



Center for Translational & Policy Research on Personalized Medicine

NEWSLETTER

Fall 2017

A Letter from Center Director Kathryn A. Phillips, PhD

Dear Colleagues,

Fall is a time of "new beginnings", and we're excited to report on new funding to develop needed evidence on the use and reimbursement for new genomic tests - whole exome sequencing in prenatal and pediatric patients and tumor sequencing. We are also pleased to congratulate Elena Elkin PhD MPA on completing the prestigious Robert Wood Johnson Foundation Health Policy Fellows program in Washington DC, and we report on our continued engagement in helping to direct genomics research in Canada.

As always, we welcome your thoughts, comments, and ideas for collaboration.

Best,

A handwritten signature in black ink that reads 'Kathryn'.

Kathryn Phillips, PhD
TRANSPERS Center Director

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TRANSPERS to lead reimbursement studies in NIH award to UCSF to accelerate the use of genome sequencing in clinical care

TRANSPERS is delighted to be part of the UCSF team awarded an \$11.7 Million grant to launch a new [Program in Prenatal and Pediatric Genomic Sequencing](#) (P³EGS). TRANSPERS will lead a project to examine the role of reimbursement for new genomic tests for pediatric disorders and fetal anomalies, asking what tests are covered by payers, why tests are covered or not covered, and how reimbursement influences testing decisions in actual clinical practice.

This research is being funded as part of the Clinical Sequencing Evidence-Generating Research (CSER2) Consortium, which includes six clinical sites and a coordinating center. The new awards will generate innovative approaches and best practices to ensure that the effectiveness of genomic medicine can be applied to all individuals and groups, including diverse and underserved populations, and in healthcare settings that extend beyond academic medical centers. [More information from NHGRI.](#)

TRANSPERS receives funding to address key gap in evidence on reimbursement for new genomic tests: Who pays? Who benefits?

Little is known about whether and how reimbursement takes place in clinical practice and what type of evidence can be collected and analyzed to understand how and why new genomic tests are reimbursed. These new tests can be costly and be variably reimbursed by payers, creating uncertainty and *ad hoc* solutions that are unsustainable. TRANSPERS has been awarded two pilot studies at UCSF to examine the process and outcomes of reimbursement for patients receiving whole exome sequencing or tumor sequencing. Initial results on whole exome sequencing indicate that there is an urgent need to understand how test costs and reimbursement impact patients and providers, to streamline the test ordering and reimbursement process, and to develop evidence using multiple, complementary data sources.

Elena Elkin, TRANSPERS collaborator, completes her Robert Wood Johnson Foundation Health Policy Fellows program in Washington, D.C.

Elena Elkin PhD MPA has returned to her position at Memorial Sloan Kettering Cancer Center and the Weill Cornell Medical College after completing the Robert Wood Johnson Fellowship Program in Washington DC. For the past 40 years, this non-partisan fellowship has offered exclusive, hands-on policy experience with the most influential congressional and executive offices in the nation's capital to exceptional mid-career health professionals and behavioral and social scientists with an interest in health and health care. Elena worked with Senator Sheldon Whitehouse (D-RI). Congratulations to Elena!



TRANSPERS Director Kathryn Phillips appointed to Genome Canada Board of Directors to help direct Canada's national strategy for genomics research

Kathryn is delighted to have joined the [Genome Canada Board of Directors](#), joining 15 individuals drawn from the academic, private and public sector communities and continuing her long history of working with our neighbors to the North. [Genome Canada](#) is a not-for-profit organization established in 2000 to develop and implement a national strategy for supporting large-scale research projects in genomics and proteomics. Along with co-funders, Genome Canada has invested over \$3 billion, serving as a catalyst for making Canada a leader in this area. Kathryn will be particularly focused on Genome Canada's commitment to

addressing economic, environmental, ethical, legal, and social issues. Kathryn welcomes input and discussion relevant to these activities.

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