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Remote Monitoring of Patient- and Family-Generated Health Data in Pediatrics

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Abstract

Remote patient monitoring (RPM) is a form of telemedicine that involves the collection and transmission of health data from a patient to their health care team by using digital health technologies. RPM can be leveraged to aggregate and visualize longitudinal patient-generated health data for proactive clinical management and engagement of the patient and family in a child's health care. Collection of remote data has been considered standard of care for years in some chronic pediatric conditions. However, software limitations, gaps in access to the Internet

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and technology devices, digital literacy, insufficient reimbursement, and other challenges have prevented expansion of RPM in pediatric medicine on a wide scale. Recent technological advances in remote devices and software, coupled with a shift toward virtual models of care, have created a need to better understand how RPM can be leveraged in pediatrics to improve the health of more children, especially for children with special health care needs who are reliant on high-quality chronic disease management. In this article, we define RPM for the general pediatric health care provider audience, provide case examples of existing RPM models, discuss advantages of and limitations to RPM (including how data are collected, evaluated, and managed), and provide a list of current RPM resources for clinical practitioners. Finally, we propose considerations for expansion of this health care delivery approach for children, including clinical infrastructure, equitable access to digital health care, and necessary reimbursement. The overarching goal is to advance health for children by adapting RPM technologies as appropriate and beneficial for patients, families, and providers alike.

Telemedicine is defined broadly as the exchange of medical data from one site to another by using technology.[1] The coronavirus disease 2019 pandemic brought rapid expansion of telemedicine in the form of video visits and unique challenges and opportunities to care for children in a new model of care.[2,3] Remote patient monitoring (RPM) is a distinct form of telemedicine that involves the "collection, transmission, evaluation, and communication of individual health data from a patient to their healthcare provider or extended care team from outside a hospital or clinical office (i.e., the patient's home) using personal health technologies including wireless devices, wearable sensors, implanted health monitors, smartphones, and mobile apps."[4] Unlike health data collected in clinics or physiologic monitoring in ICUs, RPM provides data about a patient's health during a typical day (ie, in situ), whether at home, school, or play, by the day, minute, hour, and even second. RPM extends data collection beyond finite health care encounters and holds promise to aid in the management of chronic disease with an integrated and proactive patient- and family-centered approach.

In this review, we focus on data monitored remotely for health care purposes, generally referred to as patient-generated health data (PGHD). PGHD are "created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern."[5] Examples of PGHD include health histories, standardized symptom reporting, and physiologic or biometric data (eg, heart rate, glucose level, weight).[5] Because of reimbursement, operational, and technological constraints, RPM in pediatrics has been limited. However, new payment models have led to significant innovation in adult care, including physiologic data mining from wearable devices, predictive algorithms, multimodal devices, rapid advances in artificial intelligence–based decision-making, and machine learning for clinical decision support.[6,7] Now is the time for RPM to be adapted for pediatric populations to enable similar innovative advancements in care.

In this article, we explain the basics of RPM in patient care and then discuss general advantages and limitations of RPM and provide case examples of existing RPM models.[4] Finally, we propose a path for expansion of RPM in pediatrics (including clinical infrastructure, policies needed to ensure equitable access to digital health care, and reimbursement strategies) as well as a list of practical resources for the use of RPM by pediatric practitioners. Altogether, we describe how pediatric practitioners can adapt RPM technologies with a focus on quality and equity to advance health care for children, especially for children and youth with special health care needs (CYSHCN), who have varied chronic care management needs.

RPM BASICS

For RPM to operate within patient care, PGHD must first be measured, collected, and/or reported and then either entered manually by the child or caregiver or automatically detected by an RPM platform or application (app). The data are then displayed numerically and/or graphically. In some systems, an additional manual or automatic transmit step is needed when the device collecting the data is different from the device displaying the data. Once displayed, the value must be interpreted as normal or abnormal by comparing to a historical trend or physiologic norms. Interpretation may be automated (computer-based algorithm) or manual (clinician or patient and/or family evaluation). The information is then acted on. Actions could range from an automated message to seek care, to a telephone call to review and discuss the findings, to a recommendation to continue monitoring without a change in care. This cycle may repeat constantly (eg, thousands of times per day) or sporadically (eg, monthly), based on the clinical context, and may be integrated with other data collection, including laboratory studies.

