Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

HHS Public Access

Author manuscript

*Pharmacogenet Genomics*. Author manuscript; available in PMC 2018 May 01.

Published in final edited form as:

*Pharmacogenet Genomics*. 2017 May ; 27(5): 179–189. doi:10.1097/FPC.0000000000000275.

# Assessment of Patient Perceptions of Genomic Testing to Inform Pharmacogenomic Implementation

**Yee Ming Lee, PharmD**[1], **Ryan P. McKillip, BS**[2], **Brittany A. Borden, MA**[1], **Catherine E. Klammer, BS**[1], **Mark J. Ratain, MD**[1,3,4], and **Peter H. O'Donnell, MD**[1,3,4]

[1]Center for Personalized Therapeutics, The University of Chicago, Chicago, USA

[2]The University of Chicago Pritzker School of Medicine, Chicago, USA

[3]Committee on Clinical Pharmacology and Pharmacogenomics, The University of Chicago, Chicago, USA

[4]Department of Medicine, The University of Chicago, Chicago, USA

## Abstract

**OBJECTIVE—**Pharmacogenomics seeks to improve prescribing by reducing drug inefficacy/toxicity. However, views of patients during pharmacogenomic-guided care are largely unknown. We sought to understand attitudes and perceptions of patients in an institutional implementation project and hypothesized that views would differ based on experience with pharmacogenomic-guided care.

**METHODS—**Two focus groups were conducted–one group consisted of patients who had previously submitted to broad pharmacogenomic genotyping with results available to physicians (pharmacogenomic group), while the other had not been offered genotyping (traditional care). Five domains were explored: 1) experiences with medications/side-effects, 2) understanding of pharmacogenomics, 3) impact of pharmacogenomics on relationships with healthcare professionals, 4) scenarios involving pharmacogenomic-guided prescribing, and 5) responses to pharmacogenomic education materials.

**RESULTS—**Nine pharmacogenomic and 13 traditional care participants were included. Participants in both groups agreed pharmacogenomics could inform prescribing and help identify problem prescriptions, but expressed concerns over insurance coverage and employment discrimination. Both groups diverged on who should be permitted to access pharmacogenomic results, with some preferring access only for providers with a longstanding relationship, while others argued for open-access. Notably, traditional care participants showed greater skepticism about how results might be used. Case scenarios and tested educational materials elicited strong desires on the part of patients for physicians to engage participants when considering pharmacogenomic-based prescribing, and to utilize shared decision-making.

Corresponding author: Peter H. O'Donnell, MD, Contact Information: 5841 S. Maryland Avenue, MC 2115, Chicago, IL 60637, podonnel@medicine.bsd.uchicago.edu, phone: (773) 702-7564, Fax: (773) 702-3163.

**CONFLICTS OF INTEREST AND SOURCE OF FUNDING**

Drs. Ratain and O'Donnell are named as co-inventors on a pending patent for a genomic prescribing system and are co-founders of PrescriptIQ, Inc. Dr. Ratain is a coinventor holding patents related to pharmacogenetic diagnostics and receives royalties related to *UGT1A1* genotyping. No royalties were received from the genotyping of patients in this study.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

**CONCLUSION—**Participants experiencing pharmacogenomic-guided care were more receptive toward pharmacogenomic information being used than traditional care participants. As key stakeholders in implementation, addressing patients' concerns will be important to successfully facilitate clinical dissemination.

### Keywords

pharmacogenomics; implementation; patients; precision medicine; perception

## INTRODUCTION

Pharmacogenomics studies the genetic variability governing an individual's drug response, with the aim to improve prescribing by reducing drug inefficacy and toxicity. Despite this promise, its adoption has been encumbered by hurdles pertaining to process, providers and patients [1–3]. Various solutions have been devised for the former two, including the creation of Clinical Pharmacogenetics Implementation Consortium guidelines to facilitate the use of pharmacogenomic information (process) [4,5], development of clinical decision supports to guide decision-making (process and providers) [6], and providing pharmacogenomic education to healthcare professionals (providers) [7,8].

The role of patients as key stakeholders in the successful implementation of pharmacogenomics has received less practical attention during initial implementation efforts [9–14]. Previous studies among patients and healthy volunteers reported a general receptiveness for pharmacogenomics to predict adverse effects and guide drug selection and dosing [9,11]. One study solicited perceptions of patients who had undergone thiopurine methyltransferase genotyping prior to being prescribed azathioprine [15], but the patients rarely recalled the test being done. The views of patients who experienced broad, preemptive pharmacogenomic testing are largely unknown.

We sought to explore the attitudes and perceptions of pharmacogenomics among genotyped patients actively participating in an institutional pharmacogenomic implementation project, compared with that of a control group receiving traditional care. We hypothesized that patients' views of pharmacogenomics would significantly differ based on whether they had experienced pharmacogenomic-guided care. We also aimed to illuminate important themes identified by patients that will be critical to the successful future expansion of pharmacogenomic adoption during clinical care.

## MATERIALS AND METHODS

### Participants

Study participants were recruited from an existing institutional pharmacogenomic implementation study called the 1200 Patients Project (clinicaltrials.gov #NCT01280825) [16,17]. This project provided preemptive pharmacogenomic testing for up to 1200 patients receiving care from primary care and subspecialty physicians in an outpatient setting to assess the utility of pharmacogenomic results. Full operational details of the study have been previously published elsewhere [16,17]. Briefly, participants in the genotype arm receive a

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

short explanation of pharmacogenomics during study enrollment. A one-time blood sample is taken for genotyping across a comprehensive panel of variants selected based on their published evidence as impacting drug response or toxicity. Patients' pharmacogenomic results are then delivered to their enrolling study provider(s) via a secure, electronic medical record-embedded decision-support tool called the Genomic Prescribing System. This system indicates actionable pharmacogenomic information about the patient's current medications (and, on-demand, about any medications the physician is considering prescribing) as traffic light signals (green, yellow, red, or dose calculator). Each signal is also accompanied by a concise but detailed pharmacogenomic information summary, with link-outs to supporting primary literature. All providers in the study have the autonomy to decide whether to discuss with patients if the pharmacogenomic results are relevant, and whether to act upon them. Adult patients were eligible if they were taking at least one regularly-used prescription medication but not more than six at the time of enrollment. Patients were initially enrolled into the genotyping cohort (pharmacogenomic group); enrollment into the non-genotyped cohort (traditional care group) began approximately 1.5 years later, after which both groups concurrently enrolled up to 3600 (1200 genotyped/2400 non-genotyped) patients. Both cohorts received standard medical care by the same study providers.

