Patient perspectives following pharmacogenomics results disclosure in an integrated health system

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Aim: To assess patient perceptions and utilization of pharmacogenomics (PGx) testing in an integrated community health system. **Methods:** Fifty-seven patients completed an online survey assessing their experiences with PGx testing offered through two methods: a designated PGx clinic or direct access in-home testing. **Results:** The majority of participants perceived PGx testing as helpful in their healthcare and reported understanding their results. Some had concerns about privacy and discrimination; most lacked familiarity with the Genetic Information Nondiscrimination Act. There were no significant differences in views between participants tested through either model. **Conclusion:** Participants reported value in both methods of PGx testing. Patient experiences, understanding and result utilization will play an important role in informing future development and implementation of PGx programs.

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Clinical use of pharmacogenomic (PGx) testing has the potential to improve population health and enhance patient care. By linking genetic factors to patients' responses to medications, PGx seeks to streamline therapeutic selection, limit adverse effects and ultimately lead to better patient outcomes [1–5]. PGx testing is currently offered through several delivery models, including primary care or specialist offices, integrated system pre-emptive testing, multidisciplinary PGx clinics and commercial direct-to-consumer testing [1,2,6–11]. However, logistical and clinical challenges remain when integrating PGx testing and results more broadly into healthcare [8,12–17].

Although various models of PGx testing services exist, limited information is available regarding how patients utilize and view the value of their clinical results postdisclosure. A number of studies assessed attitudes toward PGx testing in a variety of clinical and research populations, specifically in participants who had not undergone PGx testing [18–25]. Many of these studies reported that the majority of individuals queried are interested in PGx testing and that participants see value in PGx testing for its potential to provide insight into risk of side effects or to tailor medication prescribing [19–22]. However, several areas of patient concern were revealed, including cost; privacy of genetic information; and potential psychological consequences about ancillary risk information [18,19,22–26].

In addition to research examining participant views about hypothetical PGx testing, studies have also evaluated how patients who have undergone PGx testing use and view their results [1,2,27–32]. While initial studies on tested patients have identified similar themes found in hypothetical testing populations, most focus on individuals tested within a research-specific or direct-to-consumer context. More data are needed, particularly from those undergoing PGx testing in a clinical setting. Incorporating patient perspectives in the development and implementation of clinical PGx testing programs is an important element to inform best practices. In particular, learning more about how patients view specific delivery models of PGx testing will be essential in meeting patient and consumer preferences. How well programs succeed may also be influenced by patient acceptance, perception of utility and approval of the testing process [6,21,22,28,29].

Figure 1. Multi-method pharmacogenomics delivery.

Our research offers insight into an understudied population of patients – those undergoing clinical PGx testing through two service delivery models. To our knowledge, there are no previous studies comparing different delivery models within a single health system (in this case, PGx clinic testing vs direct access testing). This paper reports on an assessment of patient perceptions of clinical PGx testing and patient-reported actions after receiving clinical PGx test results.

Methods

Study participants & setting

NorthShore University HealthSystem is a four-hospital community health system in north suburban Chicago, IL, USA. Our health system has developed an infrastructure that supports two methods of ordering PGx testing: PGx clinic testing and direct access testing (Figure 1). The PGx testing process starts either by a visit to the PGx clinic (top left), which is self- or clinician-referred, or by a provider ordering a PGx panel (bottom left). During the clinic visit, PGx specialists discuss benefits, limitations and risks of testing with the patient, and the sample is collected in the healthcare provider office. In the direct access testing method, the patient watches a 4-min video [33] covering the same topics, and the sample is collected at the patient's home. PGx testing is done in-house, on a custom microarray, which includes 19 genes covering drug metabolizing enzymes, drug transporters and some drug targets (Supplementary Data 1). Once the sample is processed at the health system laboratory, the results are returned to the patient and are available to the provider in the electronic medical record as a drug-centric profile, interruptive alerts and a PDF file (Figure 1, middle). Finally, the PGx specialists are available for questions via phone or email for both patient and provider (right). A patient may elect to come into the PGx clinic for more detailed discussion about their results with the specialist.

Because no specific patient populations are targeted in our PGx service delivery, this survey reflects a mixed population which is likely to be encountered in a system-wide implementation. Study participants were NorthShore adult patients who underwent PGx testing (through either delivery model) and received results. Participants were recruited by email to participate in a voluntary and anonymous survey, and were eligible to receive a \$50 gift card through a raffle as compensation for their time. Approval for this study was received from the NorthShore University HealthSystem Institutional Review Board.