Overall Advantages and Drawbacks of RPM Care

RPM has great potential to improve pediatric health in ways not possible in most current "brick-and-mortar" care models. In a traditional model of care, routine health evaluations occur on an annual, semiannual, quarterly, or possibly monthly basis with reliance on patient and/or parental recall of the interval period. In contrast, the evaluation and communication in an RPM model of care can occur more frequently and facilitates greater opportunities for the patient and family to share information with their health care team. At its greatest potential, RPM detects developing health problems earlier than would be possible through scheduled clinical visits, thereby preventing an exacerbation of chronic disease that may lead to morbidity or mortality.[8,9]

The mere participation in an RPM program can provide reassurance and security for patients and their families, including CYSHCN,[10–12] generating a positive feedback loop that reinforces patient and family engagement in the RPM platform.[10] RPM may capture information about a condition's natural history or a clinical intervention's impact that is different from data collected in intermittent clinical assessments. This suggests a role for RPM in research, facilitating the collection of data in situ rather than in a clinical setting, which may alter physiologic parameters.

Despite advantages to RPM, known and potential drawbacks also exist. The burden to collect, report, monitor, analyze, and act on PGHD should be considered against the benefits offered above the current state. The "signal to noise" ratio must be worth the costs of the RPM program's implementation and maintenance. In the current payment landscape, RPM implementation likely would require substantial upfront investment by pediatric offices and health systems that are not yet adequately reimbursed in fee-for-service payment arrangements.[13] Out-of-pocket expenses for device purchase, time costs for the patient and family, and training costs for patients, families, and providers, as well as the potential for detection of nonevents (false-positives) leading to potential unnecessary escalation of care or overuse should be considered.[14] Although RPM may provide assurance for some, it has been shown to provide minimal clinical benefit and reinforce feelings of worry in others (ie, psychological costs).[11,12,15] Therefore, meaningful RPM adoption requires engagement and buy-in from not just pediatricians but also patients, families, and ancillary staff, who are already consumed by busy lives and medical practices.[13]

Evidenced-Based RPM Examples

RPM is already used for diagnosis and management in adult care, and there is evidence of a positive impact on health outcomes in older patients with chronic conditions.[9,16,17] Inconclusive evidence has hindered wider adoption of RPM in pediatrics,[18] but its adoption is expanding. In some cases, RPM is being integrated into care guidelines. The American Heart Association recently published a scientific statement supporting adoption of RPM for children with single ventricle heart disease, including pulse oximetry to detect excessive hypoxia and infant scales to detect weight loss.[19] This recommendation was based on consistent and significant improvements in morbidity and mortality by using RPM. The National Pediatric Cardiology Quality Improvement Collaborative demonstrated mortality reductions of >40% between 2008 and 2016.[19] The American Heart Association's scientific statement on telemedicine in pediatric cardiology also supports patch-based external rhythm monitoring and RPM of implanted cardiovascular devices[20] because of their convenience and superior performance at identifying dysrhythmias compared with traditional methods.[18,21,22]

The 2018 American Diabetes Association for Type 1 Diabetes in Children and Adolescents Position Statement identified RPM as a useful way to engage pediatric patients in diabetes management.[23] Real-time continuous glucose monitoring (CGM) with remote clinical support can improve diabetes management without safety issues.[18] A randomized control trial of remote transmission of CGM data by a wireless or cellular network cloud platform versus standard CGM in 20 pediatric patients over 320 nights revealed improved response to abnormal values (100% vs 50%), reductions in duration of hypoglycemic events (30 vs 35 minutes), and elimination of prolonged hypoglycemic events.[24] Although the use of remote CGM may be limited by its integration into a given health system's workflow,[25–27] it is expected to expand based on positive impacts on glucose control and parental mental health outcomes.[28]

Childhood asthma is another chronic condition with a growing evidence base for RPM to improve symptom control. Typically, asthma RPM interventions include a mobile app and Web site to connect patients with health providers to monitor symptoms and medication use.[29] In a prospective cohort study of children with asthma versus matched controls ($N = 327$), researchers evaluated use of an electronic self-monitoring app alerting parents and primary care physicians of early signs of deterioration and showed improved quality-of-life scores and asthma control with reduced combined ED and hospital admissions (rate ratio:

0.41; 95% confidence interval: 0.22–0.75) and oral corticosteroid use (rate ratio: 0.65; 95% confidence interval: 0.46–0.93).[29] Other RPM asthma interventions include sensors to detect inhaler use or even inhaler technique, which is transmitted to a shared digital platform for viewing.[30] Studies of sensors reveal improvements in preventive medication adherence (84% over 6 months with sensors versus 30% in controls),[31] and asthma control test scores increased by 2.2 with sensors compared with 0.6 in controls.[30] More effectiveness trials are needed to support widespread implementation.[32]

