Review

# Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review

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## ABSTRACT

**Objective**: This integrative review identifies convergent and divergent areas of need for collecting and using patient-generated health data (PGHD) identified by patients and providers (i.e., physicians, nurses, advanced practice nurses, physician assistants, and dietitians).

**Methods**: A systematic search of 9 scholarly databases targeted peer-reviewed studies published after 2010 that reported patients' and/or providers' needs for incorporating PGHD in clinical care. The studies were assessed for quality and bias with the Mixed-Methods Appraisal Tool. The results section of each article was coded to themes inductively developed to categorize patient and provider needs. Distinct claims were extracted and areas of convergence and divergence identified.

**Results**: Eleven studies met inclusion criteria. All had moderate to low risk of bias. Three themes (clinical, logistic, and technological needs), and 13 subthemes emerged. Forty-eight claims were extracted. Four were divergent and twenty were convergent. The remainder was discussed by only patients or only providers.

**Conclusion**: As momentum gains for integrating PGHD into clinical care, this analysis of primary source data is critical to understanding the requirements of the 2 groups directly involved in collection and use of PGHD.

## INTRODUCTION

As of January 1, 2018 the Centers for Medicare and Medicaid Services initiated policy changes that will incentivize and reimburse healthcare providers for reviewing and interpreting patient-generated health data (PGHD), which is expected to accelerate adoption and use of these data in clinical practice.[1,2] PGHD is a term to describe "health-related data... created, recorded, gathered, or inferred by or from patients or their designees (e.g., care partners or those who assist them) to help address a health concern."[3] Key features of PGHD are: (1) the patient, not the healthcare provider, captures the data; (2) the data are obtained outside of clinical settings; and (3) the data are both longitudinal and capable of being collected at high-frequency intervals. Patient-reported outcomes (PROs) are considered a controlled form of PGHD, typically consisting of structured data elements captured at discrete intervals.[4]

Increasingly, PGHD are collected and stored digitally via ubiquitous smartphone applications (apps), connected devices, and cloud-based platforms.[4–7] PGHD produces not only information and knowledge to support clinical decision-making for individual health care providers, but also a context for those decisions.[6,7] For instance, knowledge of circumstances external to a patient's clinical situation may call for adjustments to therapeutic decisions made by any provider within a health care team (e.g., physicians, nurses, advanced practice nurses, physician assistants, or dieticians). Current evidence on the clinical benefit of PGHD is sparse but emerging as technology and policy provide the means to incorporate it into clinical practice.[8–10]

On a policy level, digital PGHD may contribute to healthcare quality by augmenting the type, amount, and detail of health information exchanged between patients and providers.[11,12] Healthcare costs associated with unnecessary office visits and hospitalizations may decrease when patients share PGHD by allowing the provider to proactively manage illnesses and prevent complications.[4] Patients with previous barriers to healthcare for cost- or location-related reasons may now exchange health information more easily and affordably with providers because mobile device ownership is prevalent across diverse populations.[4,5,11]

The US Office of the National Coordinator for Health Information Technology has identified the value and existing challenges for patients and providers regarding PHGD, and called for evidence-based strategies to facilitate its adoption and use.[13] An understanding of PGHD from the patient and provider perspectives is needed to align concurrent federal initiatives that aim to incorporate PGHD into clinical care, such as the Medicare and Medicaid Electronic Health Record Incentive Programs Stage 3 and Modifications to Meaningful Use, and the Medicare Access and Children's Health Insurance Program Reauthorization Act of 2015 (MACRA).[13]

### Objective

A synthesis of the evidence regarding patient and provider needs for information systems that incorporate PHGD can inform their optimal development.[5,14] To our knowledge there is no review that examines empirical evidence on the needs of the 2 primary users of PGHD. Therefore, the aims of this integrative review are to (1) summarize needs of both healthcare providers and patients concerning the collection and use of digital PGHD and (2) identify areas of convergence and divergence between them. The review follows procedures and recommendations detailed by Whittemore and Knafl.[15]

## METHODS

### Information Sources and Search Strategy

Nine scholarly databases (Pubmed, Scopus, Applied Science, Medline, PsycINFO, Science Direct, CINAHL, Cochrane, and ACM Digital Library) were searched in November 2016 using the terms: "Patient generated health data," "Patient generated data," "Patient reported outcome(s) [AND] digital," "Patient reported data [AND] digital," and "Self-monitoring data." Search terms were determined in consultation with a biomedical librarian and 2 experts engaged in research involving PGHD, and iteratively by examining key words in retrieved publications. PROs are a type of patient-generated health data, which in some cases are recorded digitally; therefore, PROs were included in the search terms for thoroughness.[4,16] No filters or additional search criteria were applied. Scopus was searched for grey literature using the same terms. An inspection of reference lists from retrieved articles identified relevant publications not obtained through the database search.

### Eligibility Criteria

Publications were evaluated against the following criteria: (1) documented patients' or providers' needs; (2) PGHD was used in a "real world" rather than study setting; (3) addressed any type of digital PGHD collected for any health-related purpose (e.g., chronic disease management, post-operative monitoring, etc.), and (4) any study design (qualitative, quantitative, or mixed-methods). Exclusion criteria were: (1) published prior to 2011; (2) not a peer-reviewed article; (3) non-digital PGHD; (4) PGHD not used in "real world setting"

and clinical workflow; and (5) not reporting patients' and/or providers' perspectives. We define workflow as "a modular sequence of tasks, with a distinct beginning and end, performed for the specific purpose of delivering clinical care."[17] Studies with samples of only patients or only providers were included provided they met other inclusion criteria.