Participants were contacted via phone for potential participation in the focus groups. We pre-specified a sample size of 10 to 12 participants per group in accordance with published guidelines in the literature which recommend an ideal size of 4 to 12 participants per group [18,19]. Purposeful sampling of both cohorts (with continual assessment of the demographics of confirmed participants in order to guide subsequent phone call invitations) was utilized to ensure a demographic composition within each focus group that was representative of the demographics of the larger overall 1200 Patients Project [16,20,21]. A recruitment transcript was used to explain the purpose of the focus group—to gather patient opinions about medication use, genetic testing and their relationship with their physician and pharmacist. Potential participants were informed they would be given a $50 gift card and complementary parking as an incentive for participation. A confirmation letter with the focus group details was mailed to individuals who agreed to participate. The overall 1200 Patients Project and this sub-study were approved by the University of Chicago Institutional Review Board.

## Study Design and Data Collection

Both groups convened separately for 120-minute sessions in July 2015. At the start of each session, participants were asked to complete a short demographic questionnaire. Each session was led by three facilitators (R.P.M., Y.M.L, and P.H.O) using a semi-structured interview guide consisting of pretested questions (Supplementary Methods) to facilitate the discussion. The interviews explored five domains: (1) participants' experiences with medications and side-effects, (2) understanding of pharmacogenomics, (3) impact of pharmacogenomics on their relationship with physicians and pharmacists, 4) responses to three pharmacogenomic case vignettes, and 5) responses to two publicly available pharmacogenomic education tools: http://www.medicine.uiowa.edu/uploadedFiles/Research/Human_Genetics/Content/Clinical_Genetics/Patients/CYP2C19.pdf and https://www.stjude.org/content/dam/en_US/shared/www/patient-support/do-you-knows/pharmaco-

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

slco1b1.pdf. Each focus group was audio-recorded with full participant knowledge and written transcripts were created with patient identifiers (e.g. names) redacted.

### Data Analysis

Thematic analysis of the anonymized transcripts was conducted using a combined deductive and inductive process [22]. This approach allowed for organizing *a priori* codes based on research questions and developing *de novo* codes based on emergent themes. A conceptual framework using themes derived from prior literature on patients' knowledge and attitudes towards pharmacogenomics was used for the deductive portion. ATLAS.ti 7.5.10 (ATLAS.ti GmbH, Berlin, Germany) was used to facilitate coding. Two investigators (R.P.M and Y.M.L) first reviewed a portion of the transcripts independently to develop the coding scheme, followed by comparative analysis until thematic saturation was achieved. The agreed-upon coding framework was then applied to all transcripts with a comparison performed to establish inter-rater2 reliability (satisfactory kappa score ≥0.75). The primary outcome was to identify themes and subthemes, and representative quotations for each.

## RESULTS

### Patient Demographics

We contacted 136 participants by phone: 53 did not answer; 51 refused or were unable to participate and 32 agreed to participate. The most commonly cited reasons for declining participation were lack of interest, schedule conflict, and no means of transportation to get to the session. Ten participants who agreed by phone did not come to the focus group sessions (six in the pharmacogenomic group and four in the traditional care group) leaving nine and 13 participants in the pharmacogenomic and traditional care groups respectively. The purposeful sampling method proved successful as demographic characteristics between both groups were similar (Table 1) and were essentially identical to the overall larger institutional 1200 Patients Project population [21]: 50% were male, 55% Caucasian, and the average age was 59.5 years. Notably, 64% of participants self-reported a history of medication related side-effects. Only three pharmacogenomic group participants (33%) recalled receiving a pharmacogenomic-determined prescription, while no traditional care participants reported that pharmacogenomics was used to choose their medications. The number of study provider encounters since the time of enrollment was similar between the pharmacogenomic (4.3 ± 3.8) and traditional care (3.9 ± 2.0) groups (P=0.70).

Eight major themes emerged from the two focus groups (Table 2): participants' concerns when starting a new medication; factors influencing drug response; knowledge of genetics and pharmacogenomics; reasons to undertake a pharmacogenomic test; concerns about consenting to a pharmacogenomic test; concerns about privacy and personal pharmacogenomic information; relationship with healthcare professionals, and skepticism toward the medical field in general. The context from which these themes emerged is illustrated by a word cloud generated from the full reviewed transcripts (Fig. S1).

### Participants' Views on Pharmacogenomics, Testing, and Related Interests and Concerns

Each emergent major theme is discussed in detail below.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

**Concerns when starting a new medication—**Participants in both groups wanted to know the potential side effects associated with any new medication prescribed. Additionally, the pharmacogenomic group wanted to know if the new medication was necessary and effective, what other therapeutic options were available, and the insurance coverage of the new medication. The traditional care group was more concerned about long term effects of the medication, interactions with other medications, and if there was sufficient research conducted with the new medication.

**Factors influencing drug response—**Both groups said a person's activity level would influence his/her drug response, but only pharmacogenomic participants listed genetics and medication adherence as additional factors that could influence drug response.

**Knowledge of genetics and pharmacogenomics—**Prior to explaining pharmacogenomics, participants were asked to discuss how genetics influenced a person's drug response. Both groups demonstrated an understanding of genetics by relating it to traits inherited and traced through family history. The pharmacogenomic group had strong additional pharmacogenomics understanding, with one participant asking how pharmacogenomics informed a physician that one drug was better than another, saying: "So what in my blood tells him that this drug is better than that drug?" In contrast, the traditional care group universally confused pharmacogenomics with disease risk testing, with participants unable to provide a working definition of pharmacogenomics. Several traditional care participants remained confused about disease risk even after hearing (from the study investigators) a definition of pharmacogenomics and its potential applications.

**Reasons to undertake a pharmacogenomic test—**The majority of participants in both groups expressed a strong general interest in the concept of pharmacogenomic testing. The most popular reason cited among the pharmacogenomic group was to inform physicians' decision-making, as evidenced in this comment: "It would give us more information…and better inform as to what medication to prescribe." The second most common reason was altruistic—the pharmacogenomic participants expressed a common desire (by their being tested themselves) to potentially help others find a more effective drug (i.e., more knowledge would be gained about how medications work in general if more people submitted to pharmacogenomic testing).

In contrast, the traditional care group was more narrowly supportive of pharmacogenomic testing to inform their physicians' decision-making and avoid medication related side-effects. One traditional care participant said, "I want to know if you could skip the side effects," and this was universally agreed within the group.