Wearable devices that track movement and vital signs are now commercially ubiquitous. Research suggests that wearable activity trackers in children, even those younger than 13 years old, are feasible and acceptable to users and parents.[33] However, the application of wearables in healthy children and adolescents to promote physical activity remains mixed primarily because of decreased participation over time.[34,35] Activity-based RPM may hold the greatest promise in specific health contexts, with research showing enhancement of physical activity in childhood patients with cancer[36] and the potential to accelerate postoperative pediatric recovery in children after appendectomy.[37,38]

For RPM to be incorporated into clinical guidelines, studies must demonstrate both efficacy, whether an intervention leads to an expected result in ideal research-based circumstances, and effectiveness, which measures impact in real-world settings.[39] Sustained and feasible engagement with RPM users will be essential. Quality improvement collaboratives, such as the National Pediatric Cardiology Quality Improvement Collaborative, facilitate the translation of research-based findings into diverse practice environments.[19] We anticipate future guidelines will include a range of RPM choices for pediatric care. For example, the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition recommends choosing from several evidence-based digital ways to support pediatric inflammatory bowel disease drug adherence, including electronic pill monitoring.[40] As the evidence for RPM effectiveness grows, pediatricians and other specialists will need to be supported to adopt these rapidly advancing approaches into practice.

CONSIDERATIONS FOR ADOPTING RPM INTO PRACTICE

Specific considerations for how different types of RPM programs can be adopted are summarized in Table 1. A list of current resources for pediatric practitioners to build RPM into their practices are listed in Table 2.

What Data Are Collected

By some limited definitions, RPM refers only to the collection of discrete objective data, such as vital signs, or anthropomorphic information, such as weight.[13] Objective discrete measurements naturally lend themselves to be trended longitudinally, allowing for evaluation of a new value compared to a historical baseline. However, the precision and accuracy of physiologic data measured at home by the patient or family should be calibrated in the clinic setting before home-based collection because inaccurate or invalid data are not useful.

More expansive definitions of RPM encompass PGHD that can only be collected as a subjective construct. Example constructs include mood symptoms, stool quality, nutrition intake, or fatigue level. Ideally, subjective construct data are collected by using validated survey instruments called patient-reported outcomes and assessment measures.[41,42] For example, the assessment of pain in children can be quantified by using a numerical scale[43] or the visual Wong-Baker FACES scale.[44] When patient-reported outcomes and assessment measures are scorable, they lend themselves well to RPM and can be graphed for visualization over time in a similar way to discrete physiologic data.

A potential advantage to incorporating subjective data in pediatric RPM is that a family caregiver can provide proxy assessments of how a child is doing, which may be necessary depending on a child's developmental ability. For example, a randomized feasibility RPM trial in 50 children with medical complexity that tracked the family caregiver's report of their child's vital signs, pain, feeding and fluid intake, mental status, and seizure rate as well as parental worry demonstrated a reduction in hospital days (9.25 to 4.54 days [rate ratio: 0.49; 95% confidence interval: 0.39–0.62]).[45] Subjective data and proxy reporting should be strongly considered when building sustainable pediatric RPM programs to ensure the most complete "remote" picture of the patient.

How and When Data Are Collected, Processed, and Used

The education and training required for data collection, entry, and transfer must be balanced with the data's clinical utility and user engagement to ensure sustainability. How automatically or manually PGHD flow through an RPM program affects how easily it can be integrated into family routines and clinical care. Illustrations of how RPM programs can differ, adapted from examples in the literature, are shown in Fig 1.

Manual data collection is currently the most pervasive in pediatrics but has the most potential for error. A dedicated device is typically used to measure the value, and then the user enters the value into an RPM platform.[10] In example one (Fig 1A), a parent of a child with congenital heart disease measures their child's oxygen saturation using a pulse oximeter then enters the value into an app on their mobile phone.[10] The app identifies the value as abnormal based on the child's personalized threshold and notifies the parent to call a provider. The provider then reviews the value from a remote dashboard that displays the patient's previous trends and recommends escalation to in-person care.