Survey development & data collection

A 44 item, online survey tool was developed and informed by relevant literature, expert review and a focus group of five study eligible patient participants (Supplementary Data 2). Five cognitive interviews of individuals with similar backgrounds to the study participants were conducted to increase readability and validity of the survey tool [34]. The Tailored Survey Design method was also used as a general guide in the survey development and format [35]. A five-point Likert scale, rating level of agreement, was utilized in most of the response categories for questions assessing opinions. Categorical response options were used in other question types and one open-ended comment question was offered at the end of the survey. Six survey items were utilized or adapted, with permission, from the Haga *et al.* patient study survey tool [2]. Email invitations were sent to participants approximately 4 weeks after they were sent PGx test results – between March and September of 2017. Reminder emails were sent 2 and 4 weeks later.

Data analysis

Data were downloaded from an online survey tool, SurveyMonkey [36], and analyzed using SPSS 22.0 software [37]. Two participants requested paper-based surveys and all results were entered into the SurveyMonkey database. Descriptive statistics were used to summarize responses to all questions. For the five-point Likert scale (strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree and strongly disagree), data were first summarized and reviewed in their original form and then collapsed to three categories (agree, neutral and disagree) to facilitate analysis and interpretation. Similarly, for the four-point scale (not at all, very little, somewhat and to a great extent) data were presented in original form and collapsed to two categories (little or not at all and somewhat to a great extent) for easier reporting and interpretation. Because participants were allowed to skip individual items, the sample size varied by question. Throughout the paper, percentages reported reflect the valid percent (excludes missing answers). The comparison of survey results between patients receiving direct access testing and PGx clinic testing was performed using χ^2 test with Yates' continuity correction for small cells of frequency (≤ 5). All tests were two-sided and a p-value of ≤ 0.05 was considered statistically significant.

Results

Participant profile

A total of 150 individuals were invited to participate and 57 responded (37.3% response rate). The majority was female (72.2%), non-Hispanic/Latino (96.2%), white (98.1%) and had some college education or more (92.6%). Most participants reported taking a range of medications between one and five, and 83.4% rated their health as either fair, good or very good (Table 1). When asked who first initiated PGx testing, half of the respondents indicated that their healthcare provider brought up PGx testing, approximately 25% were self-referred and the remaining 25% learned of PGx testing from family or by other means. Patients were also queried about the extent to which various factors played a part in their decision to be tested. Helpfulness in optimizing treatment with medications (100%) and self-curiosity (87.5%) were the top two factors mentioned in influencing this decision. In terms of test cost, the majority (66.7%) of respondents indicated that they thought a fair price (out-of-pocket cost) for PGx testing should be \$200 or less, and 25.9% indicated a fair price between \$201 and \$300. Slightly over half (59.6%) of participants received PGx testing through the direct access testing mechanism and the remainder (40.4%) received testing in the PGx clinic.

Testing experience

A number of questions were asked of participants to gauge their overall PGx testing experience. Slightly over half (59.6%) of participants strongly or somewhat agreed with the statement, "I found PGx testing to be helpful to me in my healthcare decision-making at this time." As we contacted most patients approximately 1 month after receiving results, we also wanted to know if they might feel differently about potential future results benefit. In fact, 80.7% indicated that they believe PGx testing will be helpful to them in the future. To assess satisfaction with their experience, we asked about three dimensions: decision to take the test; overall testing experience; and whether they would recommend testing to others. The vast majority of participants reported that they were satisfied with their decision to take the PGx test (87.5%) and with their overall PGx testing experience (84.2%). A total of 82.5% participants would recommend PGx testing to their family or friends. There were no significant differences in these findings between patients who had testing through the direct access testing mechanism and those who had PGx clinic testing (all p-values > 0.5).

Table 1. Participant characteristics (n = 54).

Variable	n (%)
Gender	
Female	39 (72.2%)
Age range	
18–39	14 (25.9%)
40–59	24 (44.4%)
>60	16 (29.6%)
Education	
High school	4 (7.4%)
> High school, <Bachelor's degree	14 (25.9%)
Bachelor's degree	17 (31.5%)
Graduate or professional degree	19 (35.2%)
Health rating	
Excellent	3 (5.6%)
Very good	15 (27.8%)
Good	15 (27.8%)
Fair	15 (27.8%)
Poor	6 (11.1%)
Prescription medications	
0	3 (5.6%)
1–5	39 (72.2%)
>6	12 (22.2%)

Percentages may not add up to 100% due to rounding.