**Concerns about consenting to a pharmacogenomic test—**Both groups wanted to understand their underlying condition that prompted the pharmacogenomic test and subsequent prescribing of the pharmacogenomic drug. Participants were also concerned if pharmacogenomics would affect their insurance coverage and employment.

Unique concerns of the pharmacogenomic group included questions on accuracy of the test, as exemplified by the comment: "How accurate is this genetic testing related to medications?

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Is there enough track record? Is it on target?" The pharmacogenomic group was also concerned about treatment options available based on their results as well as the differences between treatment options. There was also the question of ancillary information discovered, as illuminated in this comment: "There must be other information attached to whatever they found that made me genetically different from other people." In contrast, traditional care participants asked about issues such as cost of the test and why the test was not routinely done: "Shouldn't it be automatic when you go to the doctor, they try and do everything possible for a person?"

**Concerns about privacy, and personal pharmacogenomic information—**Several concerns were raised about pharmacogenomic testing, with participants in both groups sharply divided over the issue of privacy. The majority of both groups agreed genetic information was sensitive and should be stored securely, but participants in both groups diverged in their views over who could access their pharmacogenomic results. Some participants felt any physician should have access as long as it was relevant to their practice, as exemplified in this comment: "The privacy part shouldn't matter. If that saves your life… someone else being nosy can save my life, I would appreciate that." Conversely, within both groups, some participants wanted to control who could access their information, as in this comment: "How you personally choose to share your DNA information with anybody else should be your call." Still other participants felt such privacy controls were unnecessary as nothing is secure: "There is no sense of privacy; it's all shared between insurances and other kinds of care facilities. I don't think we have a measure of privacy, no matter what the HIPAA thing says."

**Relationship with their healthcare professionals—**Both groups indicated that the nature of their relationship with the treating physician would influence their decision to undertake pharmacogenomic testing, as shown in this comment: "…if that had been my primary physician to suggest that…I would have said, 'Well okay, let's think about that. Let's talk some more.' But as far as me being in the emergency care, doctors I'm not familiar with…I know they got a protocol and Hippocratic Oath they must take…but, I'm not good with that in that situation." Notably, the pharmacogenomic group expressed a high regard for physicians who adopted pharmacogenomics as a sign of staying at the forefront of medicine. One pharmacogenomic participant narrated his positive experience of receiving a pharmacogenomic-determined prescription, saying: "My physician tell me based on my pharmaco-blood test…I needed my blood pressure medication changed…I was assured that this was a good idea to participate…I think it's a real positive thing."

When participants were asked what would impact their trust in their physicians, both groups listed various characteristics, namely physicians' personalized knowledge of the participant, knowledge of the medical field and willingness to refer participants to other providers for problems beyond their expertise. Additionally, both groups desired physicians to show personal attention by taking time to listen and discuss issues with them: "It does make a difference when your doctor takes time out with you to sit down and discuss everything, just don't be in a hurry."

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Regarding the relationship with their pharmacist, both groups agreed pharmacogenomics could help pharmacists identify problem prescriptions: “It would make the pharmacist more informed and again another double, triple check before they’re handing me the medications.” However, one traditional care participant argued it was redundant to share their pharmacogenomic information since physicians could check them when they prescribe. Another pharmacogenomic participant relied on his physician as his source of drug information, saying: “…my pharmacist is the mailman…my pharmacist doesn’t exist”, in reference to him obtaining his medicines by mail order.

**Skepticism toward the medical field in general—**The theme of skepticism uniquely emerged strongly in the traditional care group during the discussion on participants’ concerns with starting new medications and consenting to a pharmacogenomic test. Some participants expressed deep mistrust in pharmaceutical companies for deemphasizing the serious side effects of their advertised medicines, as conveyed in this comment: “…the television, if you see a certain medication, that you’re taking, or you’ve been prescribed to take, and they’ll say, real fast: ‘Side effects of such and such…’ Wait a minute, hold on, I’m gonna be dead by taking this stuff…or I’m gonna be crippled or something if I take this medication.” Another representative quotation from a traditional care participant was this: “…if I was gonna do this genetic testing it would have to be over more grave circumstances…if I don’t do it, I’m gonna die.” One traditional care participant was skeptical of physicians’ knowledge of medicines as he felt like a “guinea pig” being tested with new medicines, while other participants felt overmedicated by physicians who kept adding new medications.

## Participants’ Responses to Clinical Prescribing Vignettes Involving Warfarin, Simvastatin and Clopidogrel

Participants’ responses were elicited to three clinical vignettes that illustrated the different implications of using pharmacogenomic information. The first vignette illustrated how pharmacogenomic information predicted a lower warfarin dose due to *CYP2C9* and *VKORC1* gene polymorphisms. The second vignette involved a *SLCO1B1* transporter variation that increased participants’ risk for statin-induced myopathy, leading to a discussion (within the vignette) about sacrificing potential efficacy in order to avoid side-effects by prescribing a potentially less effective cholesterol-lowering drug. The third vignette examined drug efficacy versus cost of therapy where the participant had a *CYP2C19* poor metabolizer genotype that precluded the use of clopidogrel in preference for a more expensive alternative antiplatelet agent.

In all three vignettes, common themes emerged from both groups as highlighted in Table 3. Members of both groups wanted to know what other treatment options were available based on their pharmacogenomic results, as seen in this comment: “If X is not going to work well, and Y will work well but is extraordinarily expensive…what are my other options?”, “How significant is the difference between the different drugs…is it enough to warrant all the extra testing cost or price difference in drugs?” Participants in both groups also wanted to know if non-pharmacological approaches could circumvent the dilemma of using a less effective or more expensive drug, as in this comment: “You have to utilize other options as far as

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

health…because one is too expensive for you, the other just not gonna cooperate with your body, so what choice do you have?"

Interestingly, participants expressed high expectations of drug efficacy with a pharmacogenomic-determined medication with the preparedness to tolerate side-effects, as exemplified by this comment: "…if I know it could be really effective…even if there might be some side effects then I might be more willing to push through, knowing the benefits." There were also heightened worries about side-effects, as in this example: "…if you went into this with more information that you may be more predetermined to have these side-effects. I think it would be even stronger notion that like if I throw up tomorrow that's probably the medicine, whether it was or not."

Distinctive themes emerged from the different vignettes. With the warfarin vignette, participants wanted to understand their underlying condition that prompted the pharmacogenomic-guided prescribing of warfarin. With the simvastatin vignette, participants were concerned as to how physicians would manage when the less effective cholesterol-lowering drug failed, but were simultaneously keen on dealing with side-effects of the alternative treatment options. With the clopidogrel vignette, participants were concerned with insurance coverage of the expensive alternative and wanted to understand if the therapeutic benefit justified the higher cost incurred: "Is that the only reason that drug X was the preferred drug in the first place?…if there were other reasons I'd want to know what I was giving up, other than the cost. And then I'd be interested in who covers the cost."