The specification of "digital" data was thought to automatically exclude older studies, so publication year search filters were not initially applied. However, this approach retrieved several studies published between 1980 and 2010 reporting on now obsolete technology. The publication date criterion was added in acknowledgement of the rapid development of patient- and provider-facing health information technology within the past 5 years. Unlike nonelectronic (e.g., verbal or written) information generated by patients, digital PGHD can be collected with greater frequency and detail and computationally summarized. These features present unique opportunities and challenges, which are the focus of this review.

### Data Screening, Extraction, and Synthesis

Two reviewers used Covidence, a Cochrane technology platform, to select eligible studies from the pool of retrieved records.[18] Covidence automatically removes most duplicate records. The reviewers removed any missed duplicate records. Then, the reviewers screened titles and abstracts against the inclusion/ exclusion criteria. Full texts of the records included were rescreened using the same criteria. Any discrepancies between the reviewers were discussed and resolved.

### Methodological Quality Assessment of Studies

Quality was evaluated with the Mixed Methods Appraisal Tool (MMAT),[19] which is specifically designed for concomitantly appraising quantitative, qualitative, and mixed-methods research. MMAT was chosen for its ability to produce comparable scores across study designs,[19,20] with highly reliable inter-class correlations ranging from 0.84 to 0.94.[21–23]

The MMAT consists of 2 initial screening questions and subsequent question sets that are specific to the study design (quantitative; qualitative; or mixed-methods). The screening questions identify studies for which further appraisal may not be feasible or appropriate (e.g., no clear research question.) Studies failing either or both screening questions do not proceed to domain-specific appraisal. There are 4 domain-specific questions for qualitative studies and 4 questions for each of the 3 quantitative study designs (randomized controlled, nonrandomized, or descriptive). Mixed-methods studies are evaluated using both the qualitative and appropriate quantitative study questions; there are 3 additional questions specific to mixed-methods studies. The quality appraisal score is determined by dividing $n$ criteria met by $N$ criteria in each applicable domain. Scores are typically converted to percentages for comparison across studies.[19,20] Following this protocol, 2 reviewers (M.R., J.M.) independently appraised and calculated scores for each study. As in the earlier stage, discrepancies between the reviewers were discussed and resolved.

### Data Extraction and Qualitative Synthesis

The goals of data analysis in integrative reviews are first, to provide an unbiased and complete interpretation of primary source data, and second, to critically synthesize this data.[15] The primary author (M.R.) reviewed and extracted relevant characteristics from each study, including: sample characteristics, setting, context, PGHD collected, Health information technology (HIT) used, study design, data collection methods, data analysis methods, and study findings.

Both reviewers (M.R., J.M.) analyzed the quantitative and qualitative data using a general inductive approach to develop a unified response to the objectives of the integrative review. The steps include: (1) data reduction; (2) data display; (3) data comparison; (4) conclusion drawing and verification.[15] During data reduction, text containing the qualitative and/or quantitative findings was excerpted from each article and combined into a single corpus. The primary author (M.R.) coded this text using a general inductive approach in which codes were developed, consolidated if warranted, and then organized into a hierarchy. From this process, a set of thematic axes emerged. The second reviewer (J.M.) independently coded 50% of the records using this preliminary schema with the freedom to identify new or alternative codes. Alternative codes were discussed until consensus was reached on a final coding schema, which was used for inter-rater reliability calculation. To further distill the findings for subsequent comparison, both reviewers revisited the coded text to identify distinct expressions of a need related to PGHD, which they extracted in the form of declarative statements, or "claims." NVivo Version 11.4.1 (QSR International, Inc., Burlington, MA, USA) was used to code the data and calculate inter-rater reliability.

Second, a table of findings was created to display the data and visualize claims according to the coding theme/sub-theme and patient/provider perspectives on each claim. Third, the claims were reviewed and discussed to determine the presence of patterns and relationships. The perspectives of individual claims were reviewed and discussed to evaluate if the viewpoints expressed were convergent, divergent, or relevant only to patients or only to providers. Finally, each declarative claim was verified with primary source(s) to ensure accuracy. Specifically, the primary author (M.R.) mapped the claims back to the theme they were originally coded under, and both reviewers participated in reordering or consolidating claims if warranted.

## RESULTS

### Search Results

A total of 996 records were retrieved from 9 databases (Figure 1). Removal of duplicate records ($n = 274$) left 722 articles for the title/abstract screening. During title/abstract screening, 644 records were excluded for: publication date prior to 2011 ($n = 356$), not peer-reviewed ($n = 122$), not digital PGHD ($n = 86$), and not about integrating PGHD into the clinical workflow ($n = 80$). A full text screening of 78 remaining records excluded 67 for: reporting neither patient nor provider perspective ($n = 37$); not being a digital PGHD ($n = 17$); and not being about integrating PGHD into the clinical workflow ($n = 13$). A total of 11 records were accepted for review.[24–34] The provider perspectives covered in these records included physicians, nurses, advanced practice nurses, physician assistants, and dietitians.

### Risk of Bias

Quality appraisal results of the 4 qualitative and 7 mixed-methods studies are summarized in Table 1.

