



# When Personal Feels Invasive: Foreseeing Challenges in Precision Medicine Communication

Chelsea L. Ratcliff, Kimberly A. Kaphingst & Jakob D. Jensen

To cite this article: Chelsea L. Ratcliff, Kimberly A. Kaphingst & Jakob D. Jensen (2018) When Personal Feels Invasive: Foreseeing Challenges in Precision Medicine Communication, Journal of Health Communication, 23:2, 144-152, DOI: [10.1080/10810730.2017.1417514](https://doi.org/10.1080/10810730.2017.1417514)

To link to this article: <https://doi.org/10.1080/10810730.2017.1417514>



Published online: 26 Dec 2017.



Submit your article to this journal [↗](#)




Article views: 205



View Crossmark data [↗](#)



# When Personal Feels Invasive: Foreseeing Challenges in Precision Medicine Communication

CHELSEA L. RATCLIFF <sup>1</sup>, KIMBERLY A. KAPHINGST<sup>1,2</sup>, and JAKOB D. JENSEN<sup>1,2</sup>

<sup>1</sup>*Department of Communication, University of Utah, Salt Lake City, Utah, USA*

<sup>2</sup>*Huntsman Cancer Institute, Cancer Control and Population Sciences Program, Salt Lake City, Utah, USA*

Precision medicine (PM) draws upon individual biological and psychosocial factors to create a personalized approach to healthcare. To date, little is known about how healthcare consumers will respond to such highly personalized guidance and treatment. The assumption is that responses will generally be favorable; yet in the media and in online public discussions about PM, concerns have been raised about invasions of privacy and autonomy. Findings from the tailoring literature—relevant because PM is, in a sense, “hypertailoring”—similarly suggest a potential for provoking unintended consequences such as personalization reactance, wherein perceived threat to one’s privacy or freedom can lead to rejection of the personalized message or its source. Here, we review extant tailoring and other relevant research to identify challenges that could arise in PM communication. We then draw upon a patient-centered communication perspective to highlight elements of the communication process wherein resistance could be mitigated. This review aims to provide preliminary guidance for practitioners when communicating with patients and healthcare consumers about PM, as well as point scholars toward fruitful topics for research in this emerging health communication area.

PM is a personalized approach to healthcare based on the application of “a wide range of biomedical information—including molecular, genomic, cellular, clinical, behavioral, physiological, and environmental parameters” (Collins & Varmus, 2015, p. 794). One dimension of PM entails using such data to provide patients with individualized recommendations for prevention and treatment. PM has been heralded as an important direction for modern medicine (Jameson & Longo, 2015; Khoury & Evans, 2015), and thanks to ever-accelerating innovations in both medicine and information technology, the implementation of PM has already begun (Frey, Bernstam, & Denny, 2016; Khoury, Iademarco, & Riley, 2016).

As PM approaches unfold in clinical care, healthcare providers must be prepared to address challenges that could arise, including those that can be provoked—or mitigated—during communication processes (Scherr et al., 2017). Despite the widespread discussion of PM in health and medical spheres,

current public knowledge of PM is likely to be limited. When data-gathering efforts ramp up, healthcare providers may increasingly solicit highly personal information from patients or make recommendations based on personal information that has been administratively gathered (with or without the patient’s awareness). However, individuals might not understand why they are being asked to answer a higher volume of personal questions, to share the results of genetic testing, to use wearable devices, or to donate biospecimens for research trials. People might not be aware of the possible benefits of participation in each case, nor what the implications and potential risks are in terms of data privacy or receiving information they may not be prepared to process. Transparency, accountability, and trustworthiness have been flagged as key objectives in the launch of PM initiatives and interventions (National Research Council, 2011); however, guidelines for communication in order to achieve these aims must still be developed.

Although a full implementation of PM and its accompanying communication strategies is still materializing, extant research from relevant domains can provide insight. Numerous tailoring studies have tested how people respond to the use of their personal characteristics to make health recommendations (e.g., Butrick et al., 2011; Robinson & Coveleski, 2016; for a review, see Dijkstra, 2008). There are also growing bodies of literature that investigate how individuals react to receiving their genetic information (e.g., Ryan, De Vries, Uhlmann, Roberts, & Gornick, 2017; Wynn et al., 2017) and how they feel about self-tracking and exchanging health data (e.g., Ancker et al., 2015; Lupton, 2017; Piras & Miele, 2017). The findings highlight possible pitfalls in PM implementation, including a potential

---

Address correspondence to Chelsea L. Ratcliff, Department of Communication, University of Utah, 2400 LNCO, 255 S. Central Campus Drive, Salt Lake City, Utah, 84112. E-mail: [chelsea.ratcliff.bush@utah.edu](mailto:chelsea.ratcliff.bush@utah.edu)

Chelsea L. Ratcliff is a doctoral student in the Department of Communication at the University of Utah. Kimberly A. Kaphingst is a Professor in the Department of Communication and an Investigator in the Cancer Control and Population Sciences Program at the Huntsman Cancer Institute. Jakob D. Jensen is a Professor in the Department of Communication and a faculty affiliate of the Cancer Control & Population Sciences Core at the Huntsman Cancer Institute

for provoking unintended resistance—especially when the individualized advice or surveillance is unwanted or unexpected. At the same time, the patient-centered communication literature (e.g., Elwyn et al., 2012; Street, Makoul, Arora, & Epstein, 2009) highlights ways that patient education, patient–provider trust, and respect for patient autonomy—indeed, personalizing according to a patient’s personalization preferences—could mitigate unintended consequences in PM communication.

The promise of PM as a biomedical approach rides on public engagement, since the All of Us<sup>SM</sup> million-person cohort and other large-scale data collection initiatives will drive discovery (Hawgood, Hook-Barnard, O’Brien, & Yamamoto, 2015; Hood & Flores, 2012; Khoury et al., 2016). This makes strategic communication essential. What follows is a synthesis of literature that points to the potential for personalization reactance and other challenges in PM communication, in order to guide research programs and the creation of communication plans in clinical practice. In doing so, we highlight the important role of communication scholarship as a companion evidence base for the dissemination and implementation of PM.