### Participant Perspectives on Pharmacogenomic Education Materials

Participants were asked to critically evaluate two publicly available pharmacogenomic education handouts with the goal of understanding how pharmacogenomic information could best be presented (Table 4).

Participants favored a bullet point layout with both handouts, as it made the information easier to read and understand. With the simvastatin handout, one participant found the explanation of the physiology behind pharmacogenomics helpful, as exemplified by this comment: "This is the kind of thing they're talking about, this is how it works, this is interesting." However, the technical language and heavy use of acronyms caused some confusion among some participants, with one participant saying that the simvastatin handout was "pretty technical for a layperson to understand." The clopidogrel handout also elicited conflicting views, with one participant saying it was "[more] complicated" and the pictures were "very uninformative", while other participants found the handout "pretty straightforward." Participants questioned the completeness of the clopidogrel pharmacogenomic test, as prompted by the handout's information that the test only interrogated the common variants associated with clopidogrel, leaving concerns as to whether there were "important things…not captured?" as one participant asked.

With regard to the type of pharmacogenomic information provided, one participant preferred the content to be patient-specific than general, as shown in this comment: "I don't care about the statistics of other people because I'm hoping I'm the exception; so you address me personally…I want it to be me…All about me." In contrast, another participant was

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

comfortable with having general information to convey the risk versus benefit ratio, as in this comment: “I think numbers can be important, and I think we all can be the exception to anything, but if the doctor tells me I’ve got an 80 percent higher risk, if I don’t take this, and the side-effects aren’t that bad, and even if they are…does it outweigh me dying?” Both groups favored having handouts (compared to not), but did not want handouts to replace opportunities to discuss pharmacogenomic information with their physicians in-person. In other words, we elicited a strong desire on the part of patients for physicians to engage participants when considering pharmacogenomic-based prescribing, and to utilize shared decision-making. Participants also requested access to alternative information sources such as internet websites and online videos.

## DISCUSSION

In this study, we explored the attitudes and perceptions of participants exposed to pharmacogenomic-guided care versus those receiving traditional care. Participants who had experienced pharmacogenomic-guided care demonstrated a better understanding of pharmacogenomics and were more receptive toward the use of their pharmacogenomic information, while traditional care participants showed greater skepticism about how their genomic information might be used. Both groups held similar concerns regarding insurance coverage and employment discrimination and had widely-ranging views about who should access pharmacogenomic results. These themes identify key topics to be addressed during implementation of pharmacogenomic testing.

Our results point toward the need for physicians to engage participants during pharmacogenomic-guided prescribing. Participants nearly universally agreed that pharmacogenomics could potentially inform physicians’ prescribing decisions to maximize drug efficacy and minimize side-effects, as well as help pharmacists identify problem prescriptions. These results indicate that the general promise of precision medicine is both perceived and understood by most participants. To this point, traditional care participants even asked why pharmacogenomic testing was not routinely done as part of standard care, echoing the sentiments of patients from other studies that demonstrated a strong general receptiveness toward pharmacogenomics [11].

That being said, the participants had some appropriate reservations about the implementation of pharmacogenomics. Skepticism about how pharmacogenomic information might be used, especially among the study participants who had never before been genotyped, was a common theme. The question of who should be granted access to genomic results was the most hotly-debated topic of both focus groups, with most participants having strong, vocal opinions, distributed across the spectrum on the subject of genomic test privacy. It was interesting to note that while both groups agreed that pharmacogenomic results should be securely stored, they diverged over who should access results, ranging from strict views that only a personal, longstanding treating physician should have access, to others arguing for complete, world-wide open access among healthcare professionals. The former view contrasted that of another study where 90% of respondents were extremely or somewhat comfortable sharing their pharmacogenomic results with other physicians involved in their care [10]. Our study also found mixed views among participants about sharing their

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

pharmacogenomic information with pharmacists, in contrast with other studies where ≥ 70% of individuals would share their results with their pharmacists [10,13]. Additionally, we found that both genotyped and non-genotyped participants held concerns over insurance coverage, employment discrimination, and cost implications of pharmacogenomic-guided care, all of which have similarly been reported in previous studies [9,11–13,23–25]. As cost/reimbursement considerations remain one of the greatest barriers to more universal adoption of pharmacogenomics, these considerations will need to be addressed via practice-based or institutional standards during early phases of implementation.

The use of pharmacogenomic patient education materials could facilitate discussions around these important themes. Indeed, we plan to use the findings of this study to help create pharmacogenomic education materials that can be utilized to introduce the idea of pharmacogenomic testing to future patients, and as resources for patients already receiving pharmacogenomic-guided care. One hope is that such materials would augment the overall educational process that providers must engage in, and simultaneously assuage potential participants' common concerns. Importantly, these materials should be used as vehicles to facilitate in-person discussion around these topics rather than as replacements for such discussions. Participants also wanted to understand the different treatment options available, the rationale behind a pharmacogenomic-guided selection, and side-effect/efficacy tradeoffs. We even elicited the idea that patients might be more willing to tolerate a drug with some degree of side-effects if they knew (based on their pharmacogenomic information) that a drug was more likely to be effective. This potential for pharmacogenomics to impact participants' medication adherence concurs with the findings of another study where higher statin therapy adherence was reported among patients who were informed of their pharmacogenomic results than controls who were not [26]. To the contrary, participants wondered about their preconceived heightened sensitivity toward side-effects based on their pharmacogenomic results. Thus, while it is important to promote participants' comprehension of their pharmacogenomic results, this must be balanced with avoiding unnecessary adverse or inappropriate psychological or behavioral patient responses [27]. The educational content should also address the important difference between pharmacogenomic and disease-risk testing, as has been previously suggested in other studies [24].