Qualitative studies received 5 to 6 of 6 possible points, and the mixed-methods studies received 8 to 11 of 13 possible points. When converted to percentages, studies scored from 62% to 100%. Studies lost points in the qualitative domain for claiming a specific method (e.g., grounded theory) but describing data analysis inconsistent with that method, or for failing to acknowledge, or
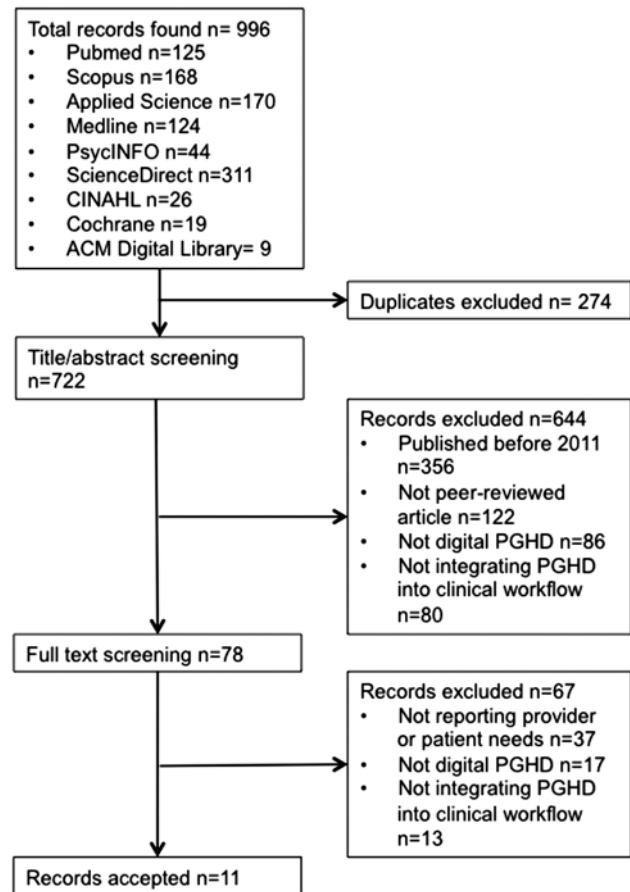


**Figure 1.** Flow diagram of study selection process.

"bracket," their interaction with study participants as a potential source of bias. Studies lost points in the quantitative domain for sampling strategies that introduced bias, or surveys not psychometrically validated.

### Characteristics of Included Studies

The characteristics of 11 studies are summarized in Table 2.

Six studies included both patients and provider participants.[24–29] Two included participants who were not patients or providers but were closely involved with them during the study period and could speak to their perspectives.[29,30]

Providers included physicians (surgeons, primary care physicians, specialists), nurses, advanced practice nurses, physician assistants, and dieticians. Their mean clinical experience ranged from 7 to 17 years. Patients' mean ages ranged from 44 to 71 and gender breakdown ranged from 30% to 100% male. The study settings ranged from large, academic medical centers to outpatient clinics, and 8 of the 11 studies examined a specific tool to collect and use the PGHD being tested. Qualitative data collection involved individual semi-structured interviews, open-ended survey questions, and observations. Quantitative data was collected through surveys and application usage reports.

### Characteristics of PGHD in Included Studies

The characteristics of PGHD in the 8 studies that were tested as an actual data tool are summarized in Table 2. PGHD included physiological, self-report, and passive sensor data targeting a wide range of

**Table 1.** Risk of Bias for 11 Studies Based on Criteria from the Mixed Methods Appraisal Tool[35]

| Domain | Criterion | Cheng et al. (2015)[24,a] | Chung et al. (2016)[25] | Cohen et al. (2016)[30,a] | Hartzler et al. (2016)[26] | Hochstenbach et al. (2016)[27] | Huba and Zhang (2012)[31,a] | Kummerow Broman et al. (2015)[28] | Lind et al. (2016)[32] | Nundy et al. (2014)[33] | Sanger et al. (2016)[29,a] | Thompson and Valdez (2015)[34] |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Screening questions | Clear research questions | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Data adequate to address research questions | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Qualitative | Relevant data sources | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ |
| | Relevant data analysis methodology | ✓ | ✗ | ✓ | ✗ | ✓ | ✓ | ✗ | ✗ | ✓ | ✗ | ✓ |
| | Consideration of setting of data collection | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Consideration of researchers' influence | ✗ | ✓ | ✗ | ✗ | ✗ | ✓ | ✗ | ✗ | ✓ | ✓ | ✓ |
| Quantitative descriptive | Relevance of sampling strategy | | ✓ | | ✓ | ✓ | | ✗ | ✓ | ✓ | | ✗ |
| | Representative sample | | ✓ | | ✗ | ✗ | | ✓ | ✓ | ✗ | | ✓ |
| | Validated measures | | ✗ | | ✓ | ✓ | | ✗ | ✗ | ✗ | | ✗ |
| | Acceptable response rate (60% or above) | | ✗ | | ✓ | ✓ | | ✓ | ✓ | ✓ | | ✓ |
| Mixed-methods | Appropriateness of mixed-methods design | | ✓ | | ✓ | ✓ | | ✓ | ✓ | ✓ | | ✓ |
| | Adequate integration of quantitative and qualitative data | | ✓ | | ✓ | ✓ | | ✓ | ✓ | ✓ | | ✓ |
| | Consideration of divergent quantitative and qualitative findings | | ✓ | | ✓ | ✓ | | ✓ | ✓ | ✓ | | ✓ |
| | Total scores | 5/6 | 10/13 | 5/6 | 10/13 | 11/13 | 6/6 | 8/13 | 10/13 | 11/13 | 5/6 | 11/13 |
| | Percentages | 83 | 77 | 83 | 77 | 85 | 100 | 62 | 77 | 85 | 83 | 85 |

[a]These studies had qualitative designs and were only evaluated with qualitative domain questions.

clinical problems. PGHD was collected in a mobile format and/or through web-based platforms. Some tools allowed both patients and providers to visualize data, while others only had a provider view. PGHD collection included manual entry into an application, automated entry from connected devices, photographs taken with digital cameras or mobile phones, text messaging, and a proprietary pen-and-paper technology. In 5 studies providers were the only intended users of PGHD, even if patients or their caregivers could view the data; in these studies patients were reportedly not acting upon their data but deferring to the provider's interpretation of it.

