DSD & Intersex Research Portfolio

A Snapshot of the NIH FY 2020 SGM Portfolio Analysis





Introduction

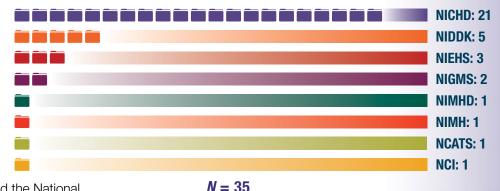
Individuals who have a "difference of sex development" (DSD) and/or identify as "intersex" may have a congenital variation in sex chromosomes; gonads or gonadal development; sex hormone synthesis, function, or profiles; and/or anatomical features that fall outside of typical binary notions of sex. These variations may also be referred to as "variations in sex characteristics" or "intersex traits." Not all individuals with a DSD identify as intersex; they may not wish to be defined by their biological histories, nor do they think of it as an identity. Conversely, not all individuals who identify as intersex or have a variation in sex characteristics were born with an identifiable DSD. Collectively in the snapshot, we will refer to this grouping of DSD & Intersex projects as DSDI.

The full portfolio of NIH-supported research projects on sexual and gender minority (SGM) populations was initially identified using the SGM category, which includes a set of key terms specific to SGM populations. The SGM portfolio was reviewed manually to determine which of the projects in the SGM portfolio were related to DSDI health. The results were compiled with projects reviewed in previous years to identify those that are DSDI-specific or -relevant¹ for FY 2020. Additionally, some projects were identified and included in this analysis based on their funding mechanism. Analyses of the 35 DSDI-related projects identified using this method are presented below. DSDI-related projects constituted roughly 1 in 20 projects of the SGM portfolio for FY 2020.

¹ We generally use the terms "specific" and "relevant" to distinguish between these two broad categories of relevance. *Specific* refers to a project focused primarily on a pertinent disease, condition, or population; *relevant* means that a project pertains to a category, but another disease area, condition, population, or other focus is considered primary.

Projects by Institute or Center

The majority (60.0%) of DSDI projects were administered by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Other Institutes that administered more than one project were the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), with five projects; the National Institute of Environmental Health



Science (NIEHS), with three projects; and the National Institute of General Medical Sciences (NIGMS), with two projects.

Key: NCATS = National Center for Advancing Translational Sciences; NCI = National Cancer Institute; NICHD = Eunice Kennedy Shriver National Institute of Child Health and Human Development; NIDDK = National Institute of Diabetes and Digestive and Kidney Diseases; NIEHS = National Institute of Environmental Health Sciences; NIGMS = National Institute of General Medical Sciences; NIMH = National Institute of Mental Health; NIMHD = National Institute on Minority Health and Health Disparities

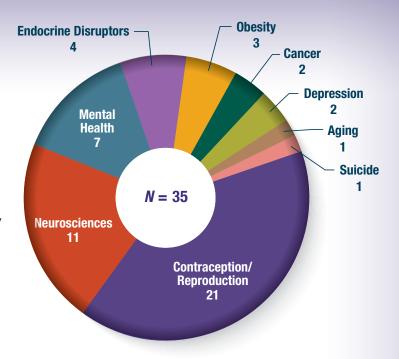
Projects by State

With six projects, Maryland had the largest proportion of DSDI projects (17.1%). California housed five projects (14.3%), and Massachusetts was home to four projects (11.4%). An additional two states had three projects (8.6%) each, two states had two projects (5.7%), and nine states housed a single project (2.9%).

The map indicates the location of the institution and not necessarily where activity on a project took place. One project located outside the United States is not depicted here.

Projects by Disease Area/Health Condition

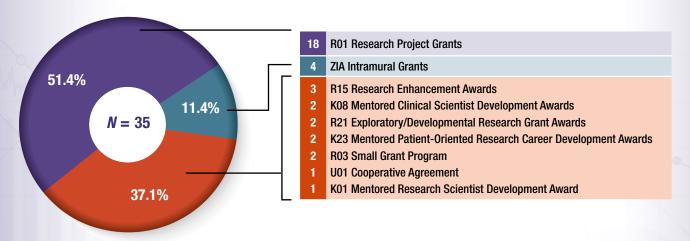
The majority (60.0%) of DSDI projects pertained to contraception/reproduction. Almost one in three (31.4%) were related to neurosciences, and one in five (20.0%) were related to mental health. DSDI projects also were related to endocrine disruptors, obesity, depression, cancer, aging, and suicide. Please note that the total number across conditions is greater than 35 because projects may be counted in more than one category.



Projects by Grant Type (Activity Code)

More than half (51.4%) of DSDI projects were funded through the R01 Research Project Grants mechanism. More than 1 in 10 projects (11.4%) were funded via the NIH intramural research program (ZIA grant mechanism); three projects (8.6%) were funded by Research Enhancement Awards (R15); and the remaining 10 projects were supported by six different funding mechanisms (K01, K08, K23, R03, R21, and U01).

More than half of the projects were funded through the R01 mechanism.



Because of changes in the administration of projects from year to year, the number of projects for the Snapshots may differ somewhat from those published in the corresponding FY 2020 Portfolio Analysis.