Creation of a Pharmacogenomics (PGx) Patient Portal complementary to an existing institutional Clinical Decision Support (CDS)

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BACKGROUND: With an increase in clinically actionable PGx findings, institutions are beginning to implement PGx into provider workflows via the creation of PGx CDS. Many patients show a lack of knowledge about PGx, which hinders ability to participate in or initiate important conversations about their treatment. Results from a previous survey show a significant improvement in PGx knowledge after viewing a mockup of a patient education and results delivery portal. There is a need for PGx CDS-complementary patient portals in order to research the role of shared decision making in PGx.

METHODS: A novel administrative web dashboard was developed with the .NET AngularJS framework to facilitate the creation of patient-targeted PGx summaries informed by our >6,000 article manually curated and annotated PGx Knowledge Base. The summaries written for patients here map directly to provider summaries in our existing provider CDS, which links genotypic information to phenotype recommendations. The dashboard supports a secure patient-centered user interface, the YourPGx Patient Portal, to serve as an educational tool and delivery system to share individualized PGx results with patients. These results correspond directly to the results available to that patient’s provider. Login to the dashboard and portal are available only through institutional SSL encrypted sign-on, and all data is housed in a HIPAA-compliant data center; all PHI is secure in transit and at rest.

RESULTS: The patient portal and administrative dashboard in tandem allow our team of pharmacists and physicians to create patient-oriented summaries based on gene-phenotype or SNP-variant combinations, which map directly to provider summaries already available in GPS. The dashboard allows the providers to save drafts, add images, reference GPS summaries, and push new summaries to YourPGx. The concordant mapping of GPS results to YourPGx results has been validated programmatically for the 58 summaries and 353 patients eligible for the first stage of rollout. Additionally, all results are further reviewed independently by two members of our team before they are delivered to patients. This workflow supports the creation of patient-oriented summaries that are inspired by and complementary to their GPS counterparts, and the secure delivery of those results in a user-friendly web-based application.

CONCLUSIONS: As of June 2019, this portal has been clinically implemented at our institution to support an NIH-funded program. The primary continuing objective is to demonstrate clinical benefit due to shared decision making facilitated by the complementary relationship of GPS and the YourPGx Patient Portal. Secondary objectives include evaluating longitudinal effects in patient comprehension and self-advocacy after being exposed to the portal, and exploring integration with the EHR to facilitate real time medication alerts for patients.