



Perceptions of personalized medicine in an academic health system: Educational findings

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ABSTRACT

Objective: Prior reports demonstrate that personalized medicine (PM) implementation in clinical care is lacking. Given the program focus at Duke University on PM, we assessed health care providers' perspectives on their preparation and educational needs to effectively integrate PM tools and applications into their clinical practices. **Methods:** Data from 78 health care providers who participated in a larger study of personalized and precision medicine at Duke University were analyzed using Qualtrics (descriptive statistics). Individuals age 18 years and older were recruited for the larger study through broad email contacts across the university and health system. All participants completed an online 35-question survey that was developed, pilot-tested, and administered by a team of interdisciplinary researchers and clinicians at the Center for Applied Genomics and Precision Medicine. **Results:** Overall, providers reported being ill-equipped to implement PM in clinical practice. Many respondents identified educational resources as critical for strengthening the PM implementation in both research and clinical practice. Responses did not differ significantly between specialists and primary providers or by years since completion of the medical degree. **Conclusions:** Survey findings support prior calls for provider and patient education in PM. Respondents identified focus areas in training, education, and research for improving PM uptake. Given respondents' emphasis on educational needs, now may be an ideal time to address these needs in clinical training and public education programs.

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INTRODUCTION

Significant advances in personalized and precision medicine (PPM) research over the last two decades have led to the recognition that PPM has an important place in clinical care [1,2]. As costs of tools like genomic testing and sequencing continue to decline and emerging data support their clinical utility in certain cases, the medical field is starting to examine effective strategies for the cost- and time-effective translation of PPM into routine clinical practice [2-5]. However, for new advances and strategies to be implemented, providers and patients must be aware of the evidence-base for PPM tools and their potential to improve health care delivery and outcomes.

Prior survey and implementation research and a state of the science review have revealed a lack of training and education in PPM in health professions education curricula and clinical

training, particularly in genomics [1,6,7]. While scientific research has moved toward understanding individual variation in health and illness, providers, and other stakeholders traditionally have worked in an environment of generalizations from aggregate data that formed the evidence-base regarding diseases and approaches to them [8]. Innovative proposals to address the need for genomics education have suggested including a strong curriculum as early as high school for personal genetics education [9], or placing genetics before other basic sciences in pre-med and medical programs [8,10]. For those providers that are finished with formal education, the shift to PPM will require clinician education, such as guidelines and other point-of-care resources to stay apprised of the current PPM evidence-base [11]. While the needs around education for this personalized medicine (PM) era have been acknowledged widely in the health professions, and competencies have been established in multiple disciplines [12], the literature has not

reported widespread assessment or improvements in addressing this gap.

The Duke University Health System (DUHS) is one of few academic health centers to have an institutionally supported program, the Center for Applied Genomics and Precision Medicine (CAGPM), focused on PPM that has the resources and multidisciplinary expertise required to advise, influence, and assess the implementation of PPM in clinical care. Since the term “PM” is used in many contexts and with varying definitions, it is important to note that the Duke CAGPM defines PPM broadly to acknowledge the important contributions of social, behavioral, and environmental risks and interventions on health outcomes, not just genetic and genomic factors. However, as with many large academic centers, not all members of the DUHS are aware of the availability and applicability of the CAGPM to their practice and research. In order to establish priorities for the CAGPM’s goal of improving the quality, safety, and outcomes of clinical care at DUHS, we conducted a survey within our institution (DUHS and Duke University) to assess the current landscape of PM. One of the major foci of the survey was to assess the preparation of clinicians in PPM and to determine the barriers and facilitators relevant to their educational needs and ongoing practice. Here, we present the findings from the subsample of respondents who self-identified as health care providers.