## Qualitative Synthesis

Qualitative synthesis results are provided in Tables 3 and 4.

Inter-rater reliability between the 2 coders was acceptable ($\kappa = 0.7280$). All coding discrepancies were discussed and resolved.

Three high-level themes emerged regarding patient/provider needs: clinical, logistic, and technological (Table 3). Thirteen sub-themes also emerged. Clinical sub-themes address patient-provider relationships; contextual metadata, and patient/provider needs for guidance. Logistic sub-themes address motivation and incentives; time; transparency; and provider preferences for patient selection. Technological sub-themes address customization; interoperability/ EHR integration; data summaries; quality, security, confidentiality; and variation in features desired by the patient/provider. A total of 48 distinct claims were extracted. Claims were grouped under 1 of the 3 major themes (16 clinical, 14 logistic, and 18 technological) and appropriate sub-theme (Table 3). Each claim was classified as convergent, divergent, or relevant to only patients or providers (Table 4).

There are 20 convergent claims in which patients and providers both acknowledge a need and share similar views (8 clinical, 3 logistic, and 9 technological). This includes claims that pertain only to a

**Table 2.** Studies Reporting Evidence on Patient and Provider Needs Regarding Patient Generated Health Data

| No. | References | Method and design | Participants | n | Setting/context | Focus | Tool | PGHD collected | PGHD user | Outcomes |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Cheng et al. (2015)[24] | Qualitative; interviews observation | MDs, RNs, RDs<br>Patients | 15<br>35 | Post discharge Neonatal Intensive Care Unit | Follow-up of clinically "high-risk" infants | Estrellita: a mobile and web-based system for monitoring and supporting development of high-risk infants | Infant diaper usage, weight, behaviors, milestones, complications, attendance at infant medical appointments | Providers | Provider experiences and reflections Actual provider use of PGHD |
| 2 | Chung et al. (2016)[25] | Mixed-Methods, descriptive; surveys interviews | MDs, APRNs, RDs<br>Patients (mean age 44) | 21<br>18 interview 211 survey | University health system and a health maintenance organization | Data sharing practices | Investigates general perspectives, no specific tool | Investigates general perspectives, no specific PGHD | Patients Providers | Expectations, concerns re: actual and potential PGHD collection and use |
| 3 | Cohen et al. (2016)[30] | Qualitative, semi-structured interviews | MDs, RNs Researchers[a] | 12<br>13 | Evaluation of 5 projects funded by Robert Wood Johnson Foundation Project Health Design | 1. asthma 2. elders at risk for cognitive decline 3. overweight young adults 4. people living w/Crohn's disease 5. caregivers of premature infants | mHealth apps and passive sensors used to collect PGHD; Summary sheets and web-based portals used to share data with providers | Medications Physiological data (peak expiratory flow, weight) Passive sensor data (physical activity, task completion), Self-reports on mood, behavior, diet, symptoms | Patients Caregivers Providers | Challenges, benefits, and general experiences of using PGHD |
| 4 | Hartzler et al. (2016)[26] | Mixed-Methods, descriptive; Surveys Semi-structured interviews | MDs<br>Male patients | 50<br>50 | Academic medical center | Prostate cancer; long-term follow-up of patient status post treatment | Web-based dashboard displaying PGHD over time compared to similar patients based on age and treatment plan | Health-related quality of life; urinary, bowel, sexual symptoms | Patients providers | Patient self-efficacy Satisfaction Communication Compliance w/ quality indicators Helpfulness of visualizations Experience using PGHD |
| 5 | Hochsten-bach et al. (2016)[27] | Mixed-Methods, descriptive; Surveys Usage Data Semi-structured interviews | RNs<br>Patients | 3<br>11 | Outpatient oncology clinic Feasibility study of PGHD-based intervention | Self-management of pain for home-dwelling cancer patients | Mobile and web-based application for collecting and reviewing PGHD, patient education, and messaging provider | Pain level, adverse effects, pain interference with sleep or activity, satisfaction with pain treatment, medication adherence | Providers | Learnability, usability, desire to use app to collect PGHD Adherence (usage data) General experiences using PGHD |

(continued)