### PM as Hypertailoring

PM often refers to personalization of care at a genomic level (e.g., matching a person’s genetic mutation to a drug that targets it specifically). Yet the term is increasingly applied more broadly. Sometimes called personalized medicine or individualized medicine, PM can describe any approach that factors in a patient’s unique characteristics—including behavioral, genetic, and environmental factors—to provide information and guidance as well as treatment (Collins & Varmus, 2015; Hawgood et al., 2015). Although genomics is an important driver of discovery in PM, other elements, such as the use of health information technology and the linking of biomarkers to environmental exposures, are considered as much or more important to the implementation of PM (Khoury et al., 2016; Rappaport & Smith, 2010).

In this sense, PM has many similarities to the communication concept of tailoring, which is the personalization or customization of information for an individual based on traits, beliefs, or preferences (Jensen, King, Carcioppolo, & Davis, 2012). *Personalization* occurs when the information is altered by an external system, whereas *customization* occurs when the user initiates and controls the process (Sundar & Marathe, 2010). Personalized tailoring is more aligned with PM, as the assumption is often that a computer-supported system will utilize patient data to generate relevant information. At the same time, PM takes tailoring of health guidance to an amplified level, providing personalized output by amalgamating data from a multitude of sources. In effect, PM can be thought of as *hypertailoring*—going above basic tailoring approaches to personalize on a maximal number of factors.

Data collected and used for PM will primarily be gathered through two contexts: biomedical research and clinical practice (National Research Council, 2011). Beyond earlier personalization systems that used only information volunteered by patients through questionnaires (see Bental, Cawsey, & Jones, 1999), PM interventions are expected to tap massive knowledge

networks (Ma, Rosas, & Lv, 2016; National Research Council, 2011). These could be increasingly robust, interlinked databases that house electronic health records, which may include not only medical history and self-reported information, but also data from human–computer interaction platforms such as wearable devices, implants, and mobile technology (Adams & Petersen, 2016; Cifuentes et al., 2015).

Taking it further, advancements in biomedical informatics could transform patient files into a rich “tapestry” interweaving a broad swathe of data from within and outside the healthcare system (Weber, Mandl, & Kohane, 2014, p. 2480). Data sources that provide insights into lifestyle (e.g., grocery store purchases, gym memberships), environment (e.g., phone GPS), and social factors (e.g., Facebook friends, Twitter hashtags) have been flagged as potentially high-value for use in PM (see Weber et al., 2014).

Why should an individual share personal health-relevant data? Doing so may contribute to advances in medical research, such as biomarker discovery and drug development (Khoury et al., 2016; Rappaport & Smith, 2010), as well as support public health efforts to detect infectious disease outbreaks and community health issues (Khoury et al., 2016; Weber et al., 2014). At an individual level, providing personal data could help align high-risk patients with relevant disease screenings or identify potential treatments (Khoury & Evans, 2015). Individualized reports could also promote the accurate perception of one’s disease susceptibility and severity (Noar, Benac, & Harris, 2007), which may positively influence health behavior (Glanz, Rimer, & Viswanath, 2015; Rogers, 1975). Finally, personal data allows communicators to craft messages that are shorter and more direct as they only need to include information relevant to the receiver. Short, direct messages could be more accessible for low-skilled groups (Jensen et al., 2012) and more effective for individuals with dispositional information overload (Jensen et al., 2014).

### Potential Challenges in PM Communication

There is an assumption that the public will generally be favorable to personalized health guidance and treatment. After all, there are numerous potential advantages, including those mentioned above. There has also been widespread adoption of consumer interactive digital technology in the United States; this means many people already use applications that track behavior and biophysiological data in exchange for receiving personalized content. Yet privacy of personal data remains a major concern for some (Adams & Petersen, 2016; Lipworth, Mason, Kerridge, & Ioannidis, 2017; Meingast, Roosta, & Sastry, 2006; Weber et al., 2014). In the media and in online public forums, concerns about PM evoke the language of freedom and rights (e.g., Lazarus 2016; Savage, 2016). In scholarly discussions, dystopian rhetoric emerges surrounding big data and PM, with references to Orwellian and Foucauldian notions of surveillance and control (Boyd & Crawford, 2012; Wears & Williams, 2016). Such concerns apply to data sharing both on a large scale (take, for example, the Personal Genome Project, which “aims to share DNA sequences, medical histories and other personal information with researchers looking to link gene variants, environment

and lifestyle habits to disease risk,” Savage, 2016, p. S71) and on an individual level (a person might not want to share everything with his/her healthcare team).

Perceived loss of autonomy is an issue that can arise with any tailored communication (see Dijkstra, 2016). In a PM context, personalized health content could be seen as not giving a patient the right to see a spectrum of options and choose which is best for himself or herself. Even though PM is meant to increase patient control and engagement (Hood & Flores, 2012), the infrastructure that will support it creates opportunities for increased paternalism (Lupton, 2013). Clearly, there are numerous potential benefits of precise health information and care, yet also many ways for PM approaches to backfire. Extant tailoring research as well as findings from the genetic communication, digital patient engagement, and health psychology literatures illuminates some of the underlying reasons this can occur.

### ***Prior Research on Tailoring and Resistance***

Tailoring refers to the personalization or customization of information (Noar et al., 2007). In the context of health communication, tailored recommendations are widely believed to be more persuasive than nontailored messages (Kreuter, Strecher, & Glassman, 1999), and there is some evidence to support this claim (e.g., Brug, Glanz, Van Assema, Kok, & Van Breukelen, 1998; Krebs, Prochaska, & Rossi, 2010). The reason could be that tailored content is perceived as more relevant to the individual (Jensen et al., 2012). Feeling understood may also lower resistance (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Message tailoring can also account for individual differences theorized to influence behavior change and has been linked to several behavior change theoretical frameworks, including the transtheoretical model and the health belief model (see Noar et al., 2007). Tailored health messages appear to motivate behavior change better than generic messages; however, it is only a slight advantage (Edwards, Evans, Hood, & Elwyn, 2006; Noar et al., 2007). Evidence that personalized risk estimates promote informed decision-making is also minimal (Edwards et al., 2006). For this and other reasons, concerns have been raised about the cost of tailoring messages relative to the benefit (Jensen et al., 2014).

Prior research also indicates that tailoring can simultaneously produce favorable and unfavorable effects (see Dijkstra, 2008). Aguirre and colleagues (2015) describe this as the “personalization paradox” (p. 34). For example, while a personalized message may lead to feeling understood, it can also lead to feeling exposed; moreover, while personalization can increase perceived relevance to the individual, it can also increase their feeling of vulnerability (Aguirre, Mahr, Grewal, de Ruyter, & Wetzels, 2015).