As technology advances, pediatric RPM will become not just more automated, in which a device will collect, store, and display the data without human input (eg, heart rate graphed on an exercise watch), but also integrated into clinical care. Figure 1B illustrates a health deterioration detection app that automatically categorizes and displays vital sign and symptom information for a child with medical complexity in an actionable way on the basis of 2 weeks of trended data. The parent can use this information to know when to call a provider to discuss a sick-day plan.[45]

Data transmission may be continuous (requiring a reliable power supply), intermittent and automated, or intermittent and requiring manual "push." RPM programs using manual data must consider the burdens of frequently collected data relative to how often an interpretation would be used to alter the care regimen. Devices that transmit data wirelessly (eg, Bluetooth-enabled technology) may miss transmitting data because of dropped or poor connectivity. Data collection that occurs automatically may unintentionally capture and transmit data that are not the patient's real values (eg, a different sibling stands on the scale and the system records the sibling's weight as the patient's weight). Data collected manually may have an extra "user's check," in which the patient or parent can validate before entry. However, manual data are at risk for mismeasurement because of complexity of a task or lack of training and typically require additional effort by family, impacting adherence.

The "right-sizing" of data timing and volume remains an understudied area in pediatrics and RPM care generally. Data may be useful even when collected as often as monthly. Figure 1C illustrates the example of a teenager monitoring their inflammatory bowel disease monthly by reporting on their symptoms, sending in a fecal sample by mail, and giving a blood sample at laboratory near home.[46] These values are integrated by the RPM program, and recommendations are displayed for the adolescent to continue their current medication regimen and monitoring.[46,47]

Once in the RPM system, the data ultimately serve to inform clinical care. The primary objective of data collection and analysis is to generate information that leads to meaningful insights on specific patient conditions and disease states. The marginal utility of remote longitudinal data collection may lie in RPM's ability to aggregate and visualize PGHD to sufficiently alter decision-making and engage patients and their families in ways traditional visit-based care does not. Consequently, RPM's value may be in promoting more proactive medical management than traditional discrete visit-based care. RPM programming, therefore, should include appropriate thresholds for escalation or action for each collected parameter relevant to the clinical context. For example, the level of activity (eg, steps per day) should have an evidence-based association with clinical deterioration in the postoperative period or a specific pain score associated with readmission.[37,48]

Device and Software Platform Characteristics

Trade-offs exist when considering which hardware (device) and software products to choose when establishing an RPM program. For objective PGHD collection, most RPM programs will need measurement tool(s) to gather the information (eg, scale, glucose monitor, pulse oximeter, etc), which may come with disposable attachments (eg, glucose strips, adhesive sensor, ventilator connector) that add to costs and require training. Worn-out or lost devices will need replacement as well.

Medical grade devices may have better reliability and validity but are likely more costly than consumer-adapted versions. Medical teams must consider the importance of accuracy and precision of the measurement over time because it may matter more that home measurement can consistently detect changes than whether it is equivalent to an in-clinic value.

Most RPM programs will need an app to display the collected PGHD. If the measurement device does not display the information, then another device may be needed, such as a tablet or smartphone with an app. The app ideally provides a way to mark a value as abnormal, alert the user(s) to abnormal values, and indicate that an abnormal value has been clinically addressed.

Choosing an app will vary on the basis of local health care resources and budgets. Because RPM technology is rapidly evolving, we encourage users to choose the app that is the minimum viable product for their population, condition(s), and local processes. Ideally, the app will have high interoperability with the electronic health record, allowing providers to visualize and document RPM alongside other care encounters. RPM programs that require providers to log in to an external Internet-based dashboard may limit uptake. Anticipating maintenance needs and software and/or hardware updates is also part of any RPM sustainability plan.

Patient, Family, and Provider Roles and Engagement

Adoption and sustained use of RPM programs are strongly influenced by end user experience. When possible, we recommend that RPM program workflows be designed with input from end users to ensure they are feasible, acceptable, and sustainable for patients, families, and health care teams.[49–51] In particular, RPM program design should include input from administrative staff, nursing, and midlevel providers who may be impacted to ensure effective integration into clinical workflows.

Once developed, program implementation should include education of patients and families on how to use the RPM program and expectation setting for each participant's role. As demonstrated in Fig 1, some programs will actively involve the patient and family at all data flow stages, from collection to interpretation and action. In other scenarios, a parent may measure and enter data but then wait for their child's health care team to review data before an action is taken or even wait to review asynchronously collected data together at a routine clinic visit.

Interpreting and acting on data requires patients and families to have more sophisticated health literacy and numeracy, which, depending on the RPM use case, may either enhance their engagement in the child's chronic disease management or just increase the burden of their current regimen. An additional driver of sustained engagement in RPM systems is real-time reinforcement that the data entered are generating meaningful information.[52] For example, visual feedback on a user interface of a wearable activity tracker can motivate continued use.[33]

We recommend RPM planning include safeguards for times when a patient or family fails to communicate an abnormal value. Changes in parent-child expectations around disease management based on the developmental maturity of the child should also be considered in program planning because some parents may welcome their child's engagement, whereas others may not depending on the perceived independence of the child. This is particularly important for CYSHCN with cognitive impairment or other disabilities as well as adolescent CYSHCN with increasing responsibility of managing their condition(s).