**Table 2.** continued

| No. | References | Method and design | Participants | n | Setting/context | Focus | Tool | PGHD collected | PGHD user | Outcomes |
|---|---|---|---|---|---|---|---|---|---|---|
| 6 | Huba and Zhang (2012)[31] | Qualitative; Semi-structured interviews | MDs, RNs | 21 | Large hospitals and outpatient clinics | Clinical practice | Investigates general perspectives (no specific tool) | Investigates general perspectives (no specific PGHD) | Providers | Current or theoretical use of PGHD |
| 7 | Kum-merow Broman et al. (2015)[28] | Mixed-Methods, descriptive; Surveys with open and close ended questions | MDs / Patients | 5 / 50 | Surgical outpatient clinic; Pilot study of PGHD-based intervention | Post-operative follow-up of patients post laparoscopy for cholecystectomy; hernia repair (ventricular, umbilical, or inguinal) | Patient portal for collecting and viewing PGHD, messaging provider | Symptoms survey, wound photos | Patients / Providers | Acceptance of PGHD / Use of PGHD / Visit times of online (PGHD-based) versus in-person clinic visits |
| 8 | Lind et al. (2016)[32] | Mixed-Methods, descriptive; Surveys with open and close ended questions; Usage data | Patients | 14 | Hospital-based home-care clinic at an academic hospital; Pilot study of PGHD-based intervention | Home-based management of patients with severe heart failure | Anoto™ digital pen-and-paper technology linked to a web-based application for receiving and storage PGHD | Responses to health diary forms (symptoms and medications) and physiological measurements (blood pressure, heart rate, oxygen saturation, weight) | Providers | Experience using PGHD / Actual usage of app to collect PGHD |
| 9 | Nundy et al. (2014)[33] | Mixed-Methods, descriptive; Semi-structured interviews; Surveys | MDs | 12 | Outpatient management program affiliated with an academic medical center; Feasibility and utility study of PGHD-based intervention | Diabetes (type I or II) self-management | CareSmarts: automated text messaging, Text-back responses to record PGHD; viewed by providers in summary sheet | Medication adherence, glucose monitoring adherence, barriers to diabetes self-management, progress on CareSmarts educational modules | Providers | Usability Helpfulness Influence on care Willingness to use General experiences and reflections |
| 10 | Sanger et al. (2016)[29] | Qualitative; Semi-structured interviews | MDs, APRNs, PAs, RNs / Patients / Patient advocates[a] | 11 / 13 / 6 | Outpatient surgical clinic affiliated with an academic medical center; Design of tool to collect and display PGHD | Post-operative surgical site infection monitoring in patients with a prior history of surgical site infections | mPOWEr: mobile Post-Operative Wound Evaluator: application for collecting PGHD and viewing PGHD, and messaging | Longitudinal detailed symptom data, wound photos, miscellaneous free-text data entry | Patients and providers | General experience using PGHD Feedback on mockups of different display systems to collect/display PGHD |

(continued)

**Table 2.** continued

| No. | References | Method and design | Participants | n | Setting/context | Focus | Tool | PGHD collected | PGHD user | Outcomes |
|---|---|---|---|---|---|---|---|---|---|---|
| 11 | Thompson and Valdez (2015)[34] | Mixed-Methods, descriptive | Patients | 87 | Web-based survey | Patient mHealth use | Investigates general perspectives (no specific tool) | Investigates general perspectives (no specific tool) | Patients | Preferences and experiences collecting/using PGHD for self and for provider |

[a]These participants spoke about the patients' and/or providers' experiences collecting and using PGHD in the study

*Abbreviations:* MD = physicians; RN = registered nurses; APRN = advanced practice registered nurses; PA = physician assistants; RD = registered dieticians.

patient or to a provider, but that both groups discuss. For instance, in a patient-provider relationship, emotional needs are directly pertinent to the patient, but providers acknowledge that patient emotional needs must be met.

There are 4 divergent claims that both groups discussed from opposing perspectives (0 clinical, 3 logistic, and 1 technological). For example, patients want a response to their PGHD within a few hours, while providers fear responding that quickly would disrupt their work.

There are 5 claims identified only by patients (2 clinical, 1 logistic, and 2 technological). There are 19 claims identified only by providers (6 clinical, 7 logistic, and 6 technological).

## DISCUSSION

### Convergence and Divergence of Perspectives

This integrative review identified 3 broad themes concerning patient and provider needs around collecting and using PGHD, from 11 primary sources of quantitative and qualitative data. Synthesis of the findings produced a set of 48 distinct claims. Half of the claims (24 of 48) were discussed by one group only, suggesting a mutual unawareness of each other's needs. There were several points of convergence on claims pertinent to one group, but acknowledged by the other. For example, patients acknowledged that providers need interoperability and EHR integration, and providers recognized that patients need education and guidance on PGHD collection. This suggests that collection and use of PGHD is a bi-directional relationship: patients and providers are cognizant of at least some of the other's needs and are inextricably linked in the PHGD process. Thus well-designed informatics solutions must include capability for patients and providers to work with PGHD collaboratively, not in isolation.

Unsurprisingly, there were many more instances of providers noticing a patient need than vice versa. This may reflect providers' awareness of patient needs as a clinical skill, and of patients limited knowledge of provider workflows and clinical practices. For instance, all 3 claims that referred to time limitations were provider-generated; patients did not specify time as an issue in these 11 studies.

An analysis of points of convergence and divergence found that patients and providers agree more about clinical and technological needs than they do about logistic needs. Our analysis suggests a general tension between patients needing more: more support, more guidance, more feedback on data, and providers needing less: less time burden, less data to review, less liability. There is also a suggestion that underlying anxieties surrounding PGHD and the health problems for which it is collected are also at odds: patients are anxious to understand their health status, while providers are anxious about the implications of PGHD for their clinical practice, including liability, reimbursement, and time. Finally, the findings suggest that while patients want more flexibility with the data (which providers supported in some cases), providers still need methods for standardizing and limiting the data received.