People may also perceive personalized content to be freedom-limiting if it tells them specifically what they should do, as opposed to making a general recommendation upon which they could exert personal values in selecting a specific course of action. The mechanism by which this limiting effect seems to occur is related to the concept of psychological reactance. Psychological reactance theory posits that when individuals encounter dogmatic language and a clear persuasive intent,

they are likely to perceive a threat to their freedom to do, think, or feel as they choose (Brehm & Brehm, 1981). This, in turn, can lead to negative affective responses (e.g., anger, annoyance) and negative cognitive responses (e.g., counterarguing) as the individual attempts to restore a sense of freedom.

In the advertising literature, privacy concerns and psychological reactance frequently pose a threat to the persuasive efficacy of personalized content (e.g., Aguirre et al., 2015; Bleier & Eisenbeiss, 2015; White, Zahay, Thorbjørnsen, & Shavitt, 2008). In fact, advertising researchers have examined personalization reactance as a major area of concern (White et al., 2008). Certainly, health recommendations are not the same as advertisements. Individuals may be more receptive to personalized information that will improve their health. However, whereas tailored advertisements are easy to ignore or dismiss as optional, health recommendations may feel more obligatory. Health recommendations can also have overt persuasive undertones that trigger reactance, as shown by the robust body of reactance research specific to health communication (see Dillard & Shen, 2005, for an overview).

Finally, prior research indicates that individuals may be uncomfortable being singled out for sensitive or stigmatized health issues. Studies of race-based tailoring (Butrick et al., 2011) and weight-based tailoring (Robinson & Coveleski, 2016) found that people reacted negatively to obvious attempts to tailor health materials to these attributes. Relatedly, being confronted with data about one’s unhealthy food purchases, alcohol use, or prison record (Weber et al., 2014)—although these may be meaningful predictors of health risk or indicators of beneficial solutions—could be threatening to one’s self-image. As individuals are typically highly motivated to preserve a positive self-image (see Klein & Cerully, 2007), a PM message that provokes defensiveness could cause backlash that outweighs potential benefit.

### ***Insights from the Genetic Communication Literature***

Findings from studies of genetic/genomic communication can also foretell challenges in PM communication. Primary areas for backlash in this context include information mismatch (e.g., providing more information than a patient wants; Brothers et al., 2017; Joseph et al., 2017; Ryan et al., 2017) and issues of privacy and custodianship (e.g., whether a patient controls who learns their test results; Offit, Groeger, Turner, Wadsworth, & Weiser, 2004; Wynn et al., 2017). It follows that such issues could apply—and in fact, be magnified—in PM approaches that involve hypertailoring on multiple genetic, psychosocial, and environmental factors.

Although there is some evidence that tailoring recommendations in a high-risk genetic context (e.g., *BRC1/2*) can positively influence behavior (e.g., mammography), there has been limited evidence that gene-based tailoring for multifactorial conditions has the same impact (see reviews by Hollands et al., 2016; and McBride, Koehly, Sanderson, & Kaphingst, 2010). Hollands and colleagues (2016) found across studies that communicating DNA-based risk estimates for common complex diseases did not significantly alter participants’ behavior or intentions with regard to smoking, alcohol use, medication use,



diet, exercise, or sun protection. McBride and colleagues (2010) found minimal behavioral impact of information based on single-gene variants, while noting that “testing scenarios in which genetic risk is based on numerous genetic variants is largely unexplored” (p. 89).

Whether hypertailored PM interventions can move the needle of health behavior better than gene-based tailoring alone, especially for the prevention or treatment of common complex diseases, remains to be seen. At the same time, PM approaches could produce a more directive type of messaging than what generally occurs in genetic counseling, perhaps suggesting a greater potential for patient resistance in PM. Also of note, assessments of the negative impact of receiving genetic information have typically focused on anxiety and depression (Heshka, Palleschi, Howley, Wilson, & Wells, 2008; Hollands et al., 2016; Meiser & Halliday, 2002); psychological reactance and other forms of resistance or backlash could be undetected in genetic communication studies to date.

### *Patient Resistance to Digital Engagement with Healthcare*

We assume that patients are likely to adopt emerging health information technologies when informed of the benefits (Hood & Flores, 2012). The little evidence that exists, however, suggests a potential for resistance from sizable segments of the population. Findings from the Health Information National Trends Survey (HINTS) in 2011 and 2014 revealed mixed public trust in the healthcare system regarding the collection and safekeeping of patient data (National Cancer Institute, n.d.). Roughly half of the respondents were only “somewhat confident”—and one-quarter had low confidence—that safeguards were in place to protect their medical information and that they had a say in who could collect, use, and share it.

Willingness among the public to electronically share health data such as vital information and lifestyle behaviors also appears mixed. In HINTS data from 2013, roughly one-third of the respondents were only “somewhat” or “a little” willing and one-third “completely” unwilling to provide such information to providers. Entrusting healthcare systems with one’s health data is considered integral to the implementation of PM, so it will be important to dig deeper into the underlying reasons for patient reluctance.

Scholars examining patients’ experiences with wearables and other self-monitoring devices have observed a potential for psychological reactance and subsequent alienation from the healthcare system. For example, Lupton (2013) writes:

[Patients] may find the obligation of self-surveillance overwhelming, forcing them to confront their illness, engage in routine actions they would rather avoid or deal with digital interactions that are tiresome. Some patients respond to the disciplinary and surveillance imperatives of self-care and self-monitoring by resisting or evading healthcare providers’ directions and the obligations expected of them. (pp. 261-262)

Ancker and colleagues (2015) similarly observed that patients do not always feel empowered by their health data. A major finding in their qualitative study was that “personal medical data for individuals with chronic conditions are not simply objective

facts, but instead provoke strong positive and negative emotions, value judgments, and diverse interpretations” (p. e202). For patients with multiple conditions, personal data tracking means constantly being “reminded you’re a sick person” (p. e202). Such insights from digital patient engagement and quantified self studies underscore the need for understanding how to best implement PM.

### **Possible Moderators of Patient Resistance to PM**

Several factors could influence how patients feel about a given PM approach, such as whom the information comes from, how it is delivered, and whether the patient has the option to exercise preferences about it. In this respect, communication theory, methods, and research can provide useful frameworks for examining and guiding PM implementation efforts. Here we illustrate three of the possible ways that patient response to PM could be influenced during communication processes.