Participant roles and responsibilities should be clearly delineated among clinical team members, including who will review RPM data and how frequently. Proactive planning is necessary to determine how an abnormal value will be addressed (action or inaction) and recorded within the child's electronic health record by the provider team. Clinical teams contemplating RPM also should consider how clinicians' work schedules might affect frequency of data review and interpretation, including whether values will need to be addressed outside regular clinic hours as well as need for an off-hours escalation plan.

What level of clinical expertise is needed to respond to an abnormal value will impact who in a pediatric office or health care system is assigned these tasks. In some RPM programs, a care-coordinator or nurse[45] may be tasked with initial review and then consult a practitioner for final interpretation and action, whereas in another, the patient and family will manage the entire data cycle alone for months before engagement with the health care team. Maintaining a feedback loop wherein the data entered by the patient or caregiver are acknowledged and acted on is critical to maintaining patient and caregiver engagement in RPM systems.

Privacy and Security Considerations

RPM programs should include safeguards to ensure the accuracy, privacy, and security of PGHD collected for clinical purposes. PGHD are distinct from other data generated in clinical settings and through provider encounters, in that the patient and family are principal in collecting and recording data.[53] We recommend that health care administrators, providers, RPM platform developers, and policy makers prioritize the safeguarding of personal information and limiting of business exploitation of data, while enabling the use of data for research and clinical use.[54] Some RPM platforms, particularly those that leverage machine learning, may aggregate deidentified data and share it with a third-party. In one study, researchers found that the level of comfort in sharing data with providers and technology researchers was acceptable and was higher than the level of comfort in sharing data with insurance companies.[55] Security considerations include multiple data sharing sources, Bluetooth-enabled devices, and prevention of ransomware attacks.

Privacy considerations are especially pertinent to adolescent patients taking increasing ownership of their own care who may share devices with other family members. RPM design and implementation developers should consider how enrolled adolescents will transmit data and interact with the health care team, and with what level of family involvement, to protect confidentiality and support a proactive health care transition into adulthood.

RPM Reimbursement and Billing

A direct mechanism to provide financial reimbursement has not been available for RPM in traditional fee-for-service payment models. Evaluation and management codes for RPM were included in the 2018 Centers for Medicare and Medicaid Services fee schedule[56] and have been updated in subsequent years[57] to include payment for the first 20 minutes plus a potential additional 20 minutes with reimbursement codes 99457 and 99458. These codes present an opportunity for clinicians to be reimbursed for the time and expertise required to manage chronic disease proactively. Despite this step forward, RPM codes are not always accompanied by actual reimbursement, especially for patients with public coverage. Medicaid payment for these codes is on a state-by-state basis (see Table 2) and often covers specific conditions focused on adult populations, such as congestive heart failure or chronic obstructive pulmonary disease, which limits pediatric usage.

Without a mechanism for reimbursement for RPM services as they relate to predominantly pediatric health conditions, physicians, other health care providers, and health systems have yet to broadly invest in the technology, data requirements, and implementation costs to remotely monitor children and youth at home. Still, for CYSHCN in particular, RPM has potential to improve the care within a pediatric patient–centered medical home, regardless of direct reimbursement for RPM services.[58,59]

Value-based payment includes a range of strategies that emphasize cost-effectiveness to achieve the best possible outcomes with available resources.[60] Among these strategies are accountable care organizations that may take full financial risk for their patients' outcomes and are inherently incentivized to innovate care models. RPM has a natural role within value-based payment models that reimburse for the overall care delivered to a patient rather than focusing on face-to-face care alone. Reviews of studies that evaluate cost reveal proven and potential benefit across a range of conditions, primarily due to decreased travel (family cost) and face-to-face time (health care cost).[9,61] Future payment models could include RPM as part of a package of care to better engage patients and families of CYSHCN in chronic care management tied to existing guideline-based quality and outcomes. We recommend that cost models take a societal perspective to fully capture the value of pediatric telehealth services among all involved parties, including patients, families, health systems, and payers.[62]

We recognize that payers may express concern for fraud and abuse with new RPM programs, particularly in respect to fraudulent data capture or overuse. False data entry into the platform or device sharing should be proactively addressed with built-in checks and secure authentication. However, increasing the availability of timely care, particularly for underresourced populations, has been shown to reduce long-term costs.[63] To fully realize value-based care, more research and guidance are needed to determine which PGHD within RPM programs are effective at improving child health outcomes. Building an evidence base will help ensure widespread adoption of RPM in pediatrics.