### Sustained patient engagement as a major barrier

Patients indicated that if the data and/or the tools to collect and view it did not meet their needs or produce some immediate benefit, their participation would be dampened or discontinued altogether. This corroborates recent evidence suggesting that sustained engagement with self-monitoring is a critical problem.[36–38] There is evidence that certain subsets of patients only collect data because providers ask them, rather than out of a natural curiosity or desire

**Table 3.** Claims Generated from Qualitative Synthesis[a]

| Claim | Explanation (Source) |
|---|---|
| **Clinical sub-theme: Effect of PGHD on the patient-provider relationship** | |
| PGHD can enhance the working relationship between patients and providers | Patients reported PGHD involved them in their care, and informed providers of their day-to-day experience[2,8] |
| PGHD can facilitate provider monitoring | A significant positive correlation ($r = 0.79$) was observed between frequency of abnormal PGHD and patient-provider communication.[8] |
| Patient emotional needs can be met by providing PGHD | Examples of emotional needs include empathy for symptoms and praise for progress.[2,3] |
| PGHD can worsen the patient-provider relationships | Communication, thoroughness, and rapport were lost when review of PGHD was substituted for clinic visits; it is not a substitute for "face-to-face" with providers.[7,11] |
| **Clinical sub-theme: contextual metadata is helpful for patients and providers** | |
| PHGD not directly pertaining to a clinical problem, or "contextual metadata," can be valuable for understanding the relevant PGHD | For patients, value was in provider understanding their daily life, comorbidities, and anxieties.[2,10] For providers, value was in decision making supported by contextual metadata: patient goals, moods, experiences, behaviors, perceptions, and quality of life.[1,6,9] |
| Contextual metadata can be used for decision making to improve care | As in the case of a pediatrician who received images of babies on a scale to convey weight data, and incidentally noted signs and symptoms that prompted follow up.[1] |
| Providers may want access to PGHD collected for other purposes or for other providers | Especially for conditions that are rare or that transcend specialties, such as psychiatric disorders, to facilitate referrals, and communication with colleagues.[1,6] |
| PGHD has value in emergency situations | When no one can provide a medical history. One provider said, "Something's better than nothing."[6] |
| **Clinical sub-theme: patients need guidance** | |
| Patients need training and support before collecting PGHD | Patients lack understanding of how to take health-related measurements and record them, leading them to incorrectly report their data.[5] One patient said, "I don't trust myself... I don't know what to look for."[7,8] |
| Patients need help interpreting their data | Patients need to identify trends and correlations in their data to interpret in context of average values.[2,4] Providers can guide patients on which data are/are not significant (with a goal of patient independence).[2,4,10] |
| Providers can leverage PGHD for health education and counseling | For example, one provider noticed a patient nonadherence to calorie requirements and used the data to reinforce education on calorie counting and weight management[2] |
| Patients may want providers to constantly monitor their PGHD to dispel their doubts | Patients may distrust their own ability and/or the ability of software algorithms to detect abnormal data.[4,10,11] Patients react positively to the idea of multiple providers monitoring (eg, nurse, physician, and pharmacist), e.g., "someone looking over your shoulder every day."[5] |
| **Clinical sub-theme: providers need guidance** | |
| PGHD is not customary in current provider work flows. Providers need protocols to guide their responses to PGHD | For instance, one nurse described an algorithm her group practice devised to categorize PGHD into acuity "zones" each with corresponding actions.[3] |
| Providers may have questions about their role when responding to PGHD | A nurse said, "At times I'm not sure... What is allowed? When do I intervene? ...What does the treating physician want? When do I interfere and take over care?"[3] |
| Providers have legal and ethical concerns about receiving PGHD that is outside of their scope of practice | Patients may not be aware of the scope of a provider's expertise, both in terms of clinical specialty and provider type (RN, MD, etc.). Providers are concerned that once they receive the data, they are responsible for it.[1,2,10] |
| Providers may need to delegate data management | Providers delegate when they do not have the knowledge or experience to manage data themselves.[2,10] |
| **Logistic sub-theme: motivation and incentives** | |
| Patients and providers can lose motivation to collect and use PGHD | They are motivated to collect and use PGHD when it saves time (eg, not missing work, fewer office visits) and is easy, but not when the process is distracting, time-consuming, or inconvenient.[7,9–11] |
| Patient motivation can wane if benefits from self-monitoring are not immediate | Providers recognized this and reported trying to help patients see value in collecting PGHD even if benefits were not immediate[2,11] |
| Patient motivation to collect PGHD can increase with peer and provider support | However, fear of being "judged" by peers or providers can decrease motivation.[2,11] |
| Provider motivation to review PGHD can improve with incentives | Examples of incentives include saved time and financial reimbursement[2,7,10] |
| Providers' current clinical workflows and incentive structures reduce their motivation to review PGHD | Providers lost motivation because they felt the work that went unrecognized and was not billable.[2,10] One provider said the incentive structure "has a perverse, mixed message: collect the data but you don't have time to do it."[2] |