#### *Communication Source*

In a clinical setting, patients may be asked for highly personal data—or may receive personalized recommendations—from any number of healthcare workers, including general practitioners, specialists, nurses and support staff, administrative staff at check-in, and via electronic/online patient portals. When making decisions about health, such as evaluating the risks of a new biotechnology, individuals often use trust as a heuristic (Gigerenzer & Gaissmaier, 2011; Priest, Bonfadelli, & Rusanen, 2003; Trumbo, 2002). Thus, trust in the healthcare system and in one’s various providers may influence how a patient feels about personalized information and even the PM movement as a whole.

Butrick and colleagues (2011) found that patients reacted negatively to race-based personalization when exposed to hypothetical medical prescription vignettes. Compared with participants in the conventional and genetically personalized vignette conditions, those receiving race-based personalization exhibited lower trust in the vignette physician and lower belief that the physician respected them. In turn, trust and perceived respect were associated with participants’ beliefs about the efficacy of the recommendation and their willingness to take it. The authors noted “a relative reluctance to embrace personalized medicine technology, especially among racial minorities,” yet also suggested that the study “highlights enhancement of adherence through improved doctor-patient relationships” (p. 421). These findings highlight an important possible link among trust, perceived respect, response to personalization, and patient adherence.

While Mechanic (2004) and others have postulated that trust in one’s doctor can transfer to the organization, it is also possible that communication about PM will be less favorably received from supporting clinical staff or providers with whom the patient does not have an established relationship. Thus, when it comes to PM, patients may be more likely to trust a primary care provider to act in their best interest. Individuals generally have a higher level of trust in their regular doctors, with trust and continuity of care being closely linked (Mainous, Baker, Love, Gray, & Gill, 2001).

At the same time, how primary care providers communicate about PM with patients could make or break this level of trust. Competence and technical proficiency have a profound influence on patients' trust in providers and medical institutions (Hall, Dugan, Zheng, & Mishra, 2001; Mechanic, 2004). Currently, most general practitioners have only limited knowledge of genetics and genetic testing (Hamilton et al., 2017; Salari, 2009) and may be equally unprepared to navigate other types of PM data. Potentially, a provider's knowledge deficiencies about PM—such as how the patient's personal data will be gathered, protected, and used—could impact patient reactions to PM.

### **Communication Channel**

In addition to considering whom PM communication should come from, it may be important to consider the mode of communication. Is computer-mediated communication acceptable, or should it occur in person? There are many benefits to supplementing clinical visits with electronic communication, including lowering the threshold between patients and providers and making communication with patients more time-efficient and scalable (Andreassen, Trondsen, Kummervold, Gammon, & Hjortdahl, 2006). Clinicians and patients are increasingly communicating via online portals and email (Hesse, Greenberg, & Rutten, 2016) and web-based platforms are being explored as a viable way to supplant in-person genetic counseling (Biesecker et al., 2017).

At the same time, unique problems can arise in digital communication. Communicators tend to overestimate the degree to which recipients will comply with email (vs. face-to-face) requests, as well as the degree to which email requests will seem trustworthy (Roghanizad & Bohns, 2017). Relatedly, the potential for misunderstanding is higher in mediated communication (Waterworth & Waterworth, 2006). An observation from Andreassen and colleagues (2006, p. 242) bears considering: "Although the level of trust in the one-to-one relationship between doctor and patient seems to be important for the use of new communication technology, the reverse also seems to apply: Communicating electronically affects the aspect of trust."

### **Individual Patient Preferences**

Preference for level of personalization is likely to vary among patients, as well as for a single person depending on the health domain. We know that health choices are driven as much by complex psychological motivations (Klein & Cerully, 2007) and beliefs and values (Street et al., 2009) as by the rational use of information. A patient may not wish to know, for instance, about being at high risk for a certain condition, if not knowing allows him or her to maintain hope and optimism (Brashers, 2001) or positive self-perceptions (Klein & Cerully, 2007).

Characteristics that distinguish early and late adopters of technological innovation—such as fatalism, attitude toward change, tolerance of risk, and socioeconomic and education variables (Berwick, 2003; Rogers, 2003)—could conceivably play a role in whether patients embrace PM. Potentially, so might health literacy level (Parker, Bakken, & Wolf, 2016),

technological efficacy (Sundar & Marathe, 2010), religious identification (Wynn et al., 2017), and dispositional reactance (i.e., one's proneness to perceiving freedom threats; Hong & Faedda, 1996).

Given the individual differences in uncertainty management, motivations, values and more, engaging personalization preferences during communication processes—perhaps in face-to-face conversations between patients and providers, or by seeking consent before delivering personalized health interventions—could facilitate patient adoption of PM approaches.

## **Discussion**

The notion of a precise approach to healthcare is gaining momentum as developments in genomic medicine and biomedical informatics flourish (Collins & Varmus, 2015). These innovations will drive PM forward on the medical and technological sides; yet less attention has been paid to how patients will respond to PM and the role of communication in its implementation (Scherr et al., 2017).

As we herald this new era of medicine, it has largely been assumed that personal is better—that is, that healthcare consumers will welcome and benefit from recommendations and treatments tailored on multiple factors. However, this review illustrates the possibility that such personalization will have little or no effect on health behavior, or even that the highly personalized nature of PM approaches will arouse personalization reactance.

PM interventions have been envisioned as drawing on a plethora of data from within and outside the healthcare system in order to generate hypertailored health profiles (Wears & Williams, 2016; Weber et al., 2014). For example, disease risk can be indicated through biomarkers or through data about a person's occupation, stress level, diet, BMI, or geographic location (Rappaport & Smith, 2010; Weber et al., 2014). Thus, PM will ask that patients—and, more broadly, consumers of healthcare services and content—share access to a great deal of data about themselves (National Research Council, 2011). Backlash could be triggered if patients receive unwanted personalized information, especially when it is based on data amalgamated without their awareness.

At the population level, public and patient buy-in is critical to the success of PM as a biomedical approach (Hawgood et al., 2015; Khoury et al., 2016). For example, the All of Us Research Program (formerly the Precision Medicine Initiative), which aims to accelerate the discovery of PM prevention and treatment strategies (Collins & Varmus, 2015), will be supported by the assemblage of a one-million-person cohort of patients and healthy people across the United States who agree to share their health data (National Institutes of Health, 2017). At the individual level, patient adoption of PM has implications for the patient's health, as well as patient-provider relationships and preservation of trust in the healthcare system.