Test results discussion

Questions were then asked to elicit participant views on the receipt of results and postresults discussion processes. One question aimed to tap patients' perceptions of whether or not they understood their results. To answer this question, participants were asked if they agreed or disagreed with this statement: "I have a clear understanding of my test results from PGx testing." In response, 63.2% of participants strongly or somewhat agreed with this statement. However, 24.6% indicated that they somewhat or strongly disagreed with the statement that they had a clear understanding of their results and 12.3% neither agreed nor disagreed. A total of 63.2% reported that they discussed PGx test results with their provider and the majority (80.6%) agreed with the statement: "My healthcare provider seemed confident in explaining the meaning of PGx results to me." We also explored whether study patients were interested in learning further information after receiving their PGx results. After discussing results with their providers, 40.0% of respondents indicated that they 'looked up additional information' and a similar percent (35.7%) relayed that they would like additional follow-up from their healthcare provider to discuss their PGx test results. Many participants (79.6%) also reported that they discussed their PGx results with a family member. There were no significant differences in these findings between direct access testing and PGx clinic testing groups (all *p*-values >0.5). However, patients who had PGx clinic testing tended to report a higher percent of self-perceived understanding of their test results than those who had direct access testing (77.3 vs 51.5%; *p* = 0.06).

Patient perceptions & feelings post-PGx results disclosure

To learn more about patients' views after receiving their results, we explored their perceptions and specific feelings about their PGx test results. These questions are listed in [Table 2](#). After learning about their PGx test results, 57.1% of the participants indicated that they were more likely to take medications prescribed by their provider. Approximately three-fourths (73.2%) felt more confident that medications prescribed will not cause side effects and/or will help with their condition, compared with past prescriptions received without PGx testing.

In the patient focus group and cognitive interviews conducted to inform the survey, some patients described stories about how they tried to explain to their physicians that medications were not working, or that they needed a stronger dose (for pain, etc.). They expressed that they did not always feel believed by their physician. Several patients described how PGx test results confirmed what they believed as true, in terms of their medication

Table 2. Patient perceived utility.

Question	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
After learning my PGx test results, I am more likely to take medications prescribed by my healthcare provider (n = 56)	16 (28.6%)	16 (28.6%)	18 (32.1%)	5 (8.9%)	1 (1.8%)
After learning my PGx test results, I feel more confident that medication(s) prescribed to me will not cause side effects and/or will help my condition, compared with past prescriptions I have received without testing (n = 56)	24 (42.9%)	17 (30.4%)	7 (12.5%)	6 (10.7%)	2 (3.6%)
After learning my PGx test results, I feel more validated about my medication experiences (n = 56)	30 (53.6%)	9 (16.1%)	10 (17.9%)	7 (12.5%)	0 (0%)

Percentages may not add up to 100% due to rounding.
PGx: Pharmacogenomic.

Table 3. Feelings post pharmacogenomic results.

Please indicate how often you have experienced these feelings since receiving PGx results	Never	Rarely	Sometimes	Often
Felt disappointment about my PGx test result (n = 56)	31 (55.4%)	11 (19.6%)	11 (19.6%)	3 (5.4%)
Felt relieved about my PGx test result (n = 55)	12 (21.8%)	9 (16.4%)	19 (34.6%)	15 (27.3%)
Felt regret about my PGx test result (n = 55)	50 (90.9)	1 (1.8%)	4 (7.3%)	0 (0%)
Felt happy about my PGx test result (n = 56)	13 (23.2%)	10 (17.9%)	23 (41.1%)	10 (17.9%)
Felt confused about my PGx test result (n = 55)	15 (27.3%)	19 (34.6%)	15 (27.3%)	6 (10.9%)

Percentages may not add up to 100% due to rounding.
PGx: Pharmacogenomic.

experiences. Results information in turn was described as ‘validating’ their previous experiences. In the present study, the majority (69.6%) of participants reported that they felt more validated about their previous medication experiences after learning their PGx results. Anecdotally, several patients in the PGx clinic mentioned no longer wanting to see their provider, after learning their ‘validating’ PGx results. We therefore posed a question about this, and found that 11.1% of patients reported that they are looking to change members of their healthcare team after learning their PGx results; 13.0% were unsure.

