;
- Data entry into MCS (DOC liaisons/PDs, CRCHD, or “batch submission”);
- Comparability from year to year (i.e., trends analysis).

Comparison of DOC PD and RAEB Coding, FY 2015 MHHD

2015 Total Project Funding Amount (RCDC)	FY 2015 Category	FY 2015 % Minority Health	% MH used	$ MH	FY 2015 % Health Disparities	% HD used	$ HD	RAEB FY 2015 % Minority Health	RAEB FY 2015 % Health Disparities
$ 411,243	C	100	100	**$ 411,243**	100	100	**$ 411,243**	100	100
$ 307,724	C	100	100	**$ 307,724**	100	100	**$ 307,724**	100	100
$ 596,049	C	0	0	$ -	100	100	**$ 596,049**		100
$ 479,121	C	100	100	**$ 479,121**	100	100	**$ 479,121**	100	100
$ 256,783	C	100	100	**$ 256,783**	100	100	**$ 256,783**	100	100
$ 313,388	C	100	100	**$ 313,388**	100	100	**$ 313,388**	100	100
$ 373,140	C	100	100	**$ 373,140**	100	100	**$ 373,140**	100	100
$ 263,351	C	100	100	**$ 263,351**	100	100	**$ 263,351**	100	100
$ 652,124	C	100	100	**$ 652,124**	100	100	**$ 652,124**	80	80
$ 322,152	C	100	100	**$ 322,152**	100	100	**$ 322,152**	100	100
$ 481,774	C	44	50	**$ 240,887**	45	50	**$ 240,887**	50	50
$ 461,250	C	100	100	**$ 461,250**	100	100	**$ 461,250**	100	100
$ 462,358	C	100	100	**$ 462,358**	100	100	**$ 462,358**	100	100
$ 125,000	O	100	100	**$ 125,000**	150	100	**$ 125,000**	3	2
$ 208,336	O	90	100	**$ 208,336**	90	100	**$ 208,336**		

Improvement Opportunities

- Serious effort to automate MHHD data collection and retrieval across NIH (verification / validation by PDs still essential for data integrity);
- Automated data retrieval/ interface with relevant data sources, e.g., HSS (accrual database);
- Possibility of “batch submission” – CRCHD has offered to work with the NIH RCDC/ MCS Team;
- Retain NCI’s ability to collect data for internal uses (e.g., research categories, percentages and $$$ for “disparities populations”, etc.);
- Support in-depth analysis for NCI (e.g., cancer continuum research in specific “disparities populations” using CSO codes).

Thank You !!!

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