Patient resistance toward PM may at times be well-founded. Individuals should not be coerced into participating in personalized health programs or research trials. Nor should legitimate ethical and privacy concerns surrounding big data be dismissed without consideration (Iliadis & Russo, 2016). Data is needed on

the balance of PM's benefits and harms, including potential social, ethical, and psychological consequences (Hey & Barsanti-Innes, 2017; Khoury et al., 2016; Lipworth et al., 2017; Weber et al., 2014). If a health intervention provokes psychological reactance or another boomerang effect but provides little benefit, it should not be used (Ringold, 2002).

Yet there are likely to be times when a personalized option is indeed beneficial and would be desired by a patient, but the packaging is off-putting. Resistance can be triggered on an unconscious level (Lazarus & Lazarus, 1994) and people often rely on heuristics and "gut" instincts when making decisions in health contexts (Gigerenzer & Gaissmaier, 2011). Thus, it will be important to understand whether factors during the communication process—such as who communicates about PM, by what channel, and whether the patient can exercise personalization preferences—influence whether healthcare consumers embrace PM.

Communication scholars can make an important contribution to this effort, helping identify patient attitudes and preferences as well as areas for potential for backlash and patient alienation in PM contexts. Communication research can investigate potential moderators of patient response to PM that occur during communication processes, including those noted here. Communication insights can also make the personalized approach more participative.

### Conclusion and Directions for Research

This review highlights the need for research that examines possible patient resistance to PM, and it underscores the role of communication scholarship in supporting evidence-based PM dissemination and implementation. Although PM communication research is still materializing, we synthesize findings from several relevant domains, including tailoring, genetic communication, health psychology, and digital patient engagement. Extant research points to twofold potential: highly personalized or hypertailored health content may be well-received and lead to positive health outcomes in some cases, yet be perceived as an invasion of privacy or threat to freedom in others.

The potential to draw on extant theoretical perspectives and research findings and use these to study and develop PM-specific communication approaches is promising. Shared decision-making (SDM) could be one useful framework to guide PM communication research and practice. SDM emphasizes protecting patient autonomy by incorporating patient values and preferences, providing a range of options, and giving the patient sufficient education to make an informed choice (Elwyn et al., 2012; Makoul & Clayman, 2006). In particular, it will be important to understand (a) the best ways to communicate with patients about the benefits, risks, and privacy implications of PM; and (b) how to factor in patient preferences and/or seek consent for personalized health recommendations.

Applying SDM and other patient-centered communication principles (see Street et al., 2009), as opposed to a paternalistic or one-size-fits-all approach to delivering personalized health information, could lower the potential for resistance triggered by lack of autonomy or lack of understanding. Communication scholars can explore whether giving healthcare consumers a

choice (as has been examined in genomic sequencing, for example; Ryan et al., 2017) has an impact on attitudes about PM. Relatedly, trust-building strategies, such as those that have been found to mitigate personalization reactance in other contexts (Aguirre et al., 2015; Bleier & Eisenbeiss, 2015), are another avenue for investigation.

PM has the potential to exacerbate health disparities (Joseph et al., 2017; Smart, Martin, & Parker, 2004), making this another important focus for PM communication research. Diverse underserved populations, including racial/ethnic minorities and individuals with lower socioeconomic status, have been less aware of and less likely to use genetic and genomic testing (Agurs-Collins et al., 2015; Goddard et al., 2009; for review, see Kaphingst & Goodman, 2016). Racial minorities have also been reluctant to embrace personalized medicine technology (Butrick et al., 2011) and expressed concerns about gene-based discrimination (Diaz, Mainous, Gavin, & Wilson, 2014). Diversity is often overlooked in the design of information and communication technologies (Oudshoorn, Neven, & Stienstra, 2016), which could alienate underserved populations in PM's biomedical informatics applications. Communication research can explore potentialities for diversity—including racial, ethnic, cultural, age, and gender diversity—to get lost in the design of PM approaches and identify ways to empower diverse patient groups through communication processes.

Healthcare providers may also wish to consider—and future studies could examine—when and by whom highly personalized requests or recommendations should be made. Research could also help answer whether resistance to PM approaches will be more likely to occur among certain groups of patients, such as those with low health literacy or high trait reactance, or who are late adopters of technological and medical innovation.

Finally, behavioral theories will be important to consider in this context, as these can illuminate reasons other than resistance for why PM approaches might sometimes fail. Precision lifestyle medicine (Ma et al., 2016), an emerging PM approach with a behavioral dimension, could be an excellent avenue in which to apply such insights.

Together, these communication-oriented investigations can help carry forward the promises of precise, personalized, patient-centered medicine.

### Acknowledgments

The authors are grateful to Bradford W. Hesse, William M. P. Klein, and two anonymous reviewers for their thoughtful comments on earlier drafts of this manuscript.

### ORCID

Chelsea L. Ratcliff  <http://orcid.org/0000-0002-8066-1233>

### References

- Adams, S. A., & Petersen, C. (2016). Precision medicine: Opportunities, possibilities, and challenges for patients and providers. *Journal of the American Medical Informatics Association*, 23, 787–790. doi:10.1093/jamia/ocv215
- Aguirre, E., Mahr, D., Grewal, D., de Ruyter, K., & Wetzels, M. (2015). Unraveling the personalization paradox: The effect of information