METHODS

This survey was conducted by the CAGPM and was considered exempt by the DUHS Institutional Review Board. An interdisciplinary team of researchers developed and administered an online 35-question survey through Qualtrics software (Qualtrics, LLC, Provo, UT). The survey was developed to assess perspectives and attitudes about PPM, including the current status of PPM in clinical care and research at Duke. The definition of PPM provided in the survey to provide a context for responses to items was “an evidence-based approach to personalizing patient care, from health to disease, using a multidisciplinary structure to promote health and wellness, patient education and satisfaction, and customized disease prevention, detection, and treatment including genomic, genetic, social, behavioral, and environmental risk assessment.” This definition was provided to participants prior to the survey items analyzed in this manuscript, in order to give a common context to the questions. Most of the questions were on a Likert scale, with two open-ended questions at the end of the survey inquiring about the greatest opportunities and challenges regarding PPM implementation at our institution. Eligible participants had to be aged 18 years or older.

Broad recruitment strategies were used to reach as many clinicians as possible, including listservs, departmental distribution lists, and individual identification of potential participants through web-based directories. This resulted in some duplicate receipts of the emailed letter and survey link, but was necessary to ensure a broad distribution. Email instructions for participation included the following: “Please complete

this survey only if you have encountered, thought about, or implemented PM as part of your work responsibilities.”

Using this email recruitment strategy, 3,817 individuals were contacted with estimates that approximately 25% would be potentially eligible. Of those contacted, 198 responded, 197 consented, and 166 completed the survey (overall response rate of 5%; adjusted response rate from potentially eligible individuals 20.7%; survey completion rate of 84.3%). Of those who participated, 78 (39.8%) self-identified as a health care provider and constitute the sample reported in this manuscript. No compensation was provided to respondents for survey completion; however participants who completed the survey had the option to be entered into a drawing at the conclusion of the study for one of the three iPad minis.

Analysis

Participants anonymously entered data into Qualtrics, and all analyses were conducted using the Qualtrics software. Descriptive statistics was used to analyze the responses to the survey items. The Qualtrics software allowed the researchers to query the survey data in aggregate, to generate reports of response frequencies and qualitative (open-ended) data, and to compare responses by provider characteristics (e.g., specialty vs. non-specialty providers; years since completion of highest degree).

RESULTS

Respondent Characteristics

Table 1 depicts the characteristics of the providers, who comprise our sample. The vast majority (74.4%) of the 78 providers were physicians. Of the 78 providers, 83% identified as specialist providers. There was a high degree of variation in the specialty practice areas of the providers with many identifying as “other” (23%).

Perceptions of PM in Education – Status, Facilitators, Barriers

Of the 68 providers who responded regarding institutional preparation to implement PPM in the clinic setting, a majority reported that they did not believe they had adequate preparation (42%) [Figure 1]. Only 18% agreed that preparation was adequate, with the remainder reporting a neutral perception, disagreement, or declining to respond. We did not observe a difference in how specialists or non-specialists perceived institutional preparation for PM clinical implementation. In terms of implementation of PM research, the only difference noted was that many non-specialist providers noted that the institution had addressed their needs as compared to specialist providers and in comparison to the clinical implementation preparation. In addition, 42.9% of providers reported that not having time to educate themselves or to consider how to implement PPM hindered implementation in their clinical practice [Table 2].

A majority of respondents reported that education of clinicians ($n = 48$) was the most important focus area for PPM efforts at

