Center for Translational & Policy Research on Personalized Medicine

Pediatric and Prenatal Whole Exome Sequencing: Coverage, Price, and Reimbursement

TRANSPERS Objectives:

TRANSPERS is conducting a sub-aim on reimbursement as part of an NHGRI-funded study on the clinical utility of neurocognitive disorders in a pediatric cohort (NDPC) and structural birth defects in a prenatal cohort (SBDPC) for multigene tests (panels and sequencing tests). We are examining “coverage, price, and reimbursement” (“CPR”): what tests are covered by payers, why are tests covered or not covered, and how CPR influences testing decisions and practices in clinic settings.

Parent Grant Overview:

The UCSF Program in Prenatal and Pediatric Genome Sequencing (P3EGS), which is part of the multi-site Clinical Evidence-Generating Research (CSER) consortium funded by the National Human Genome Research Institutewill study the utility of whole exome sequencing as a tool for 1) diagnosing infants and children with serious developmental disorders, and, 2) providing genetic information to parents when a prenatal study reveals a fetus with a structural anomaly. We will also address ethical, social and economic issues in the delivery of genomic sequencing results to diverse populations, such as underrepresented minorities and the medically underserved.

TRANSPERS Contribution:

We published a review of WES payer coverage policies for WES in pediatric neurocognitive disorders (Douglas, 2019) and a paper on payers' decisionmaking for WES in pediatric neurocognitive disorders and prenatal genetic anomalies (Trosman 2020). We are also investigating payer coverage and the decisionmaking process for whole genome and whole exome sequencing across CSER2 sites.

Study outcomes will improve understanding and transparency of coverage policies and provide information on what issues need to be addressed and possible solutions. The outcomes will also improve the understanding of the decisions making process that ultimately impact patients, providers, and society by impacting health and economic outcomes.

References:

Douglas MP, Parker SL, Trosman JR, et al. Private Payer Coverage Policies for Exome Sequencing (ES) in Pediatric Patients: Trends Over Time and Analysis of Evidence Cited. Genet Med. 2019;21(1):152-160.

Trosman JR, Weldon CB, Slavotinek A, Norton ME, Douglas MP, Phillips KA. Perspectives of US private payers on insurance coverage for pediatric and prenatal exome sequencing: Results of a study from the Program in Prenatal and Pediatric Genomic Sequencing (P3EGS). Genet Med. 2020;22(2): 283-291.

TRANSPERS

Launched in 2008, the Center for Translational and Policy Research on Personalized Medicine (TRANSPERS) at the University of California, San Francisco is a first-of-its-kind research center dedicated to developing evidence-based information for patients, providers, industry, researchers and policymakers to objectively assess how personalized medicine can be most beneficial and efficient in improving health outcomes. The TRANSPERS Center has been funded by grants from the National Institutes of Health (NIH) and several foundations.

Key Collaborators: UCSF (Phillips, Kwok [PI], Koenig, Risch, Slavotinek, Norton, Douglas); Executive Frameworks (Trosman, Weldon)

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TRANSPERS Center, UCSF | 3333 California Street #415, Box 0613, San Francisco, CA 94143

T: 415.502.4025 | transpersinfo@ucsf.edu | https://pharm.ucsf.edu/transpers