- collection and trust-building strategies on online advertisement effectiveness. *Journal of Retailing*, 91, 34–49. doi:10.1016/j.jretai.2014.09.005
- Agurs-Collins, T., Ferrer, R., Ottenbacher, A., Waters, E. A., O'Connell, M. E., & Hamilton, J. G. (2015). Public awareness of direct-to-consumer genetic tests: Findings from the 2013 US health information national trends survey. *Journal of Cancer Education*, 30, 799–807. doi:10.1007/s13187-014-0784-x
- Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van de Graaf, M., & Wei, E. (2015). “You get reminded you’re a sick person”: Personal data tracking and patients with multiple chronic conditions. *Journal of Medical Internet Research*, 17(8), e202. doi:10.2196/jmir.4209
- Andreassen, H. K., Trondsen, M., Kummervold, P. E., Gammon, D., & Hjortdahl, P. (2006). Patients who use e-mediated communication with their doctor: New constructions of trust in the patient-doctor relationship. *Qualitative Health Research*, 16, 238–248. doi:10.1177/1049732305284667
- Bental, D. S., Cawsey, A., & Jones, R. (1999). Patient information systems that tailor to the individual. *Patient Education and Counseling*, 36, 171–180. doi:10.1016/S0738-3991(98)00133-5
- Berwick, D. M. (2003). Disseminating innovations in health care. *Jama*, 289, 1969–1975. doi:10.1001/jama.289.15.1969
- Biesecker, B. B., Lewis, K. L., Umstead, K. L., Johnston, J. J., Turbitt, E., Fishler, K. P., ... Biesecker, L. G. (2017, October). Non-inferiority of a web platform compared to in-person counselor return of carrier results: A randomized controlled trial. Paper presented at the 67th Annual Meeting of the American Society of Human Genetics, Orlando, FL.
- Bleier, A., & Eisenbeiss, M. (2015). The importance of trust for personalized online advertising. *Journal of Retailing*, 91, 390–409. doi:10.1016/j.jretai.2015.04.001
- boyd, d., & Crawford, K. (2012). Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon. *Information, Communication & Society*, 15, 662–679. doi:10.1080/1369118X.2012.678878
- Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, 51, 477–497.
- Brehm, S. S., & Brehm, J. W. (1981). *Psychological reactance: A theory of freedom and control*. New York, NY: Academic Press.
- Brothers, K. B., East, K. M., Kelley, W. V., Wright, M. F., Westbrook, M. J., Rich, C. A., ... Myers, J. A. (2017). Eliciting preferences on secondary findings: The preferences instrument for genomic secondary results (PIGSR). *Genetics in Medicine*, 19, 337–344. doi:10.1038/gim.2016.110
- Brug, J., Glanz, K., Van Assema, P., Kok, G., & Van Breukelen, G. J. (1998). The impact of computer-tailored feedback and iterative feedback on fat, fruit, and vegetable intake. *Health Education & Behavior*, 25, 517–531. doi:10.1177/109019819802500409
- Butrick, M., Roter, D., Kaphingst, K., Erby, L. H., Haywood, C., Beach, M. C., & Levy, H. P. (2011). Patient reactions to personalized medicine vignettes: An experimental design. *Genetics in Medicine*, 13, 421–428. doi:10.1097/GIM.0b013e3182056133
- Cifuentes, M., Davis, M., Fernald, D., Gunn, R., Dickinson, P., & Cohen, D. J. (2015). Electronic health record challenges, workarounds, and solutions observed in practices integrating behavioral health and primary care. *The Journal of the American Board of Family Medicine*, 28 (Supplement 1), S63–S72. doi:10.3122/jabfm.2015.S1.150133
- Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. *New England Journal of Medicine*, 372, 793–795. doi:10.1056/NEJMp1500523
- Diaz, V. A., Mainous, A. G., III, Gavin, J. K., & Wilson, D. (2014). Racial differences in attitudes toward personalized medicine. *Public Health Genomics*, 17, 1–6. doi:10.1159/000354785
- Dijkstra, A. (2008). The psychology of tailoring-ingredients in computer-tailored persuasion. *Social and Personality Psychology Compass*, 2, 765–784. doi:10.1111/j.1751-9004.2008.00081.x
- Dijkstra, A. (2016, April). Personalization/computer-tailoring in persuasive technology: Tailoring ingredients target psychological processes In R. Orji, M. Reisinger, M. Busch, A. Dijkstra, A. Stibe, & M. Tscheligi (Eds.). *Proceedings of the International Workshop on Personalization in Persuasive Technology (PPT'16)*. Salzburg, Austria.
- Dillard, J. P., & Shen, L. (2005). On the nature of reactance and its role in persuasive health communication. *Communication Monographs*, 72, 144–168. doi:10.1080/03637750500111815
- Edwards, A. G., Evans, R., Hood, K., & Elwyn, G. J. (2006). Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database of Systematic Reviews*, (4). doi:10.1002/14651858.CD001865.pub2
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... Edwards, A. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, 27, 1361–1367. doi:10.1007/s11606-012-2077-6
- Frey, L. J., Bernstam, E. V., & Denny, J. C. (2016). Precision medicine informatics. *Journal of the American Medical Informatics Association*, 23, 668–670. doi:10.1093/jamia/ocw053
- Gigerenzer, G., & Gaissmaier, W. (2011). Heuristic decision making. *Annual Review of Psychology*, 62, 451–482. doi:10.1146/annurev-psych-120709-145346
- Glanz, K., Rimer, B. K., & Viswanath, K. (2015). *Health behavior: Theory, research, and practice* (5th ed.). San Francisco, CA: John Wiley & Sons.
- Goddard, K. A., Duquette, D., Zlot, A., Johnson, J., Annis-Emeott, A., Lee, P. W., ... Rafferty, A. (2009). Public awareness and use of direct-to-consumer genetic tests: Results from 3 state population-based surveys, 2006. *American Journal of Public Health*, 99, 442–445. doi:10.2105/AJPH.2007.131631
- Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: What is it, can it be measured, and does it matter? *Milbank Quarterly*, 79, 613–639. doi:10.1111/1468-0009.00223
- Hamilton, J. G., Abdiwahab, E., Edwards, H. M., Fang, M. L., Jdayani, A., & Breslau, E. S. (2017). Primary care providers’ cancer genetic testing-related knowledge, attitudes, and communication behaviors: A systematic review and research agenda. *Journal of General Internal Medicine*, 32, 315–324. doi:10.1007/s11606-016-3943-4
- Hawgood, S., Hook-Barnard, I. G., O'Brien, T. C., & Yamamoto, K. R. (2015). Precision medicine: Beyond the inflection point. *Science Translational Medicine*, 7(300), 1–3. doi:10.1126/scitranslmed.aaa9970
- Hawkins, R. P., Kreuter, M., Resnicow, K., Fishbein, M., & Dijkstra, A. (2008). Understanding tailoring in communicating about health. *Health Education Research*, 23, 454–466. doi:10.1093/her/cyn004
- Heshka, J. T., Pallechi, C., Howley, H., Wilson, B., & Wells, P. S. (2008). A systematic review of perceived risks, psychological and behavioral impacts of genetic testing. *Genetics in Medicine*, 10, 19–32. doi:10.1097/GIM.0b013e31815f524f
- Hesse, B. W., Greenberg, A. J., & Rutten, L. J. (2016). The role of Internet resources in clinical oncology: Promises and challenges. *Nature Reviews Clinical Oncology*, 13, 767–776. doi:10.1038/nrclinonc.2016.78
- Hey, S. P., & Barsanti-Innes, B. (2017). Epistemology, ethics, and progress in precision medicine. *Perspectives in Biology and Medicine*, 59, 293–310. doi:10.1353/pbm.2016.0026
- Hollands, G. J., French, D. P., Griffin, S. J., Prevost, A. T., Sutton, S., King, S., & Marteau, T. M. (2016). The impact of communicating genetic risks of disease on risk-reducing health behaviour: Systematic review with meta-analysis. *British Medical Journal*, 352, i1102. doi:10.1136/bmj.i1102
- Hong, S. M., & Faedda, S. (1996). Refinement of the Hong psychological reactance scale. *Educational and Psychological Measurement*, 56, 173–182. doi:10.1177/0013164496056001014
- Hood, L., & Flores, M. (2012). A personal view on systems medicine and the emergence of proactive P4 medicine: Predictive, preventive, personalized and participatory. *New Biotechnology*, 29, 613–624. doi:10.1016/j.nbt.2012.03.004