Previous studies have evaluated postgenetic test reactions; we also asked a series of five ‘feelings’ statements that participants responded to. As we did not have pretest data, these questions were used only to assess how often participants reported experiencing specific feelings about their PGx test results after disclosure: disappointment; relief; regret; happiness; and confusion. The wording of these statements and findings are listed in [Table 3](#). Approximately 60% of the study patients indicated that they sometimes or often feel relieved or happy about their PGx results. The remainder reported rarely or never having those feelings. The vast majority (92.7%) never or rarely felt regret and three-fourths never or rarely felt disappointment about their PGx test results. Close to 62% of participants relayed that they rarely or never felt confused about their PGx results. There were no significant differences in these findings between participants in the direct access testing and the PGx clinic testing groups regarding these perceptions or postdisclosure feelings (all p-values >0.5).

Testing actions & outcomes

To learn more about how the study patients used their PGx findings, they were asked about their actions after learning their PGx test results. Close to a third (29.6%) of participants reported making changes to a current medication (such as discontinued it or made a change in dose) with the guidance of their healthcare provider, and 7.4% indicated plans to do so. We also queried participants to find out about medication changes made on their own, without the guidance of a healthcare provider. A small percentage (12.7%) of participants reported making changes on their own, without the guidance of their healthcare provider ([Table 4](#)). In terms of other outcomes, slightly over 18% stated that they started a new medication, and 66.7% indicated plans to avoid taking a medication in the future, after learning their PGx test results. The ‘most valuable outcome’ of PGx testing, reported by 50% of participants, was decreased trial-and-error in prescribing medications ([Table 5](#)). There were no significant differences in these responses between the direct access testing and the PGx clinic testing groups (all p-values >0.5).

Table 4. Medication changes.

Question [†]	Yes	No	Plan to do so
After learning my PGx test results, I made a change in taking a current medication (such as discontinued it or made a change in dose), with the guidance of my healthcare provider (n = 54)	16 (29.6%)	34 (63.0%)	4 (7.4%)
After learning my PGx test results, I made a change in taking a current medication (such as discontinued it or made a change in dose), on my own without the guidance of my healthcare provider (n = 55)	7 (12.7%)	48 (87.3%)	0 (0%)

[†]In a pairwise review of the data in Table 4, 12 patients reported making changes to their medications with the guidance of their provider only, while one patient reported making changes to their medications without the guidance of their provider only; four patients answered yes to both questions and reported making changes to their medications with the guidance of their provider and on their own without guidance.
PGx: Pharmacogenomic.

Table 5. Single most valuable outcome (n = 54).

Category	n (%)
Decreased trial and error in prescribing my medications	27 (50.0%)
Increased medication effectiveness	8 (14.8%)
More confidence in my prescribing healthcare provider	8 (14.8%)
Decreased side effects	7 (13.0%)
More willing to try a new medication	4 (7.4%)
Decreased cost of medications	0 (0%)
Decreased cost of related healthcare	0 (0%)

Table 6. Privacy and protection of information.

Question	Not at all	Very little	Somewhat	To a great extent
How concerned are you about the privacy of your PGx test results? (n = 55)	19 (34.5%)	14 (25.5%)	14 (25.5%)	8 (14.5%)
How concerned are you about the potential for discrimination based on your PGx test results? (n = 55)	22 (40.0%)	16 (29.1%)	12 (21.8%)	5 (9.1%)
How familiar are you with the Genetic Information Nondiscrimination Act? (n = 55)	28 (50.9%)	13 (23.6%)	8 (14.5%)	6 (10.9%)

Percentages may not add up to 100% due to rounding.
PGx: Pharmacogenomic.

Privacy & confidentiality

We were also interested in assessing privacy and confidentiality concerns in our patient population. Our study findings revealed that slightly over one-third of participants indicated that they were concerned (either somewhat or to a great extent) about the privacy of their PGx test results (40.0%), and nearly one-third indicated concern about the potential for discrimination (30.9%). Information on the Genetic Information Nondiscrimination Act (GINA) of 2008 is provided to all patients prior to PGx testing; therefore, we explored self-perceptions of their understanding of this act [38]. The majority (74.5%) reported that they had no, or very little familiarity with GINA (Table 6) [38]. There were no significant differences in these findings about privacy and protection of genomic information between respondents in the direct access testing and the PGx clinic testing groups (all p-values >0.5).