Health Equity

Disparities in pediatric health care stem from numerous causes, including geography, educational and socioeconomic factors, access to adequate health insurance, structural racism, and physical and language barriers.[64,65] The rapid implementation of new technologies raises concerns for a digital divide in telehealth, particularly around access to devices, access to high-speed Internet, and the availability of software platforms in languages other than English. RPM program developers should consider diverse patient populations with varied barriers to care to avoid widening current health inequities through divergent adoption in research, dissemination, and quality improvement efforts.[66,67] RPM programs should be designed to accommodate populations with low health literacy and numeracy, with language preferences in mind.[68,69]

Equitable access to digital technology, specifically to the Internet, is a barrier to address. Whereas ~80% of American households, including urban racial and ethnic minority communities,[70–72] currently have access to a smart phone,[73] the remaining 20% may experience barriers to participation in smart phone–based programs. Therefore, federal and state RPM policies should support and/or subsidize access to affordable, if not free, devices and data services (ie, Wi-Fi access and/or data streaming) for patients and families meeting designated household income or medical need–based eligibility criteria.

CONCLUSIONS

RPM has the potential to revolutionize management of pediatric chronic conditions through capture of PGHD in the settings where children spend most of their time: at home and in the community. Health care is amid a digital transformation, underscoring the need for integrated models of pediatric care as we shift away from in-office, episodic care to more continuous care in the home. More clinical and health services research will be needed to identify how RPM can optimally provide effective, high-quality, equitable, and patient- and family-centered care across different clinical conditions and practice settings. To achieve this, adequate payment by private and public payers will be needed for sufficient implementation, sustainability, and scalability to reach broad populations equitably. Through RPM, we can reinforce and enhance continuity of care within the medical home and shape the future of value-based care to achieve the best possible health outcomes for all children, especially those with special health care needs.

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ABBREVIATIONS

CGM	continuous glucose monitoring
CYSHCN	children and youth with special health care needs
PGHD	patient-generated health data
RPM	remote patient monitoring

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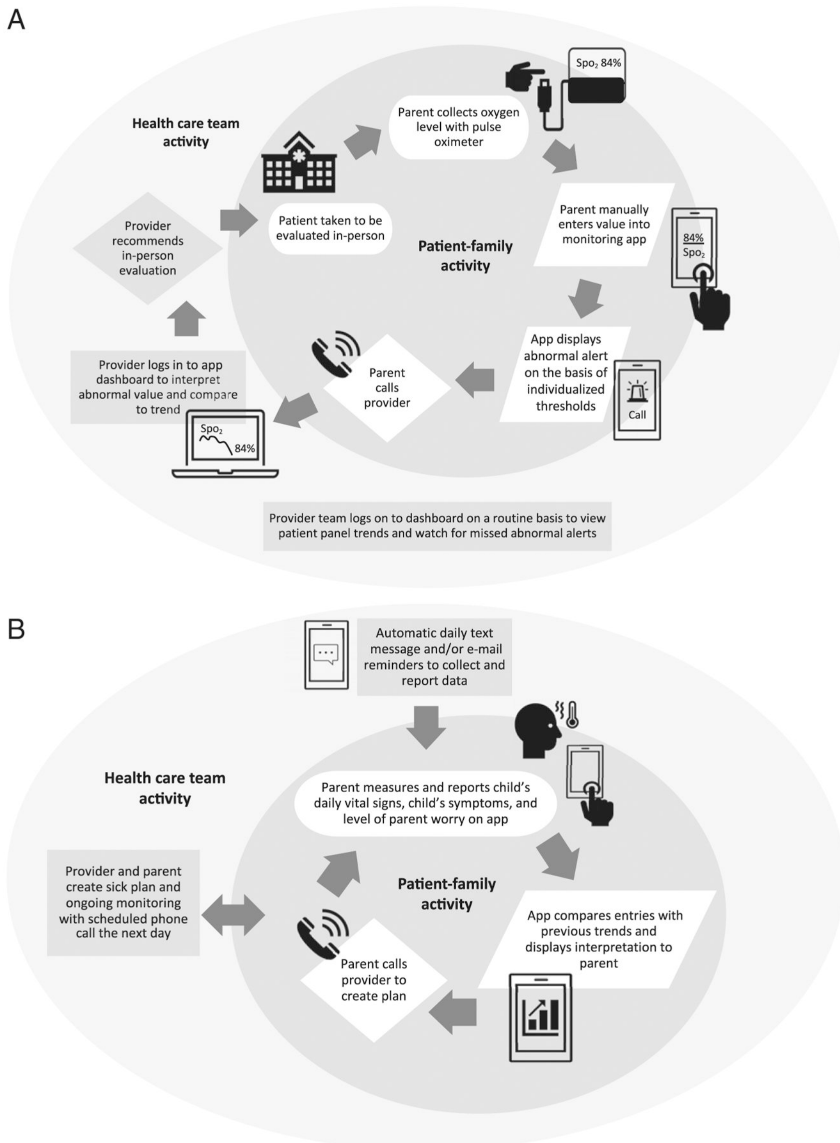
A
Health care team activity
Parent collects oxygen level with pulse oximeter
Spo2 84%
Patient taken to be evaluated in-person
Parent manually enters value into monitoring app
84% Spo2
Patient-family activity
Provider recommends in-person evaluation
App displays abnormal alert on the basis of individualized thresholds
Call
Parent calls provider
Provider logs in to app dashboard to interpret abnormal value and compare to trend
Spo2 84%
Provider team logs on to dashboard on a routine basis to view patient panel trends and watch for missed abnormal alerts
B
Automatic daily text message and/or e-mail reminders to collect and report data
Health care team activity
Parent measures and reports child's daily vital signs, child's symptoms, and level of parent worry on app
Provider and parent create sick plan and ongoing monitoring with scheduled phone call the next day
Patient-family activity
App compares entries with previous trends and displays interpretation to parent
Parent calls provider to create plan