This study had several limitations. First, participants were recruited from an existing institutional pharmacogenomic implementation study where the participants' relationships with their physician could have influenced their decision to enroll, hence potentially introducing bias with the self-selection of a highly interested group. The larger study (The 1200 Patients Project) was also non-randomized. Second, while our study did not ascertain whether some patients were simply more informed about pharmacogenomics *a priori* versus whether the experience of participating in this study constituted an important primary education, it is nonetheless possible that the pharmacogenomic-group participants may have been more receptive to pharmacogenomic-guided care simply because they received additional education and exposure to the subject during enrollment and participation. If this is true, it would suggest that general public acceptance of genomic-guided care will only increase as the practice becomes more mainstream and as immersive education occurs. Third, the focus groups were held during the daytime of a work week, so they were a

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

convenience sample of participants who were available to attend the sessions. Nevertheless, the demographic characteristics of the participants matched those of the larger study (which has now enrolled >1400 patients) and the emergent themes from the focus groups dovetail with those that have emerged from other studies in this arena. The major advantage of our work compared to all other prior studies is that we examined both patients who had never been genotyped alongside patients who had been pharmacogenomically tested and were actively being treated within physician practices where pharmacogenomic information was routinely being utilized.

In conclusion, we found that participants who experienced pharmacogenomic-guided care had a better understanding of pharmacogenomics and were more receptive toward the use of their information as compared to traditional care participants who were generally more skeptical. Physicians need to actively engage participants during the testing and prescribing processes, as participants' perceptions of pharmacogenomics and genomic-determined prescribing may influence their perceptions of anticipated medication efficacy and side-effects. As adoption of pharmacogenomic testing becomes more widespread, understanding patients' attitudes and perceptions of pharmacogenomics and addressing concerns will be increasingly important in the design of pharmacogenomic implementation models.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

This research was supported by National Institutes of Health (NIH) grants K23 GM100288-01A1 (PHO) and 5T35DK062719-28 (Pritzker School of Medicine Summer Research Program), and the William F. O'Connor Foundation.

## References

1. Lam YW. Scientific challenges and implementation barriers to translation of pharmacogenomics in clinical practice. ISRN Pharmacol. 2013; 2013:641089. [PubMed: 23533802]
2. Manolio TA, Chisholm RL, Ozenberger B, Roden DM, Williams MS, Wilson R, et al. Implementing genomic medicine in the clinic: the future is here. Genet Med. 2013; 15(4):258–267. [PubMed: 23306799]
3. McKinnon RA, Ward MB, Sorich MJ. A critical analysis of barriers to the clinical implementation of pharmacogenomics. Ther Clin Risk Manag. 2007; 3(5):751–759. [PubMed: 18473000]
4. Clinical Pharmacogenetics Implementation Consortium. [Accessed April 4 2016] Stanford University and St. Jude Children's Research Hospital. Available at: https://cpicpgx.org/publications/
5. Caudle KE, Klein TE, Hoffman JM, Muller DJ, Whirl-Carrillo M, Gong L, et al. Incorporation of pharmacogenomics into routine clinical practice: the Clinical Pharmacogenetics Implementation Consortium (CPIC) guideline development process. Curr Drug Metab. 2014; 15(2):209–217. [PubMed: 24479687]
6. Bell GC, Crews KR, Wilkinson MR, Haidar CE, Hicks JK, Baker DK, et al. Development and use of active clinical decision support for preemptive pharmacogenomics. J Am Med Inform Assoc. 2014; 21(e1):e93–99. [PubMed: 23978487]
7. Formea CM, Nicholson WT, McCullough KB, Berg KD, Berg ML, Cunningham JL, et al. Development and evaluation of a pharmacogenomics educational program for pharmacists. Am J Pharm Educ. 2013; 77(1):10. [PubMed: 23459098]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript


8. Nickola TJ, Green JS, Harralson AF, O'Brien TJ. The current and future state of pharmacogenomics medical education in the USA. Pharmacogenomics. 2012; 13(12):1419–1425. [PubMed: 22966890]
9. Haddy CA, Ward HM, Angley MT, McKinnon RA. Consumers' views of pharmacogenetics--A qualitative study. Res Social Adm Pharm. 2010; 6(3):221–231. [PubMed: 20813335]
10. Haga SB, Kawamoto K, Agans R, Ginsburg GS. Consideration of patient preferences and challenges in storage and access of pharmacogenetic test results. Genet Med. 2011; 13(10):887–890. [PubMed: 21673581]
11. Haga SB, O'Daniel JM, Tindall GM, Lipkus IR, Agans R. Survey of US public attitudes toward pharmacogenetic testing. Pharmacogenomics J. 2012; 12(3):197–204. [PubMed: 21321582]
12. Haga SB, Tindall G, O'Daniel JM. Public perspectives about pharmacogenetic testing and managing ancillary findings. Genet Test Mol Biomarkers. 2012; 16(3):193–197. [PubMed: 22047505]
13. Lachance K, Korol S, O'Meara E, Ducharme A, Racine N, Liszkowski M, et al. Opinions, hopes and concerns regarding pharmacogenomics: a comparison of healthy individuals, heart failure patients and heart transplant recipients. Pharmacogenomics J. 2015; 15(1):13–19. [PubMed: 24980785]
14. Rogausch A, Prause D, Schallenberg A, Brockmoller J, Himmel W. Patients' and physicians' perspectives on pharmacogenetic testing. Pharmacogenomics. 2006; 7(1):49–59. [PubMed: 16354124]
15. Fargher EA, Eddy C, Newman W, Qasim F, Tricker K, Elliott RA, et al. Patients' and healthcare professionals' views on pharmacogenetic testing and its future delivery in the NHS. Pharmacogenomics. 2007; 8(11):1511–1519. [PubMed: 18034616]
16. O'Donnell PH, Danahey K, Jacobs M, Wadhwa NR, Yuen S, Bush A, et al. Adoption of a clinical pharmacogenomics implementation program during outpatient care--initial results of the University of Chicago "1,200 Patients Project". Am J Med Genet C Semin Med Genet. 2014; 166C(1):68–75. [PubMed: 24616296]
17. O'Donnell PH, Bush A, Spitz J, Danahey K, Saner D, Das S, et al. The 1200 patients project: creating a new medical model system for clinical implementation of pharmacogenomics. Clin Pharmacol Ther. 2012; 92(4):446–449. [PubMed: 22929923]
18. Halcomb EJ, Gholizadeh L, DiGiacomo M, Phillips J, Davidson PM. Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups. J Clin Nurs. 2007; 16(6):1000–1011. [PubMed: 17518876]
19. Tang KC, Davis A. Critical factors in the determination of focus group size. Fam Pract. 1995; 12(4):474–475. [PubMed: 8826068]
20. Hussain S, Kenigsberg BB, Danahey K, Lee YM, Galecki PM, Ratain MJ, et al. Disease-Drug Database for Pharmacogenomic-Based Prescribing. Clin Pharmacol Ther. 2016
21. McKillip RP, Borden BA, Galecki P, Ham SA, Patrick-Miller L, Hall JP, et al. Patient perceptions of care as influenced by a large institutional pharmacogenomic implementation program. Clin Pharmacol Ther. 2016
22. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. American Journal of Evaluation. 2006; 27(2):237–246.
23. Avey JP, Hiratsuka VY, Beans JA, Trinidad SB, Tyndale RF, Robinson RF. Perceptions of pharmacogenetic research to guide tobacco cessation by patients, providers and leaders in a tribal healthcare setting. Pharmacogenomics. 2016; 17(4):405–415. [PubMed: 26871371]
24. De Marco M, Cykert S, Coad N, Doost K, Schaal J, White B, et al. Views on personalized medicine: do the attitudes of African American and white prescription drug consumers differ? Public Health Genomics. 2010; 13(5):276–283. [PubMed: 19776555]
25. Issa AM, Tufail W, Hutchinson J, Tenorio J, Baliga MP. Assessing patient readiness for the clinical adoption of personalized medicine. Public Health Genomics. 2009; 12(3):163–169. [PubMed: 19204419]
26. Charland SL, Agatep BC, Herrera V, Schrader B, Frueh FW, Ryvkin M, et al. Providing patients with pharmacogenetic test results affects adherence to statin therapy: results of the Additional KIF6 Risk Offers Better Adherence to Statins (AKROBATS) trial. Pharmacogenomics J. 2014; 14(3):272–280. [PubMed: 23979174]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