- Iliadis, A., & Russo, F. (2016). Critical data studies: An introduction. *Big Data & Society*, 3(2), 1–7. doi:10.1177/2053951716674238
- Jameson, J. L., & Longo, D. L. (2015). Precision medicine—Personalized, problematic, and promising. *Obstetrical & Gynecological Survey*, 70, 612–614. doi:10.1097/01.ogx.0000472121.21647.38
- Jensen, J. D., Carcioppolo, N., King, A. J., Scherr, C. L., Jones, C. L., & Niederdeppe, J. (2014). The cancer information overload (CIO) scale: Establishing predictive and discriminant validity. *Patient Education and Counseling*, 94, 90–96. doi:10.1111/j.1460-2466.2012.01668.x
- Jensen, J. D., King, A. J., Carcioppolo, N., & Davis, L. A. (2012). Why are tailored messages more effective? A multiple mediation analysis of a breast cancer screening intervention. *Journal of Communication*, 62, 851–868. doi:10.1016/j.pec.2013.09.016
- Jensen, J. D., King, A. J., Carcioppolo, N., Krakow, M., Samadder, N. J., & Morgan, S. (2014). Comparing tailored and narrative worksite interventions at increasing colonoscopy adherence in adults 50–75: A randomized controlled trial. *Social Science & Medicine*, 104, 31–40. doi:10.1016/j.socscimed.2013.12.003
- Joseph, G., Pasick, R. J., Schillinger, D., Luce, J., Guerra, C., & Cheng, J. K. Y. (2017). Information mismatch: Cancer risk counseling with diverse underserved patients. *Journal of Genetic Counseling*, 26, 1090–1104. doi:10.1007/s10897-017-0089-4
- Kaphingst, K. A., & Goodman, M. S. (2016). Importance of race and ethnicity in individuals' use of and responses to genomic information. *Personalized Medicine*, 13, 1–4. doi:10.2217/pme.15.39
- Khoury, M. J., & Evans, J. P. (2015). A public health perspective on a national precision medicine cohort: Balancing long-term knowledge generation with early health benefit. *Jama*, 313, 2117–2118. doi:10.1001/jama.2015.3382
- Khoury, M. J., Iademarco, M. F., & Riley, W. T. (2016). Precision public health for the era of precision medicine. *American Journal of Preventive Medicine*, 50, 398–401. doi:10.1016/j.amepre.2015.08.031
- Klein, W. M., & Cerully, J. L. (2007). Health-related risk perception and decision-making: Lessons from the study of motives in social psychology. *Social and Personality Psychology Compass*, 1, 334–358. doi:10.1111/j.1751-9004.2007.00023.x
- Krebs, P., Prochaska, J. O., & Rossi, J. S. (2010). A meta-analysis of computer-tailored interventions for health behavior change. *Preventive Medicine*, 51, 214–221. doi:10.1016/j.ypmed.2010.06.004
- Kreuter, M. W., Strecher, V. J., & Glassman, B. (1999). One size does not fit all: The case for tailoring print materials. *Annals of Behavioral Medicine*, 21, 276–283. doi:10.1007/BF02895958
- Lazarus, D. (2016, October 14). *DNA database could help predict your disease — Then get you fired*. Retrieved from <http://www.latimes.com/business/lazarus/la-fi-lazarus-healthcare-dna-database-20161014-snap-story.html>
- Lazarus, R. S., & Lazarus, B. N. (1994). *Passion and reason: Making sense of our emotions*. New York, NY: Oxford University Press.
- Lipworth, W., Mason, P. H., Kerridge, I., & Ioannidis, J. P. (2017). Ethics and epistemology in big data research. *Journal of Bioethical Inquiry*, 1–12. doi:10.1007/s11673-017-9771-3
- Lupton, D. (2013). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*, 11, 256–270. doi:10.1057/sth.2013.10
- Lupton, D. (2017). How does health feel? Towards research on the affective atmospheres of digital health. *Digital Health*, 3, 1–11. doi:10.1177/2055207617701276
- Ma, J., Rosas, L. G., & Lv, N. (2016). Precision lifestyle medicine: A new frontier in the science of behavior change and population health. *American Journal of Preventive Medicine*, 50(3), 395–397. doi:10.1016/j.amepre.2015.09.035
- Mainous, A. G., Baker, R., Love, M. M., Gray, D. P., & Gill, J. M. (2001). Continuity of care and trust in one's physician: Evidence from primary care in the United States and the United Kingdom. *Family Medicine*, 33, 22–27.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60, 301–312. doi:10.1016/j.pec.2005.06.010
- McBride, C. M., Koehly, L. M., Sanderson, S. C., & Kaphingst, K. A. (2010). The behavioral response to personalized genetic information: Will genetic risk profiles motivate individuals and families to choose more healthful behaviors? *Annual Review of Public Health*, 31, 89–103. doi:10.1146/annurev.publhealth.012809.103532
- Mechanic, D. (2004). In my chosen doctor I trust. *British Medical Journal*, 329, 1418–1419. doi:10.1136/bmj.329.7480.1418
- Meingast, M., Roosta, T., & Sastry, S. (2006). Security and privacy issues with health care information technology. Engineering in Medicine and Biology Society, 2006. 28th Annual International Conference of the IEEE (pp. 5453–5458). doi:10.1109/IEMBS.2006.260060
- Meiser, B., & Halliday, J. L. (2002). What is the impact of genetic counseling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Social Science & Medicine*, 54, 1463–1470. doi:10.1016/S0277-9536(01)00133-2
- National Cancer Institute (n.d.). *Health Information National Trends Survey (HINTS)*. Retrieved from <https://hints.cancer.gov>
- National Institutes of Health (2017). *All of us research program*. Retrieved from <https://allofus.nih.gov>
- National Research Council. (2011). *Toward precision medicine: Building a knowledge network for biomedical research and a new taxonomy of disease*. Washington, DC: National Academies Press.
- Noar, S. M., Benac, C. N., & Harris, M. S. (2007). Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. *Psychological Bulletin*, 133, 673–693. doi:10.1037/0033-2909.133.4.673
- Offit, K., Groeger, E., Turner, S., Wadsworth, E. A., & Weiser, M. A. (2004). The “duty to warn” a patient's family members about hereditary disease risks. *Jama*, 292, 1469–1473. doi:10.1001/jama.292.12.1469
- Oudshoorn, N., Neven, L., & Stienstra, M. (2016). How diversity gets lost: Age and gender in design practices of information and communication technologies. *Journal of Women & Aging*, 28, 170–185. doi:10.1080/08952841.2015.1013834
- Parker, R. M., Bakken, S., & Wolf, M. S. (2016). Getting it right with precision medicine initiative: The role of health literacy. *Commentary, National Academy of Medicine*. Washington, DC: National Academies Press. Retrieved from <http://nam.edu/wp-content/uploads/2016/02/Getting-it-Right-with-the-Precision-Medicine-Initiative-the-Role-of-Health-Literacy.pdf>
- Piras, E. M., & Miele, F. (2017). Clinical self-tracking and monitoring technologies: Negotiations in the ICT-mediated patient-provider relationship. *Health Sociology Review*, 26, 38–53. doi:10.1080/14461242.2016.1212316
- Priest, S. H., Bonfadelli, H., & Rusanen, M. (2003). The “trust gap” hypothesis: Predicting support for biotechnology across national cultures as a function of trust in actors. *Risk Analysis*, 23, 751–766. doi:10.1111/1539-6924.00353
- Rappaport, S. M., & Smith, M. T. (2010). Environment and disease risks. *Science*, 330, 460–461. doi:10.1126/science.1192603
- Ringold, D. J. (2002). Boomerang effects in response to public health interventions: Some unintended consequences in the alcoholic beverage market. *Journal of Consumer Policy*, 25, 27–63. doi:10.1023/A:1014588126336
- Robinson, B., & Coveleski, S. (2016). Don't say that to ME: Opposition to targeting in weight-centric intervention messages. *Health Communication*, 1–9. doi:10.1080/10410236.2016.1250189
- Rogers, E. M. (2003). *Diffusion of innovations* (5th ed.). New York, NY: Free Press.
- Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *The Journal of Psychology*, 91, 93–114. doi:10.1080/00223980.1975.9915803