Open comments

Of note, a third (31.6%) of participants wrote free text in the comments section at the end of the survey. Key issues participants described were: helpfulness of results for treatment planning (saving time and cost); validation of past medication experiences; reassurance going forward; concern with privacy and data sharing of results; and need for more education in the results explanation.

Discussion

To our knowledge, this is one of the first survey studies assessing patients' perspectives of clinical PGx testing in an integrated health system using a multiple service delivery model. This study explores the attitudes of patients with

respect to their PGx testing experiences, including satisfaction with testing, perceived utility, patient outcomes and data privacy issues. The participants were primarily female, white and had some college education or more.

Our findings revealed that delivery mode of PGx testing did not significantly affect patients' views of testing. Specifically, there were no significant differences between satisfaction of PGx testing experience, perceived helpfulness or understanding of results, discussion of results with provider, or concern regarding privacy and confidentiality between the direct access testing and the PGx clinic testing groups. Physicians offering PGx testing in this health system previously described the need for flexible PGx testing options [39]. This study suggests, from a patient perspective, that multiple delivery models can be utilized successfully within a health system. This finding is of interest, as the multi-method delivery model was implemented to expand the capacity of PGx testing to meet the patient demand of the health system.

The majority of study patients were satisfied with their decision to undergo PGx testing, with over half reporting results being helpful at the time of the survey – and most thinking results would be helpful in the future. After learning their results, the majority also reported that: they feel more confident that prescribed medications will not cause side effects and/or will help with their condition; they were more likely to take medicines prescribed by their provider; and they felt more validated about their previous medication experiences. These outcomes were previously reported as perceived patient benefits by physicians who ordered PGx testing in this health system [39]. We also queried participants about feelings after receiving PGx test results. Both our study and a previous patient study reported similar percentages of respondents indicating sometimes or often feeling happiness or relief about their PGx test results [2]. In addition, our study revealed a significant majority of patients reporting never or rarely feeling regret or disappointment about their PGx results. Whether these perceived benefits and positive feelings about PGx testing translate into changes in patient behavior, such as increased adherence, is an important area of further study. Variable, though generally high, perceptions of PGx testing value and use by patients have been previously reported by patients undergoing PGx testing in other studies [2,27,30,32]. However, in contrast, one direct-to-consumer study showed that less than half of respondents would use their results to guide medication choices in the future [31]. Demonstrating patient perceived utility is important for implementation of PGx testing into health systems [40,41]. Our study findings, using a clinical cohort that utilized two PGx delivery models, support previous reports of perceived patient value in PGx testing.

The current study results were consistent with previous findings that the majority of patients perceive having a clear understanding of their PGx results [2,30]. However, approximately one-fourth of our study participants reported not having a clear understanding of their results and approximately 40% indicated that they felt confused by their PGx test results. In addition, physicians from multiple disciplines have self-reported a difficulty in understanding PGx results; primary care providers ordering PGx testing have expressed the need for easily interpretable reports for both themselves and the patient [39,42,43]. These findings highlight the challenges in assessing the full impact of testing on patients, and therefore the need for more education efforts in both patient and physician populations. Providing physicians with the necessary tools to interpret and communicate PGx test results to patients has been proposed as an important consideration for effective clinical implementation [26,42,44–46]. Based on the findings of this patient study, and from a previous qualitative provider study conducted at our institution, a number of changes have been implemented [39]. Multiple methods are used for provider education, including a short presentation during practice site monthly business meetings and a prerecorded webinar. In addition, PGx specialists are available via pager. In terms of the PGx results report, the genetic interpretations have been expanded to provide more comprehensive patient education. Graphic depictions are now included in the PGx results report, illustrating for patients how their results compare to the general population. Our system has also undertaken a review of the direct access testing workflow in order to determine areas for potential improvement in report use by physicians. As the pool of patients using PGx testing grows, it will be important to examine how physicians are utilizing results of PGx testing in their therapeutic decisions.