**Table 3.** continued

| Claim | Explanation (Source) |
|---|---|
| **Logistic sub-theme: time** | |
| Providers need to make time for PGHD data review | Practices varied greatly; some providers continuously monitored PGHD, some reviewed before a patient visit, and some only reviewed during the visit. Some providers resorted to evenings and weekends to catch up on data review[1,2] |
| Providers need methods to reduce the time burden for PGHD review | Alerts when at-risk patients generate abnormal data,[1,10] and brief summary reports[9,10] were 2 reportedly successful methods to reduce the burden for providers |
| Providers have concerns about liability and the risk of "information overload" | They feel they need to negotiate with patients on data received. They saw this as a fluid process of negotiating data elements based on the patients' evolving status[1,2,10] |
| **Logistic sub-theme: transparency** | |
| Patients have concerns about how their data is used, re-used, and how extensively it might be shared | This concern is exacerbated by use of mHealth apps for which privacy and confidentiality standards can vary enormously[2,11] |
| Patients want a timely response (e.g., within 4 h) while providers fear a requirement for rapid response may disrupt workflows and care of other patients | When patients were unaware of the provider response process they are anxious: "Because sometimes you're just sitting there waiting... and it's like God, what am I supposed to do?"[10] Providers wanted patients to have "realistic expectations of how available I am to them"[10] |
| Providers need to manage patient expectations regarding the review process | Patients want to know who will review their data and if/when they will be contacted.[10] Many times providers felt communication was only warranted if the data was abnormal[1,10] |
| Goals for collecting and using PGHD may be different | Patients want to indefinitely monitor their health with their provider, while providers aim to empower the patient so that they will transition to more independently monitor[2,10] |
| **Logistic sub-theme: patient selection varies by provider** | |
| Providers may need to select a subset of patients from whom to receive PGHD | Examples of patient subsets included: those whose disease is poorly controlled,[3,9] those who are poor historians,[9] and those who are at increased risk for complications per an objective risk measure[10] |
| Providers may need to encourage all of their patients to self-monitor. | One provider said, "So anyone who has a phone and can text I think ... let's use it... offer this to anyone who wants to really"[9] |
| **Technology sub-theme: customization** | |
| Patients and providers need visualizations to be customizable | The need the ability to: <br> • Vary amount of detail seen[4] <br> • View data in different ways (graphs, tables, etc.)[3–5] <br> • Mark-up visualizations with notes and color-coding[4,5] |
| Providers need to customize visualizations to save time | One provider said, "Just going through this much data was going to be so time consuming. [would help if] we could see all the graphs at once, and see if anything correlated."[3] |
| Patients can use visualizations to help them make life style adjustments that improve their health condition | If the visualization didn't facilitate this type of insight patients often stopped using them. General visualization preferences included charts and line graphs over data tables or pictographs, and data visualized in chronological order[2,4,5] |
| Patients may need to customize data entry | A lack of customizable data entry can discourage patients from self-monitoring and cause nonuse, especially for patients who need to track multiple, specific data points, and can lead to errors in data entry[2,5] |
| Providers may need customized patient data entry to support clinical decision-making | Some providers noted that data entry that is too open-ended could cause data to be unnecessarily complex and irrelevant, so they favored some form of structure to "nudge [the patient] in the right direction"[5,10] |
| **Technology sub-theme: interoperability/EHR integration** | |
| Patients and providers need PGHD integrated into existing systems | There was a strong preference for systems that integrate PGHD to "building on existing technical systems" so that the review process would be streamlined[3,6,10] |
| PGHD integrated into existing systems may reduce confusion and frustration | Commonly, providers must use different systems and modes of communication to view and respond to PGHD. Providers become less willing to use PGHD and patient-provider communication about PGHD was increasingly complex when the provider workflow was not streamlined[2,3,10] |
| PGHD integrated into existing EHRs could improve care coordination and communication across providers | Care plans and patient instructions generated by one provider can be viewed and taken into account by other providers caring for the same patient[1,6] |
| **Technology sub-theme: data summaries** | |
| Patients and providers need a summary of the data that is rapidly understandable and cues them to action | PGHD can be complex, heterogeneous, and high frequency. Data summaries that help providers quickly make sense of large amounts of data could save time, inform decision-making, and improve patient care[4–6] |
| Patients expect data summaries may answer their questions without having to contact their provider | For instance, longitudinal trends can answer their questions about their progress quickly[2,4,10] |
| Patients and providers may not trust automated data summaries | They reported skepticism about the algorithms used to condense and present PGHD[2,10,11] |

**Table 3.** continued

| Claim | Explanation (Source) |
|---|---|
| **Technology sub-theme: quality, security, confidentiality** | |
| Patients are confused about whether their PGHD collection is private and confidential | Patients did not know if the mHealth apps they were using to collect and view PGHD fully complied with privacy and confidentiality regulations.[2,11] One study showed that over 20% of patients were concerned about the privacy and confidentiality of their PGHD[11] |
| Providers are concerned about privacy issues with PGHD from minors | One provider said, "There are some things that when they talk to us about sexually re-lated issues, substance abuse, mental health, after age 12, they're protected from us talking to their parents about it. There would be a selective bias... about what they enter"[3] |
| Providers are concerned about the quality of PGHD | For instance, photographs in a post-operative wound monitoring study were poor quality or only show part of the wound.[7] In 1 study 76% of providers worried that patients could incorrectly measure or report PGHD[6] |
| Providers need to distinguish data recorded by patients vs by healthcare professionals in other settings | Objective measurements can be more accurate when recorded by healthcare professio-nals.[7,9] However patient-reported data (e.g., medication adherence) can be more accu-rate because there is less pressure to "please the doctor" with answers as there is in face-to-face visits[9] |
| **Technology sub-theme: desired additional features vary by patient and provider** | |
| Patients want the option to electronically communicate with providers about their PGHD, while providers fear it could compromise the professional relationship | Patients liked the ability to electronically communicate with their provider for nonurgent questions that would help them understand their health conditions[1,5] Providers felt text messages and other free-text data would be, "totally disruptive... I don't want that kind of access with patients," but in one study this perception was more common in physicians than nurses[10] |
| Providers need standardized data summaries to reduce the time burden of sifting through PGHD | They acknowledged that some data types lend themselves to standardization (eg, blood glucose) while varied and complex data do not (e.g., nutrition data)[2,10] |
| Providers need standardized definitions of data types | For instance, "physical activity" can mean any movement or vigorous exercise[2] |

[a]Sources refer to the numbered studies listed in Table 2.

to learn.[39,40] In 5 of the 8 studies that evaluated a tool, the PGHD was intended for provider use only (Table 2). As healthcare shifts to a patient-provider collaboration model,[7,41,42] research is needed on factors that contribute to sustained patient engagement with the process of collecting and using PGHD.