C

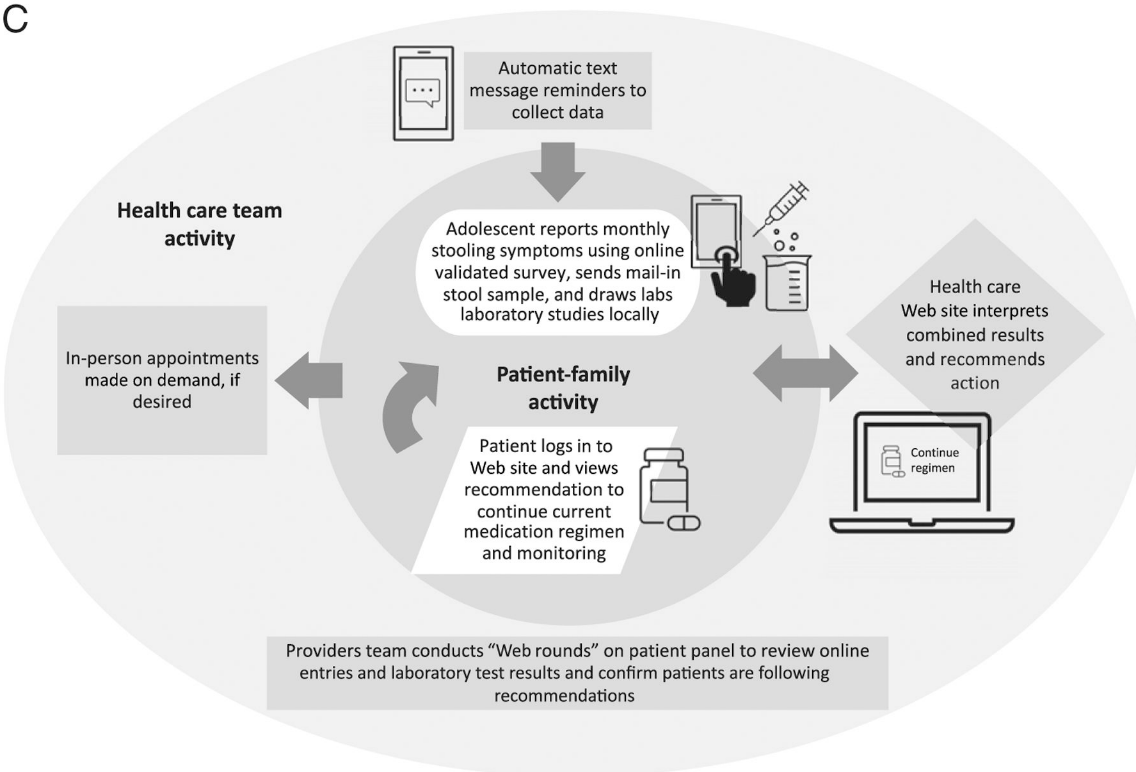

FIGURE 1.

