

Intersex and Variations in Sex Characteristics Research Portfolio



National Institutes of Health
Sexual & Gender Minority Research Office

A Snapshot of the NIH Fiscal Year 2021 SGM Portfolio Analysis

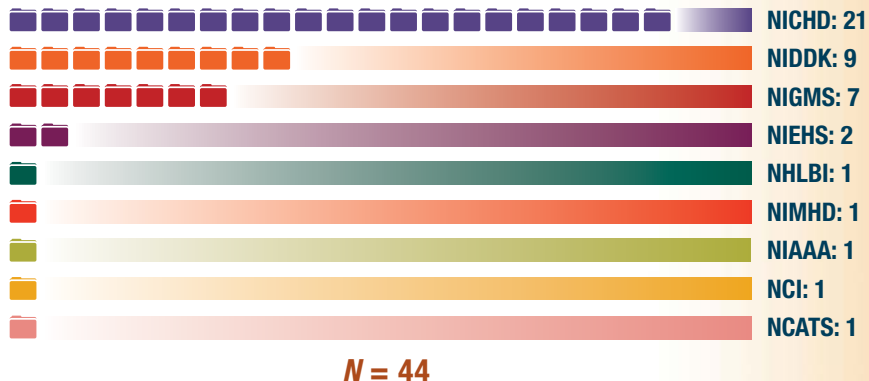
Introduction

Intersex individuals may identify as “intersex” and/or 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 variation in sex characteristics 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 condition. In the snapshot, we collectively will refer to the group of projects that covers both intersex identity and variations in sex characteristics as Intersex and Variations in Sex Characteristics (IVSC).

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 then reviewed manually to determine which of the projects in the SGM portfolio were related to IVSC health. Analyses of the 44 IVSC-related projects identified using this method are presented below. IVSC-related projects constituted 8.1% of projects in the SGM portfolio for fiscal year 2021 (FY21).

Projects by Institute or Center

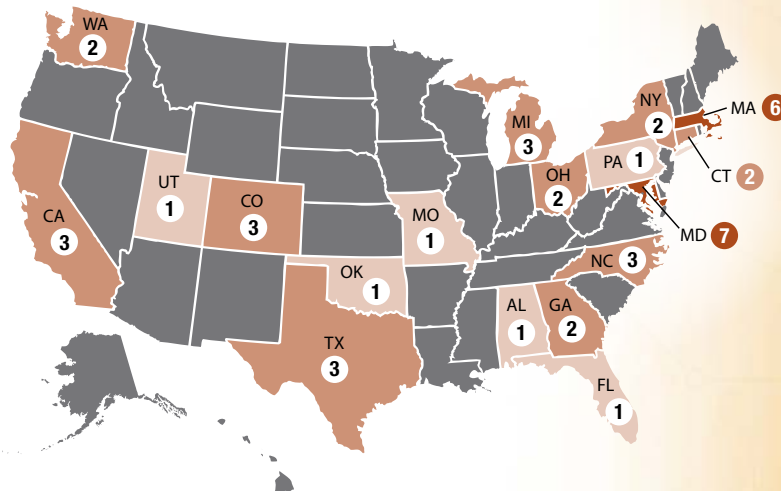
Almost half (47.7%) of IVSC projects were administered by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Other institutes that administered more than one project were the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), with nine projects; National Institute of General Medical Sciences (NIGMS), with seven projects; and National Institute of Environmental Health Sciences (NIEHS), with two projects.



Key: NCATS = National Center for Advancing Translational Sciences; NCI = National Cancer Institute; NHLBI = National Heart, Lung, and Blood Institute; NIAAA = National Institute on Alcohol Abuse and Alcoholism; 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; NIMHD = National Institute on Minority Health and Health Disparities

Projects by State

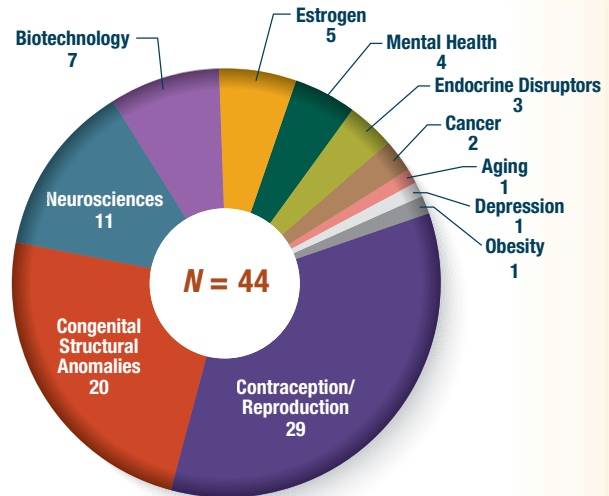
With seven projects, Maryland had the largest proportion of IVSC projects (15.9%) and included projects in the NIH Intramural Research Program. Massachusetts was home to six projects (13.6%), while a number of states had three projects (6.8%) each—California, Colorado, Michigan, North Carolina, and Texas. An additional five states had two projects (4.5%) each, and six states were the administrative home to a single project (2.3%).