## Significance of This Review

Our analysis draws upon prior research that compared the perspec-tives of patients and providers on PGHD,[24–29] and extends that work by generating an integrated set of requirements substantiated by multiple primary sources. The findings of this review substantiate findings from a federally-commissioned report, which relied on ex-pert opinion,[13] with an analysis of primary source data from the 2 groups directly involved in collection and use of PGHD. Rich pri-mary data from patients and providers offers increased validity and depth of understanding of the technical challenges, policy and reim-bursement issues, the need for clinical guidelines, and the lack of sustained engagement by patients recording PGHD. Furthermore, by analyzing patient and provider needs in relation to each other, points of convergence and divergence emerged. This information may be applied to developing systems to improve the collection and use of PGHD through accommodating the needs of both user groups, thereby potentially increasing the likelihood of success.

## Implications for Policy and Design

Overall, the findings suggest that expectations should be set between patients, providers, and other relevant stakeholders (e.g., adminis-trators, reimbursing agencies, and technology vendors) from the very beginning of the process – including identifying and reconciling differences in those expectations. Transparency in this process may be an approach to avoid frustration and confusion. Goals for col-

lecting and using PGHD need to be explicit, as our findings illustrate that these can be different. Before implementing a tool, technology vendors are advised to follow best practices for engaging patients and providers in specifying system requirements for flexibility, stan-dardization, visualizations, messaging, data summarization, and in-tegration.[43,44] Administrators can identify and seek to mitigate workflow barriers such as scheduling, role delegation, and scope of practice. Policymakers should analyze current incentive structures for patients and reimbursement for providers. Future research that examines the health outcomes and the cost-benefit of PGHD com-pared to standard care can produce the evidence to drive policy to-wards incentivizing the collection and use of PGHD.

## CONCLUSION

Patients and providers share many common needs when collecting and using PGHD in practice. These needs are clinical (maintain a relation-ship, data interpretation, contextual metadata), logistic (motivation, negotiation, convenience/usability, and transparent provider roles), and technological (customizable visualizations, flexible data input, elec-tronic integration, simple actionable data summaries, and management of data quality and security concerns). Differences between patients and providers arose in these 3 main categories as well, mainly centering on patients' needs for reassurance, instruction, and communication with providers, as compared to providers' needs to limit scope of PGHD, standardize it, receive it from only certain patients (in many cases), and have clear clinical guidelines to follow in responding to it.

Patients and providers are the 2 primary stakeholders directly in-volved with PGHD collection and use, and their needs in this pro-cess are inextricably linked. As momentum gains for PGHD to become fully integrated into the healthcare system, these perspec-tives are critical to ensure their needs are concurrently being met.

**Table 4.** Synthesis of Claims According to Theme and User Group

| Theme | Convergence: patients and providers identified a need and shared similar perspectives | Divergence: patients and providers identified a need and held opposite perspectives | Patient identified need | Provider identified need |
|---|---|---|---|---|
| Clinical | PGHD can enhance the working relationship between patients and providers<br>PGHD can facilitate provider monitoring<br>Patient emotional needs can be met by providing PGHD<br>PGHD can worsen the patient-provider relationships<br>PHGD not directly pertaining to a clinical problem, or "contextual metadata," can be valuable for understanding the relevant PGHD<br>Contextual metadata can be used for decision making to improve care<br>Patients need help interpreting their data<br>Providers can leverage PGHD for health education and counseling | | Need training and support before collecting PGHD<br>May want providers to constantly monitor their PGHD to dispel their doubts | May want access to PGHD collected for other purposes or for other providers<br>PGHD has value in emergency situations<br>PGHD is not customary in current provider workflows. Need protocols to guide responses to PGHD<br>May have questions about their role when responding to PGHD<br>Legal and ethical concerns about receiving PGHD that is outside of their scope of practice<br>May need to delegate data management |
| Logistic | Patients and providers can lose motivation to collect and use PGHD<br>Patient motivation can wane if benefits from self-monitoring are not immediate<br>Patient motivation to collect PGHD can increase with peer and provider support | Patients want a timely response (e.g., within 4 h) while providers fear a requirement for rapid response may disrupt workflows and care of other patients<br>Providers need to manage patient expectations regarding the review process<br>Goals for collecting and using PGHD may be different | Concerns about how their data is used, re-used, and how extensively it might be shared | Motivation to review PGHD can improve with incentives.<br>Current clinical workflows and incentive structures reduce motivation to review PGHD<br>Need to make time for PGHD data review<br>Need methods to reduce the time burden for PGHD review<br>Concerns about liability and the risk of "information overload"<br>May select a subset of patients from whom to receive PGHD<br>May encourage all of their patients to self-monitor |
| Technology | Patients and providers need visualizations to be customizable<br>Patients can use visualizations to help them make lifestyle adjustments that improve their health condition<br>Patients may need to customize data entry<br>Providers may need customized patient data entry to support clinical decision-making<br>Patients and providers need PGHD integrated into existing systems<br>PGHD integrated into existing systems may reduce confusion and frustration<br>PGHD integrated into existing EHRs could improve care coordination and communication across providers<br>Patients and providers need a summary of the data that is rapidly understandable and cues them to action<br>Patients and providers may not trust automated data summaries | Patients want the option to electronically communicate with providers about their PGHD while providers fear it could compromise the professional relationship | Expect that data summaries may answer their questions without having to contact provider<br>Confusion about whether their PGHD collection is private and confidential | Need to customize visualizations to save time.<br>Uncertain about privacy issues with PGHD from minors<br>Providers are uncertain about the quality of PGHD.<br>Need to distinguish data recorded by patients versus by healthcare professionals in other settings<br>Need standardized data summaries to reduce the time burden of sifting through PGHD<br>Need standardized definitions of data types |

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## CONTRIBUTORS

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