Examples of the flow of PGHD and family-generated health data in a pediatric RPM program. PGHD can flow through a remote monitoring system in different ways via assorted automated processes. This figure provides 3 different examples adapted from published literature to illustrate how remote monitoring systems can support management of chronic conditions in children. Health care team (provider) and patient-family activities are shown in separate circles connected by arrows to show how each user's role supports remote monitoring. A, Parental monitoring in an infant with congenital heart disease discharged from the hospital after surgery. Postdischarge parental monitoring of an infant with congenital heart disease identifies low oxygen saturation (SpO_2), which leads to an escalation of care. B, Parent vital sign and symptom monitoring in a child with medical complexity to identify early health deterioration. The parent identifies new-onset fever and decreased fluid intake, but the patient is otherwise well. The provider and parent develop a sick-day plan and continue monitoring with a scheduled follow-up call the next day. C, Symptom and laboratory monitoring for chronic care management in an adolescent with inflammatory bowel disease. The adolescent with well controlled inflammatory bowel disease provides monthly symptom information and laboratory studies. The health care team recommends maintaining the current medication regimen and ongoing monitoring.

TABLE 1

Considerations When Adopting a Remote Monitoring Program Into Practice

Domain	Ways Monitoring Systems May Vary	Additional Considerations
Data type		
Objective data	Direct count (eg, respiratory rate)	Ability for information to be trended over time
	Device collection based (eg, scale-measured wt)	Accuracy and precision of objective values measured at home
Subjective data (constructs):	Patient-reported outcome measures (eg, asthma control measures; depression or anxiety scores)	Availability of validated instrument for subjective constructs can be scored with a value that can be trended over time
	Diary entries (eg, nutrition)	
Data collection and processes		
Passive (automatic)	Device measures, collects, and displays data directly (eg, activity watch)	Frequency of data collection relative to anticipated changes in patient's condition and/or needs
	Device collect and transfers data for display (eg, Bluetooth-enabled scale for wt)	Convenience of data collection within patient and family routine
Active (manual)	Device only measures data (eg, digital wt scale)	Adherence of patient and family to data entry
	Device measures and enters but does not display	Literacy with technology and numeracy by patient and family
		Privacy and other data protection standards (eg, dual factor authentication)
Device characteristics		
Hardware	Data measurement tool (eg, glucose monitor, pulse oximeter)	Reliability, precision, and cost of device and software
	Attachments (eg, strips, adhesive sensor)	Integration of data measurement with display software
	Data entry or display device, if applicable (eg, tablet)	Option for abnormal data alarm management in software
Software	Platforms or apps for the data collection, entry, transfer, display, and action	Integration of software with electronic health record or other apps
		Connection of device and software with cellular data or Wi-Fi
User roles		
Patient and family	Role(s) in training, collection, entry, transfer, interpretation, and action	Clearly defined roles and responsibilities of each user type
Providers	Role(s) in training, transfer, interpretation, and action	Education and training in use and roles
Health system	Role in setting agreements with third-party vendors on health data privacy and security	Data accessibility (ie, viewing rights), including for adolescent patients
		Integration of RPM care into existing workflows

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TABLE 2

Available Resources for Adopting Remote Monitoring into Practice

Source	Sample Information	Link
American Academy of Pediatrics	Practice management support, including approaches for minimizing barriers to telehealth care	https://www.aap.org/en/practice-management/care-delivery-approaches/telehealth/
American College of Physicians	Technology guidance, regulation and waiver information, billing and coding, education module(s), virtual technology hub information	https://www.acponline.org/practice-resources/business-resources/telehealth/remote-patient-monitoring
American Medical Association	Digital health playbook for implementing digital health technology into practice that includes guidance on workflows, care team engagement, and scaling	https://www.ama-assn.org/system/files/2018-12/digital-health-implementation-playbook.pdf
Center for Connected Health Policy	Medicaid and Medicare regulatory and reimbursement policies, organized by federal and state-level information as applicable	https://www.cchpca.org/topic/remote-patient-monitoring/
National Consortium of Telehealth Resource Centers	Remote Patent Monitoring Toolkit with information on preimplementation, program planning, installation and testing, and outcome evaluation	https://telehealthresourcecenter.org/resources/remote-patient-monitoring-toolkit/
Digital Medicine Society	Quick start guide and playbook for design and implementation by clinicians, researchers, and public health officials that includes guided checklists accompanied by reference materials and worksheets	https://playbook.dimesociety.org/playbooks/the-playbook/