27. Haga SB, Mills R, Bosworth H. Striking a balance in communicating pharmacogenetic test results: promoting comprehension and minimizing adverse psychological and behavioral response. Patient Educ Couns. 2014; 97(1):10–15. [PubMed: 24985359]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

**Table 1**

Demographics of the participants in the pharmacogenomic (PGx) and traditional care (TC) focus groups.

| | Total (N=22) | PGx group (N=9) | TC group (N=13) | P-value |
|---|---|---|---|---|
| Male – no. (%) | 11 (50) | 4 (44) | 7 (54) | 1.00 |
| Age – mean ± SD | 59.5 ± 15.0 | 55.9 ± 15.6 | 61.9 ± 14.7 | 0.37 |
| Race – no. (%) | | | | |
| ■ Caucasian | 12 (55) | 6 (67) | 6 (46) | 0.41 |
| ■ African-American | 10 (45) | 3 (33) | 7 (54) | |
| Education– no. (%) | | | | 0.34 |
| ■ High school or less | 3 (14) | 2 (22) | 1 (8) | |
| ■ Some college | 6 (27) | 2 (22) | 4 (31) | |
| ■ Bachelor's degree | 3 (14) | 0 (0) | 3 (23) | |
| ■ Advanced degree | 9 (41) | 5 (56) | 4 (31) | |
| ■ Not reported | 1 (5) | 0 (0) | 1 (8) | |
| No. of prescription medications – no. (%) | | | | 0.14 |
| ■ 1 to 3 | 10 (45) | 6 (67) | 4 (31) | |
| ■ 4 to 6 | 10 (45) | 2 (22) | 8 (62) | |
| ■ At least 7 | 1 (5) | 1 (11) | 0 (0) | |
| ■ Not reported | 1 (5) | 0 (0) | 1 (8) | |
| Self-reported history of medication related side-effects – no. (%) | 14 (64) | 5 (56) | 9 (69) | 0.66 |
| Recalls receiving a PGx-determined prescription – no. (%) | 3 (14) | 3 (33) | 0 (0) | 0.21 |
| No. of study doctor outpatient visits since enrollment | 4.1 ± 2.8 | 4.3 ± 3.8 | 3.9 ± 2.0 | 0.70 |

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

## Table 2

Leading themes identified from the pharmacogenomic (PGx) and traditional care (TC) focus groups, with similar (shaded) and contrasting subthemes within each shown.

| THEME | SUBTHEMES AND REPRESENTATIVE QUOTATIONS | PGx | TC |
|---|---|---|---|
| ***1. Concerns when starting a new medication*** | | | |
| Similar | What are the side effects? | X | X |
| Different | Is this drug necessary and effective? | X | |
| | Will my insurance cover it? | X | |
| | What other options are available? | X | |
| | What are the long term effects?<br>*"If it's a new medication I'd have like the standard concern of what are the long term consequences…" (TC)* | | X |
| | How does it interact with other drugs? | | X |
| | Is there sufficient research?<br>*"And they keep telling me it ain't gonna get absorbed by your blood stream and stuff but, I don't feel confident about that because there's not enough, you know, research and stuff. This is a new disease and they don't know how to deal with it. And they're using me to find out…"(TC)* | | X |
| ***2. Factors influencing drug response*** | | | |
| Similar | Activity level<br>*"Lifestyle. How active you are or what you're doing on a daily basis."(TC)* | X | X |
| Different | Medication adherence | X | |
| | Genetics<br>*"It's genetic. One person's genetic makeup reacts to drugs differently than someone else's. Isn't that true?" (PGx)* | X | |
| ***3. Knowledge of genetics and pharmacogenomics*** | | | |
| Similar | Understanding that genetics relates to hereditary<br>*"…when we say genetic test, are we talking about something related to, uh, heredity? Or something that runs in the family?" (PGx)* | x | x |
| Different | Curious about PGx physiology<br>*"What do they find out when they say 'by my blood test' and the picture of me? So what in my blood tells him that this drug is better that drug?" (PGx)* | x | |
| | Confused PGx with disease risk testing<br>*"My situation goes with this question very well. My dad and sister have ulcerative colitis … 2 years ago I was diagnosed with Crohn's disease. So I was assumed to have colitis as well." (TC)* | | x |
| ***4. Reasons to undertake a pharmacogenomic test*** | | | |
| Similar | Informed decision-making<br>*"It would give us more information…and better inform as to what medication to prescribe." (PGx)* | x | x |
| Different | Benefit family member or other users | x | |
| | Finding a more effective drug<br>*"My doctor said because of your volunteering for this program, your blood pressure is not coming down on the current medication, and through research, this is a better match for you." (PGx)* | x | |
| | Avoid side effects<br>*"I want to know if you could skip the side effects…(TC)* | | x |
| ***5. Concerns about consenting to a pharmacogenomic test*** | | | |

