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An Integrated Genomics and Clinical Resource for Data-Driven Health Services Policy and Practice Decisionmaking

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Objectives

Biomedical understanding of cancer is evolving rapidly. Post-genomics cancer research is also being taken up in prevention, screening, treatment, and survivor programs to better identify and manage the risks and sequelae of cancer. In order to translate these findings into effective and efficient healthcare throughout the cancer care trajectory, risk stratification is needed, based on a comprehensive set of genetic, clinical, sociodemographic, and health system factors, to deliver targeted, sustainable care within specific health systems.

Approach

Data linkage of records can be conducted using unique person-specific provincial Personal Health Numbers for all British Columbia (BC) residents.

Results

At the BC Cancer Agency we have linked person-based, longitudinal registry, clinical, and health administrative records for the approximately 32 thousand breast cancer patients diagnosed to BC residents from 1989-2011, and followed to end 2013, in order to assess mortality/survival, morbidity, healthcare utilization, access and quality of care, and predictors of these outcomes, throughout the cancer care trajectory. For approximately 1000 of these patients, we have collected biological samples (either blood or saliva) from which DNA was extracted, and questionnaire-based information on education; ethnicity; health, medical and reproductive history; family history of cancer; lifestyle characteristics; as well as lifetime occupational and residential histories. Tissue microarrays are being created from the tumour blocks. Genotyping is also being performed. For approximately 720 patients, data is available on ten genetically-distinct molecular subgroups with different survival rates, including a high-risk,

estrogen-receptor-positive 11q13/14 cis-acting subgroup and a favourable prognosis subgroup without somatic copy number aberrations. Linkage of these datasets is pending.

Conclusion

This resource can be made available for ongoing research into patient and healthcare (including utilization, quality, and sustainability of care provision) outcomes. A strength of this resource is the detailed clinical and treatment information available for the majority of patients. Among oncologists and other cancer specialists, this work will raise awareness of issues; identify treatment toxicities; contribute to clinical decision-making; inform survivor care guideline development; and encourage research into treatment alternatives. Among family physicians and other care providers, this work will raise awareness of risks of late complications among their patients; identify high-risk survivors; and support targeted risk-based care in primary care. Among policymakers and program managers, findings will identify resource issues; and support cost-effective models of care. And, among cancer patients, this work will raise awareness of the implications of genomics on their long-term care.

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