Table 1: Provider characteristics

Characteristics	N (%)
Total number of providers	78
Specialist provider	65 (83)
Specialties	
Allergy/Immunology/Rheum	2 (3)
Cardiology	3 (5)
Gastroenterology	6 (9)
Hematology/Oncology	5 (8)
Nephrology/Urology	2 (3)
OB/Gyn	3 (5)
Ophthalmology	4 (6)
Orthopedics	5 (8)
Pediatrics	3 (5)
Radiation Oncology	2 (3)
Radiology	6 (9)
Surgery	8 (12)
Other	15 (23)
Decline to respond	1 (2)
Department or clinic affiliation	
University Health System	41 (53)
University Medical Center	57 (73)
University	4 (5)
University Affiliated Practice	6 (8)
Non-University Affiliated Practice	3 (4)
Other (Private Diagnostic Clinics)	2 (3)
Highest level of education completed	
High School	2 (2.6)
Associates Degree	5 (6.4)
Bachelor's Degree	5 (6.4)
Advanced Practice Degree	3 (3.8)
Master's Degree	3 (3.8)
Doctorate	2 (2.6)
Medical Degree	58 (74.4)
Years since completing highest degree	
0-10	16 (20.5)
11-20	14 (17.9)
21-30	20 (25.6)
>31	5 (6.4)
Involved in conducting research (including screening, recruitment)	62 (79)
Investigator on clinical trial involving personalized medicine	7 (9)

our institution [Table 2]. To obtain the necessary education, a majority of the clinicians (78.8%) reported that continuing education was “very” or “somewhat” important for them and their clinical team; only 10.6% reported that this was “not important.” Respondents rated the five most effective educational strategies for PPM as: (1) online continuing medical education (CME)/continuing education units (CEU) (54%), (2) professional conferences (42%), (3) peer-reviewed literature (37%), (4) on-site CME/CEU (36%), and (5) online tools such as webinars or podcasts (32%). Figure 2 depicts the full responses regarding other potential educational strategies.

Specialist and non-specialist providers were similar in their assessments of educational needs in PPM, although some differences were noted [Table 2]. Both groups identified research in PPM – including patient-centered outcomes research – as a critical focus area for PPM. One noted difference was that non-specialist providers rated improvements in the electronic medical record (EMR) as being among the top five areas to focus on in terms of approaches for PPM, but this was not among the top five areas for the specialist providers. Another difference was that specialists reported research on genomic PPM approaches as a top five area of focus, but non-specialty providers did not rate this as a top five area.

The results by years since completion of formal education did not reveal significant differences in responses [Table 3]. All providers identified lack of time and training within the clinical community as barriers to implementation of PPM in the clinic, regardless of time since degree completion. Interestingly, the importance of continuing education showed a trend toward higher importance as the time since education completion decreased. The most effective educational strategies did differ somewhat by years since degree completion; however, online CME/CEU and peer-reviewed literature were among the top five for all groups [Table 3]. In terms of the most important focus areas for PPM efforts, clinician education was the top priority for all respondents. Clinicians who completed their formal education more recently reported genomic and non-genomic



Figure 1: Perceived institutional preparation for personalized and precision medicine implementation. Participants were asked whether they agreed with the statement “Duke has adequately prepared me to implement personalized medicine (PM) in the clinic” (a) and “Duke has adequately addressed my needs in preparing me to use PM in my research” (b). For both statements, participants were provided with the following six answer choices: strongly agree, agree, neither agree nor disagree, disagree, strongly disagree, and decline to respond. For analysis purposes, we grouped “strongly agree” and “agree” responses together into an “agree” category, and “strongly disagree” and “disagree” grouped into a “disagree” category; and “neither agree nor disagree” as a “neutral” category. For (a), there were 68 total respondents: 57 specialists and 11 non-specialists. For (b), there were 53 total respondents: 48 specialists and 5 non-specialists. PM: Personalized medicine.

Table 2: Specialist versus non-specialist providers' perceptions on the influence of education on PPM implementation