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

| THEME | SUBTHEMES AND REPRESENTATIVE QUOTATIONS | PGx | TC |
|---|---|---|---|
| Similar | Why do you think I have the underlying condition? (see Table 3) | X | X |
| | Will this affect insurance/employment?<br>*"If that were to be shared with the wrong people in the future, could that impact my insurance? Employment? … I trust you guys." (PGx)* | X | X |
| Different | How accurate is the pharmacogenomic test?<br>*"How accurate is this genetic testing related to medication? Is there enough track record? Is it on target?" (PGx)* | X | |
| | What will my options based on the PGx results? (see Table 3) | X | |
| | What is the significance difference between the drug treatments? (see Table 3) | X | |
| | Ancillary findings<br>*"There must be other information attached to whatever they found that made me genetically different from other people, and I want to know anything that is potentially understood based on that test…" (PGx)* | X | |
| | How expensive is it? | | X |
| | Why isn't this routine procedure?<br>*"Shouldn't it be automatic when you go to the doctor, they try and do everything possible for a person?" (TC)* | | X |
| ***6. Concerns about privacy and personal pharmacogenomic information*** | | | |
| Similar but spanning both ends of the spectrum | The information should be secure but readily available.<br>*"We're giving away extensive information and we don't know what it means. Right now I do this in an environment of a sense of trust." (PGx)*<br>*"I don't want my DNA floating everywhere." (TC)*<br>*"I would think that any doctor who's treating me should be able to have access to my full information." (PGx)*<br>*"The privacy part shouldn't matter. If that saves your life…someone else being nosy can save my life, I would really appreciate that." (PGx)* | X | X |
| | I would like control over who has access.<br>*"I would like to be asked about it…I would just want to know, and just be able to get an OK with that." (PGx)*<br>*"How you personally choose to share your DNA information with anybody else should be your call." (TC)* | x | x |
| | We have no privacy. Hackers can access anything.<br>*"There is no sense of privacy; it's all shared between insurances and other kinds of care facilities. I don't think we have a measure of privacy, no matter what that HIPAA thing says." (PGx)* | x | x |
| ***7. Relationship with healthcare professionals*** | | | |
| Similar | Physician-patient relationship can affect patient's decision to undergo for pharmacogenomic testing.<br>*"…this is his primary physician he has a relationship with. I was here in the emergency room…if that had been my primary physician to suggest that…I would have said, 'Well okay, let's think about that. Let's talk some more.' But as far as me being in the emergency care, doctors I'm not familiar with…I know they got a protocol and Hippocratic Oath they must take and what-have-you but, I'm not good with that in that situation." (TC)* | X | X |
| | Pharmacogenomics can affect the physician-patient relationship.<br>*"I see it as positive…If I have a doctor who's using this information… they're staying on the front end of available information and advances." (PGx)*<br>*"…my physician tell me based on my pharmaco-..blood test..I needed my blood pressure medication changed…I was assured that this was a good idea to participate…I think it's a real positive thing…" (PGx)* | X | X |
| | Factors impacting patients' trust in their physicians<br>*"I think a doctor willing to refer you to someone for certain issues or…that someone else could do better with." (PGx)*<br>*"That they're knowledgeable of what I'm, that they're very knowledgeable in what I'm seeking. "(TC)* | X | X |
| | *Qualities desired in a physician*<br>*"It does make a difference when your doctor takes time out with you to sit down and discuss everything, just don't be in a hurry."(PGx)*<br>*"…they listen to you, 'cause you know your body better than anyone else." (TC)*<br>*"Listening ability…their willingness to ask you questions and inquire in depth about what's happening with you and how you are dealing with certain things in regards to the illness or the medication…having good dialogue." (TC)* | X | X |
| | Pharmacogenomics can benefit the pharmacist's role. | X | X |

| THEME | SUBTHEMES AND REPRESENTATIVE QUOTATIONS | PGx | TC |
|---|---|---|---|
| | *"It would make the pharmacist more informed and again another double, triple check before they're handling me the medications, you know…efficacy of the medication…possible side effects" (PGx)* | | |
| Different | Pharmacogenomics will not affect the pharmacist-patient relationship.<br>*"…my pharmacist is the mailman…my pharmacist doesn't exist…it's the doctor." (PGx)* | X | |
| | I don't see why pharmacists need to know my pharmacogenomic information.<br>*"I get all my medical care here… I don't see any reason to open the records to pharmacists, because it could be checked here first." (TC)* | | X |
| ***8. Skepticism toward the medical field in general*** | | | |
| | Skepticism of genetics<br>*"I guess if I was gonna do this genetic testing it would have to be over more grave circumstances…if I don't do it, I'm gonna die." (TC)* | | X |
| | Mistrust in pharmaceutical companies<br>*"TV commercials. They don't tell you how bad for you everything is. " (TC)*<br>*"…the television, if you see a certain medication, that you're taking, or you've been prescribed to take, and they'll say, real fast, 'Side effects of such and such…' Wait a minute, hold on, I'm gonna be dead by taking this stuff…or I'm gonna be crippled or something if I take this medication." (TC)* | | X |
| | Skepticism of the physician's knowledge of medicines<br>*"…when you go to" the doctor and you say something is wrong, it seems like they use people for guinea pigs,…okay we got this new medicine." It just keeps going on and on 'til you don't know what the hell is working, 'cause it's so much stuff."(TC)* | | X |
| | Feeling overmedicated<br>*"When my doctor prescribes a new medication, and I look at her and I say "really? Another one? What did I do now that I need to take more meds?" (TC)* | | X |

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

## Table 3

Responses to the clinical vignettes (warfarin, simvastatin and clopidogrel) wherein pharmacogenomic results might differentially affect prescribing, with themes and representative quotations from the pharmacogenomic (PGx) and traditional care (TC) focus groups.