The majority of participants in the current study indicated they had no or little concerns about privacy and discrimination post-testing; a previous study found a similar percentage of participants who did not consider discrimination risk as a factor in the decision to undergo PGx testing [2]. However, 40% of the participants stated that they had some or a lot of concern about privacy, and approximately one-third had concerns about discrimination. Privacy and discrimination concerns have been cited in previous studies assessing patient views about hypothetical PGx testing; one study involving focus group participants with a history of psychiatric medication use reported that risks such as discrimination and breaches of confidentiality may outweigh benefits of PGx testing, and another focus group study including both PGx-tested and non-tested participants found that some individuals

stated that they would not undergo PGx testing due to privacy concerns [22,25]. Providers have also reported privacy considerations as a potential concern of patients [39]. Privacy concerns may differ depending on the specific patient situation. In one survey study, direct-to-consumer PGx-tested participants who shared results with providers were less likely to express concerns about their results being added to their medical record [1]. A secondary data analysis of another direct-to-consumer PGx-tested cohort revealed that patients with fewer concerns regarding privacy were more likely to share disease-susceptibility genetic test results with providers [47]. Although discrimination and privacy concerns have been reported in both the disease-susceptibility and PGx testing settings, attitudes may vary between these groups. Specific patient contexts such as the disease state and potential psychological and economic impacts of receiving/using results may also influence these views [48].

Of note, the majority of participants in our study did not have familiarity with GINA, which to our knowledge has not been specifically assessed in patients who have undergone clinical PGx testing. In our PGx service delivery, information about GINA is currently provided to patients through the video they watch as part of the direct access testing process and through discussion with patients in the PGx clinic. However, our patient study revealed that understanding of GINA is still lacking. Primary care physicians also reported that they felt patients may have concerns about their data and privacy and mentioned how discussions could come up about insurance companies using this information [39]. Based on this feedback, our PGx program has expanded the discussion of GINA with patients in the PGx clinic and is planning a revision of the educational video that provides information on GINA. In addition, an informational handout describing GINA has been added to the intranet portal utilized by providers. Further evaluation will be needed to determine the efficacy of these new measures.

Our study revealed a higher rate of patients changing medication(s) based on PGx results compared with both a previous clinical and direct-to-consumer study, which reported medication change rates of 16.7 and 5.6%, respectively [2,31]. It is unclear whether our patients' results revealed more actionable findings related to current medication regimens that would result in this finding, and future research assessing what influences patients to change medications following receiving results would be beneficial to maximize clinical impact.

One limitation of this study is the potential lack of generalizability due to a relatively small sample size from the same health system, and a homogenous population in terms of race, ethnicity and education. As such, results may not represent perspectives of all patient populations. In addition, 72% of the study participants were women. Consequently, our findings may be more representative of women's views than men's on PGx testing.

Conclusion

PGx testing will continue to grow as a clinical tool used by healthcare providers and patients. The role of patients, especially as consumers, in healthcare decision-making is increasingly being recognized by the medical community. Careful consideration of patient expectations and experiences will be essential in the development of effective program delivery of PGx testing and best practices. Participants in this study provided key insights into how

Summary points

- Fifty-seven patients completed a survey that assessed patient experiences with two different models of delivery of pharmacogenomic (PGx) testing (direct access testing and PGx clinic testing) in an integrated health system.
- A majority of participants perceived testing to be helpful in their current (59.6%) and future (80.7%) healthcare decision-making.
- A total of 63.2% of the participants agreed that they have a clear understanding of their PGx test results.
- Specific outcomes included: changes to a current medication (41.8%); starting a new medication (18.2%); and plans to avoid a particular medication in the future (66.7%).
- A number indicated concerns about the privacy of their PGx test results (40.0%) and potential for discrimination (30.9%). The majority (74.5%) had no or very little, familiarity with the Genetic Information Nondiscrimination Act.
- Regarding their testing experience, results discussion, perceived utility of PGx testing, testing outcomes and privacy and confidentiality, there were no significant differences in these findings between direct access testing and PGx clinic testing groups (all *p*-values >0.5).
- This study indicated a high level of patient interest in PGx testing and perceived utility of results, but also a need for increased patient understanding of results, and of privacy and discrimination protections in future implementation efforts.
- These findings, from a patient perspective, suggest that multiple delivery models can be utilized successfully within an individual health system.

they perceived their PGx testing experience and how they used their PGx test result information. The direct access and PGx clinic service delivery methods in our population revealed similar patient outcomes, highlighting patient interest and perceived utility of results. However, a need for increased patient understanding of results and considerations of privacy/discrimination was also revealed. Future research is needed from a diverse group of patients undergoing PGx testing, in a variety of service delivery models, to inform implementation in other health systems.

Supplementary data

To view the supplementary data that accompany this paper, please visit the journal website at: <https://www.futuremedicine.com/doi/suppl/10.2217/pgs-2017-0191>

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. This investigation received a waiver of in-person consent per the institutional review board; implied consent was received via participant email invitation acceptance.

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Papers of special note have been highlighted as: ● of interest; ●● of considerable interest

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