	Specialist providers (n=65)* (%)	Non-specialist providers (n=13)* (%)	All providers (n=78)* (%)
Importance of continuing education on personalized medicine for professional development			
Important	41 (74.5)	11 (100)	52 (78.8)
Neutral	7 (12.7)	0	7 (10.6)
Not Important	7 (12.7)	0	7 (10.6)
Top 5 educational strategies most effective for clinician and clinical team	Online CME/CEU (26) Onsite CME/CEU (20) Professional Conferences (20) Peer-reviewed literature (18) Online learning tools (webinars, podcasts) (13)	Online CME/CEU (6) Online learning tools (6) Professional conferences (5) Peer-reviewed literature (4) On-site seminars (3)	Online CME/CEU (32) Professional conferences (25) Peer-reviewed literature (22) On-site CME/CEU education (21) Online learning tools (webinars, podcasts) (19)
Influence of time to educate self and consider PM approaches on inclusion of PM in clinical care			
Hindered	18 (39.1)	6 (60)	24 (42.9)
Facilitated	14 (30.4)	1 (10)	15 (26.8)
Neutral	14 (30.4)	3 (30)	17 (30.4)
Influence of training within the clinical community on inclusion of PM in clinical care			
Hindered	10 (23.3)	5 (55.6)	15 (28.8)
Facilitated	8 (18.6)	2 (22.2)	10 (19.2)
Neutral	25 (58.1)	2 (22.2)	27 (51.9)
Five most important focus areas to direct effort for personalized medicine at Duke (Focus areas [number of respondents identifying area])	Clinician education (41) Demonstrate clinical validity of PM (26) Patient-centered outcomes research (21) Patient education (21) Research on genomic PM approaches (19)	Clinician education (7) Demonstrate clinical validity of PM (6) Patient-centered outcomes research (6) Improvement of electronic medical records (6) Patient education (5)	Clinician education (48) Demonstrate clinical validity of PM (32) Patient-centered outcomes research (27) Patient education (26) Genomic personalized medicine research (21)

*Note: 'n' does not equal total sample size for all items/responses due to option to decline to respond. Percentages calculated based on number of respondents. PPM: Personalized and precision medicine, CEU: Continuing education units, CME: Continuing medical education, PM: Personalized medicine

PPM research as a key focus area. All groups prioritized utility and patient-centered outcomes research, but those who had a longer duration since completing their education prioritized research demonstrating the effectiveness of PPM as a critical need.

A few responses to the open-ended items at the end of the survey, in which respondents were asked about the greatest opportunities and challenges to Duke's ability to be an international leader in PM, were relevant to educational issues. For greatest opportunities, two respondents suggested integration of clinical decision support (CDS) and provider education regarding PM strategies into the EMR system. For greatest challenges, some respondents suggested a lack of understanding of PM and the time and access to educational offerings. Full analyses of the qualitative responses are reported elsewhere (manuscript under review).

DISCUSSION

Our study demonstrates a clear need for provider education in PPM. Many (32%) of the providers had completed their formal education and degrees more than 20 years ago, and all providers acknowledged their need for continuing education in PPM. Given that the majority of providers indicated that PPM education is a priority, the field is at a key point in the translation of PPM into practice to ensure that education occurs while interest

and motivation are high. Some of the preferred venues for providing this education included online CME/CEU activities, online webinars/podcasts, and directing clinicians to appropriate professional conferences and seminal peer-reviewed literature. It also may be important to pay attention to the differences in responses by providers depending on years of experience; those who completed their education more recently reported different needs from those who had been in practice longer. However, all clinicians, regardless of years of experience, also reported that they had limited time to educate themselves, and the survey did not address whether clinicians would prioritize PPM education when meeting CEU requirements for maintaining licensures and certifications. Interestingly, specialty providers reported that research in genomic PPM strategies is needed, although non-specialty providers did not identify this as an area of need. This finding in part may reflect the fact that genomic technologies in particular are more commonly developed, studied and used in specialty care (e.g., oncology, cardiology). Furthermore, while specialty providers may be more likely to prescribe medications with pharmacogenetic/genomic indications, increasingly growing numbers of primary providers are managing common chronic diseases, and prescribing these medications (e.g., statins, warfarin for cardiovascular disease). Thus, this remains a critical need. The non-specialist providers reported that integration of PPM into the EMR was needed, reflecting their focus on the point of care decision-making and education.