| | THEMES AND REPRESENTATIVE QUOTATIONS |
|---|---|
| **Similar themes** | **What are the other treatment options?**<br>*"Is there a drug B, C or D? Not that I wouldn't take the test but it would suck to take it and find out that I can't take that (drug)…" (PGx-simvastatin)*<br>*"If X is not going to work well, and Y will work well, but is extraordinarily expensive…what are my other options?…What about Z or A or B or C?" (TC-clopidogrel)*<br><br>**What is the difference between the drug options?**<br>*"How significant is the difference between the different drugs…is it enough to warrant all the extra testing cost or price difference in drugs?" (PGx-simvastatin)*<br>*"What's the difference between the two?…from the genetic testing…what should I expect from this drug? What should I expect from this other drug?" (PGx-clopidogrel)*<br><br>**Can we use non-pharmacological options besides medication?**<br>*"…don't get too drug heavy…if the root problem is…we need to exercise more, or eat better, then we should also be striving for that…'cause more medications can probably help so far." (PGx-warfarin)*<br>*"I think how significant the side effects are and then, also are there other things you can do, in particular since we're talking about cholesterol, besides medication?" (PGx-simvastatin)*<br>*"Let's look at the other medication that in itself may be less efficacious, but, combine it with some lifestyle changes." (TC-simvastatin)*<br>*"You have to utilize other options as far as health…because one is too expensive for you, the other one just not gonna cooperate with your body, so what choice do you have?" (TC-clopidogrel)*<br><br>**Participants' perception of the pharmacogenomic-determined medication**<br>*"I'm definitely going to be less enthused to take a medication if I know it might not be effective…if I know it could be really effective…I'm at the high end of effectiveness, then even if there might be some side effects then I might be more willing to push through, knowing the benefits." (PGx-all drugs)*<br>*"And I do have higher expectations. I think "This is gonna work. He took the time. It's in this thing, you know, this study. It's in my blood!…And if it doesn't happen now, I'm gonna be really pissed off." (PGx-all drugs)*<br>*"…if you went into this with more information that you may be more predetermined to have these side effects. I think it would be even stronger notion that like, if I throw up tomorrow that's probably the medicine, whether it was or not." (TC-all drugs)* |
| **Vignette 1 (Warfarin)** | **Genetics predict a lower warfarin dose needed.**<br>Vignette Setting: *"Your test results show that your recommended starting dosage of a blood thinner is in a lower range than that of most patients in order to be effective."*<br><br>**Why do you think I have the underlying condition?**<br>*"I want to know what am I presenting? Do I have any symptoms that make you want to prescribe this medicine for me?" (PGx)*<br>*"What is causing you to think about prescribing this drug to me to begin with?" (TC)* |
| **Vignette 2 (Simvastatin)** | **Genetics resulted in a less effective cholesterol-lowering drug to avoid statin-induced myopathy.**<br>Vignette Setting: *"Your genetic test results show you have a greater likelihood of experiencing muscle aches as a side effect. Your doctor suggest an alternative medication that may not be as effective, but wouldn't give you muscle aches."*<br><br>**Dealing with the side effects of the medication**<br>*"Chronic pain wears you down…and we're back to a quality of life issue…Don't give me A…it's gonna make me miserable." (TC)*<br>*"….whereas somebody else might not care about muscle pain, I don't want to deal with muscle pain…if that other medication may have another thing that I may not want to deal with either, then I might go with the one that has the muscle pain, it's a matter of what are the side effects of both." (PGx)*<br><br>**How to manage when the less effective drug fails**<br>*"…what's my risk if the other drug doesn't work as well?…how quickly are we gonna to monitor it? Am I much more likely to have a problem between now and when we figure this out if I do it that way?" (PGx)* |
| **Vignette 3 (Clopidogrel)** | **Genetics resulted in a more expensive, but potentially more effective antiplatelet agent than clopidogrel.**<br>Vignette Setting: *"Based on your genetics, you are more likely to respond to drug Y, but it is six times more expensive than drug X".*<br><br>**Insurance coverage of the more expensive drug**<br>"*Insurance. Does it cover it?" (PGx)*<br>*"…most people would want to know…whether or not they could afford it." (TC)* |

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

| THEMES AND REPRESENTATIVE QUOTATIONS |
| --- |
| **Risk versus benefit of the different treatment options** |
| *"…is that the only reason that drug X was the preferred drug in the first place?…if there were other reasons I'd want to know what I was giving up, other than the cost. And then I'd be interested in who covers the cost." (PGx)* |
| *"…there was a six times different cost, but did you say a multi-, or how big the difference was in efficiency? … if it's 6 times more efficient then yeah I'm probably gonna pay it but if it's you know, not a big, not that big of a difference then I might not pay it, you know. Is there a generic?" (PGx)* |

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

## Table 4

Feedback from pharmacogenomic (PGx) and traditional care (TC) groups on preferred methods to communicate pharmacogenomic information in educational handouts.

| PHARMACOGENOMIC CONTENT | REPRESENTATIVE QUOTATIONS |
|---|---|
| **1. Simvastatin handout** | |
| a. Layout of information | *"If you're gonna use this acronym, the only way to do it is to write it down. There are too many letters." (TC)*<br>*"I like the three bullet points…They were very clear." (TC)*<br>*"You've got to make this type a little larger." (TC)* |
| b. Explanation of the physiology | *"My main reaction to this is Ah! This is the kind of thing they're talking about, this is how it works, this is interesting." (PGx)* |
| c. Information is too technical | *"…it seems pretty technical for a layperson to understand" (PGx)* |
| d. Where are my results? | *"Which group am I in?" (PGx)* |
| **2. Clopidogrel handout** | |
| a. Layout of information | *"I like the bullet points. I thought it was a lot easier to understand." (PGx)*<br>*"This is much more complicated…the pictures are very uninformative." (TC)*<br>*"I thought this handout…I understood it a little better than the last one…it seems pretty straightforward…" (TC)* |
| b. Is the information complete? | *"'It only tests for four responses…why only four instead of a full battery? Because what if those four I'm fine with and it turns out that number 5 or 10, which didn't get tested for, is the one that causes me to have problems."(TC)*<br>*"My initial response is that this is based on a current state of knowledge, which is very limited. They say we can only identify four categories…what's really going on, and are there likely to be important things that are not captured by those groups?" (PGx)* |
| **3. Similar themes for both handouts**<br>a. Providing general versus patient-specific information | *"I don't like hearing numbers. I want it personalized. I want you to tell me based on this and this and this that we know what's best for me. I don't care about the statistics of other people because I'm hoping I'm the exception so you address me personally….I want it to be me…All about me. Not about: "Well 97% of people" I don't care about that." (PGx)*<br>*"I think numbers can be important, and I think we all can be the exception to anything, but if the doctor tells me I've got an 80 percent higher risk, if I don't take this, and the side-effects aren't that bad, and even if they are, sometimes it's like, do the side-effects… does it outweigh me dying?" (PGx)* |
| **COMMUNICATION PREFERENCES** | **REPRESENTATIVE QUOTATIONS** |
| 1. Handouts and other communication methods | *"I like a handout. I'm a visual person." (PGx)*<br>*"…have a website here listed, because I would probably look on the website if I was curious for more information." (PGx)*<br>*"…video… something online that we could look at." (PGx)* |
| 2. In-person discussion with their physician | *"I think handouts are always good to refer to, but if the doctor goes over these types of things with you, then you can ask questions." (PGx)*<br>*"Conversation. I definitely want to talk about it…I think this is just a* supplement *(handout) to speaking to somebody who knows exactly what they're saying." (TC)* |