- Roghanizad, M. M., & Bohns, V. K. (2017). Ask in person: You're less persuasive than you think over email. *Journal of Experimental Social Psychology, 69*, 223–226. doi:10.1016/j.jesp.2016.10.002
- Ryan, K. A., De Vries, R. G., Uhlmann, W. R., Roberts, J. S., & Gornick, M. C. (2017). Public's views toward return of secondary results in genomic sequencing: It's (almost) all about the choice. *Journal of Genetic Counseling, 26*, 1197–1212. doi:10.1007/s10897-017-0095-6
- Salari, K. (2009). The dawning era of personalized medicine exposes a gap in medical education. *PLoS Medicine, 6*(8), e1000138. doi:10.1371/journal.pmed.1000138
- Savage, N. (2016). Privacy: The myth of anonymity. *Nature, 537*(7619), S70–S72.
- Scherr, C. L., Dean, M., Clayton, M. F., Hesse, B. W., Silk, K., Street, R. L., Jr., & Krieger, J. (2017). A research agenda for communication scholars in the era of precision medicine. *Journal of Health Communication, 22*, 839–848. doi:10.1080/10810730.2017.1363324
- Smart, A., Martin, P., & Parker, M. (2004). Tailored medicine: Whom will it fit? The ethics of patient and disease stratification. *Bioethics, 18*, 322–343. doi:10.1111/j.1467-8519.2004.00400.x
- Street, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling, 74*, 295–301. doi:10.1016/j.pec.2008.11.015
- Sundar, S. S., & Marathe, S. S. (2010). Personalization versus customization: The importance of agency, privacy, and power usage. *Human Communication Research, 36*, 298–322. doi:10.1111/j.1468-2958.2010.01377.x
- Trumbo, C. W. (2002). Information processing and risk perception: An adaptation of the heuristic-systematic model. *Journal of Communication, 52*, 367–382. doi:10.1111/j.1460-2466.2002.tb02550.x
- Waterworth, J. A., & Waterworth, E. L. (2006). Presence as a dimension of communication: Context of use and the person. In G. Riva, M. T. Anguera, B. K. Wiederhold, & F. Mantovani (Eds.), *From communication to presence: Cognition, emotions and culture towards the ultimate communicative experience* (pp. 81–96). Amsterdam, The Netherlands: IOS Press.
- Wears, R. L., & Williams, D. J. (2016). Big questions for “Big Data.”. *Annals of Emergency Medicine, 67*, 237–239. doi:10.1016/j.annemergmed.2015.09.019
- Weber, G. M., Mandl, K. D., & Kohane, I. S. (2014). Finding the missing link for big biomedical data. *Jama, 311*, 2479–2480. doi:10.1001/jama.2014.4228
- White, T. B., Zahay, D. L., Thorbjørnsen, H., & Shavitt, S. (2008). Getting too personal: Reactance to highly personalized email solicitations. *Marketing Letters, 19*, 39–50. doi:10.1007/s11002-007-9027-9
- Wynn, J., Martinez, J., Duong, J., Chiuzan, C., Phelan, J. C., Fyer, A., ... Chung, W. K. (2017). Research participants' preferences for hypothetical secondary results from genomic research. *Journal of Genetic Counseling, 26*, 841–851. doi:10.1007/s10897-016-0059-2