Table 3: Providers' perceptions on the influence of education on PPM implementation by years since completion of formal education

	0-10 years (n=16)	11-20 years (n=14)	21-30 years (n=20)	>31 years (n=5)
Importance of continuing education on personalized medicine for professional development (mean rating on scale of 1 - Very Important to 5 - Very Unimportant)	1.93/5	2.09/5	2.00/5	3.2/5
Top educational strategies most effective for clinician and clinical team	Professional conferences (8) Online CME (6) Peer reviewed literature (5) Newsletters (3)	Online CME (7) Online Tools (5) Onsite CME (5) Onsite Seminar (4) Peer reviewed literature (4)	Online CME (10) Onsite CME (7) Professional conferences (6) Online Tools (6) Peer reviewed literature (6)	Other (EHR integrated) (2) Online CME (1) Peer reviewed literature (1)
Influence of time to educate self and consider PM approaches (mean rating on scale of 1 - Greatly Facilitated to 5 - Greatly Hindered)	3.85/5	3.64/5	3.35/5	4.75/5
Influence of training within the clinical community on inclusion of PM in clinical care (mean rating on scale of 1 - Greatly Facilitated to 5 - Greatly Hindered)	3.85/5	3.73/5	3.19/5	5.00/5
Institution has adequately prepared me to implement PM in my clinical practice (mean rating on scale of 1 - Strongly Agree to 5 - Strongly Disagree)	3.50/5	4.09/5	3.76/5	3.50/5
Most important focus areas to direct effort for personalized medicine (top 5 or less that could be distinguished by number of respondents selecting options)	Clinician education (9) Genomic PM research (7) Demonstration of the clinical validity of PM approaches (7) Patient-centered outcomes research (7) Patient education (5)	Clinician education (8) Demonstration of utility of PM approaches (4) Non-genomic PM research (3) Genomic PM research (3)	Clinician education (12) Demonstration of the clinical validity of PM approaches (8) Patient-centered outcomes research (8) Patient education (7) Demonstration of utility of PM approaches (6)	Clinician education (2) Patient centered outcomes research (2) Demonstration of the clinical validity of PM approaches (2)

PPM: Personalized and precision medicine, CEU: Continuing education units, CME: Continuing medical education, PM: Personalized medicine

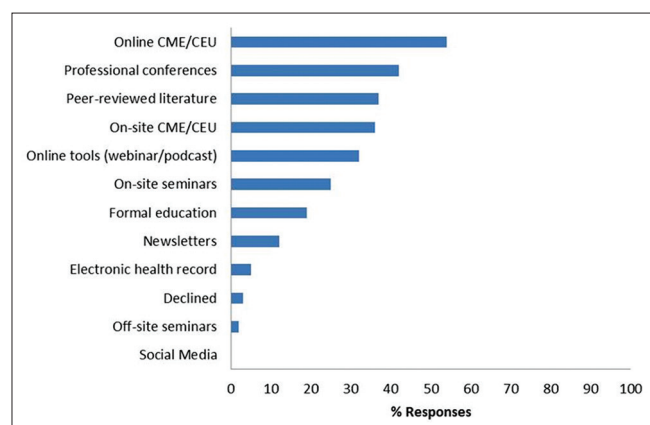


Figure 2: Provider-identified effective strategies for personalized and precision medicine education. Participants were asked to select up to three of thirteen possible answers to the question "Which educational strategies in personalized medicine are most effective for you and/or your clinical team?" Answer options provided to participants were (1) online continuing medical education (CME)/continuing education units (CEU) education, (2) on-site CME/CEU education, (3) formal education (e.g., credit or non-credit course), (4) online learning tools (e.g., webinars, podcasts), (5) on-site seminars, (6) off-site seminars, (7) professional conferences, (8) professional/clinical newsletters, (9) peer-reviewed literature, (10) social media (e.g., Twitter, Research Gate, blogs), (11) other, (12) none of the above, and (13) decline to respond. Although the information embedded in the EHR was not among the possible answer options provided, the two respondents who selected "other" both specified this as an educational strategy they used.