The map indicates the location of the funded institution and not necessarily where activity on a project took place. Six projects conducted outside the United States are not depicted.

Projects by Disease Area/Health Condition

The majority (65.9%) of IVSC projects pertained to contraception/reproduction. Almost half (45.5%) were related to congenital structural anomalies, while a quarter (25.0%) were related to the neurosciences. About 1 in 7 studies (15.9%) were related to biotechnology, just over 1 in 10 (11.4%) were related to estrogen, and just under 1 in 10 (9.1%) were related to mental health. IVSC projects also were related to endocrine disruptors, cancer, aging, depression, and obesity.

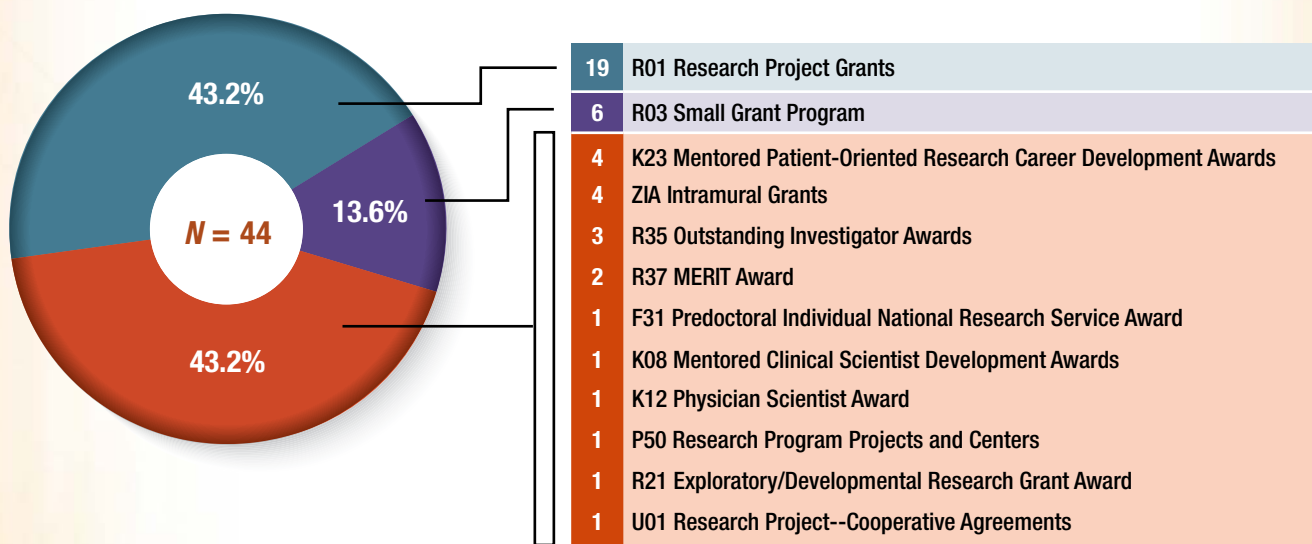


The total number of projects across conditions is greater than 44 because projects may be counted in more than one category.

Projects by Grant Type (Activity Code)

The majority (43.2%) of IVSC projects were funded through the R01 Research Project Grants mechanism. More than 1 in 10 projects (13.6%) were funded via the Small Grant Program (R03). The Mentored Patient-Oriented Research Career Development Awards (K23) and Intramural Grants (ZIA), each accounting for 9.1% of projects, rounded out the four largest categories, which amounted to a full three-quarters (75.0%) of all IVSC projects. The Outstanding Investigator Awards (R35), with three projects (6.8%), and the Method to Extend Research in Time (MERIT) Award program (R37), with two projects, accounted for the other two mechanisms that had more than one project each. The remaining six projects were supported by six other types of funding mechanisms (F31, K08, K12, P50, R21, and U01).

The majority of IVSC 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 FY21 Portfolio Analysis.