Primary care providers and those who completed their formal education more than 30 years ago noted that EMR-based tools for CDS and provider or patient education also might be effective ways to facilitate and guide clinical implementation of PPM. EMRs are anticipated to aid in the management of knowledge accumulated by health care providers to improve patient care, particularly when CDS can prompt a clinician to consider PPM decisions such as pharmacogenetic risks [13]. Ultimately, broad application of such tools will increase clinician awareness of key PPM decision points. However, the eMERGE network of centers implementing EMRs into care acknowledge that the education of providers about genetic risk tools prior to the return of results is critical to ensure that the tools are used effectively [14]. This further highlights the importance of provider education about PPM, even when providers are given tools to facilitate PPM use, so that providers know how to take advantage of the assistance provided by PPM tools.

A noteworthy finding was that a majority of clinicians did not view institutional support as adequate for implementation of PPM into research or clinical practice. Providing the right type of support for different levels of providers in different specialty areas and with varying length of clinical experience is a significant challenge for all large health care entities, academic and non-academic. Institutional commitment and resources are vital [4], and require critical evaluation and planning to ensure that both provider and health care system needs are being met. Online educational tools

increasingly are becoming the norm for meeting credentialing standards in a time-efficient manner, and the providers in our study identified online, offsite methods (e.g., online CME/CEU, peer-reviewed literature) as preferred educational methods. However, some areas of PPM are not conducive to distance-based/online methods. For example, behavioral strategies for personalizing care, such as motivational interviewing and health coaching, are best learned with at least some practice and/or mentoring of skills. Similarly, learning the skills to have conversations with patients about genomic/genetic tests and their implications for health care decisions also require practice. As such, institutions may benefit by evaluating the different types of training needed across the various areas of PPM (e.g., genetic/genomic testing, return of genome results and secondary findings, personalized behavioral management), and engaging providers in decision-making regarding how these needs are met. Examples may include, team-based approaches to integrating PPM into care, limited skills-based training for physicians, and nurse practitioners managing care with decision trees for appropriate referrals (e.g., to genetic counseling or health coaching), and effective use of CDS. Engaging providers in developing the educational strategies for PPM will aid health care organizations in maximizing benefit from generally finite resources.

Limitations

The primary limitation of this survey study is the low response rate and survey sample size despite multiple contacts; this limits the conclusions we can draw from these data. Moreover, our study design lent itself to selection bias in our sample in that we wanted to hear from providers interested in or considering PPM (i.e., those engaged in the field). However, we did achieve diversity of respondents by roles and affiliations across the institution. While the generalizability of the findings both within and outside the institution may be questioned, these findings likely have relevance for other academic health systems, as well as non-academic centers, where providers likely face some of the same educational deficits and barriers to implementing PPM into clinical care.

CONCLUSIONS

We found that both specialty and non-specialty providers at a large academic institution with a programmatic focus on PM identified education in PPM as critical to its broad implementation in clinical practice. Additional studies are needed to identify the best means for providing the necessary training and education in PPM approaches to maximize the benefit to patients. For example, integration of provider and patient education into clinical care may be facilitated by tools such as EMRs as an efficient, point-of-care approach to address this deficit. Future studies should also consider the effectiveness of different educational approaches on PPM uptake in clinical care. In addition, the PPM educational needs of nursing students, medical students, and other health professions students should be the focus of future research and education. As scientific advances continue to augment capabilities in PPM, these educational and research efforts will be critical to ensure the seamless transition of innovative tools in applied genomics and precision medicine from the bench to bedside.

AUTHOR CONTRIBUTIONS

All authors contributed to the content of the survey. SHK, MAM, NY, JR, TRB, AV, LAS, and GSG developed the survey approach. LAS solicited survey responses. AV analyzed survey data for this manuscript. All authors contributed to the manuscript.

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