

Original Scholarship

An Adaptive, Contextual, Technology-Aided Support (ACTS) System for Chronic Illness Self-Management

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Policy Points:

- Fundamental changes are needed in how complex chronic illness conditions are conceptualized and managed.
- Health management plans for chronic illness need to be integrated, adaptive, contextual, technology aided, patient driven, and designed to address the multilevel social environment of patients' lives.
- Such primary care–based health management plans are feasible today but will be even more effective and sustainable if supported by systems thinking, technological advances, and policies that create and reinforce home, work, and health care collaborations.

Context: The current health care system is failing patients with chronic illness, especially those with complex comorbid conditions and social determinants of health challenges. The current system combined with unsustainable health care costs, lack of support for primary care in the United States, and aging demographics create a frightening probable future.

Methods: Recent developments, including integrated behavioral health, community resources to address social determinants, population health infrastructure, patient-centered digital-health self-management support, and complexity science have the potential to help address these alarming trends. This article describes, first, the opportunity to integrate these trends and, second, a proposal for an integrated, patient-directed, adaptive, contextual, and technology-aided

support (ACTS) system, based on a patient's life context and home/primary care/work-setting "support triangle."

Findings: None of these encouraging trends is a panacea, and although most have been described previously, they have not been integrated. Here we discuss an example of integration using these components and how our proposed model (termed My Own Health Report) can be applied, along with its strengths, limitations, implications, and opportunities for practice, policy, and research.

Conclusions: This ACTS system builds on and extends the current chronic illness management approaches. It is feasible today and can produce even more dramatic improvements in the future.

Keywords: chronic illness care, primary care, complex adaptive systems, context, technology, self-management.

CHRONIC DISEASES ARE COMMON (TWO-THIRDS OF OLDER Americans have two or more), *expensive* (account for two-thirds of US health care expenditures), and *lethal* (responsible for more than two-thirds of deaths in America today).¹⁻⁵ Most chronic illnesses are addressed at some stage in primary care, which has limited resources and support to care for the affected patients. Advances in the conceptualization, structure, and operation of primary care, along with advances from other disciplines, form the basis for a breakthrough in the quality and effectiveness of care for people with chronic illnesses.⁶⁻¹³ This article (1) summarizes several advances in the care of patients with chronic illnesses;⁸⁻¹² (2) shows how these advances can be integrated into a more effective system of care that we call the Adaptive, Contextual, Technology-Aided Support (ACTS) System for Chronic Illness Self-Management; (3) illustrates this system in a real-world example; and (4) discusses the implications of and directions for this proposed approach.

Six Significant Advances

Chronic Disease Management

The Chronic Care Model (CCM), developed by Wagner and colleagues,¹⁴ enjoys widespread adoption and has been both validated and updated since its original formulation into an expanded CCM with a greater focus on community policies and resources.¹⁵ It applies a number of components, including disease registries, team-based care, self-management

support, deeper patient-clinician interaction, decision support, and other changes to traditional care.¹⁶⁻¹⁹ Our ACTS system builds on and expands the influential CCM.^{19,20}

Person-Oriented Care Over Disease-Oriented Care. Many patients, and most elderly patients, have multiple chronic illnesses,¹⁻³ and tackling these one disease at a time quickly becomes counterproductive. Primary care is grounded in patient-oriented or person-centered, rather than disease-oriented, care.⁶⁻⁸ This formulation of a personal care plan that includes all chronic diseases as well as health priorities, preferences, experiences, fears, motivation, and other concerns provides more comprehensive care. This emphasis on more patient-centered care is illustrated by the establishment of patient-centered medical homes,²¹ a specific example being the Program of All-Inclusive Care for the Elderly.^{22,23}

Integrated Behavioral Health With Primary Care. There is increasing evidence that integrating the treatment of mental, emotional, and behavioral health needs into primary care results in better health outcomes, higher-quality care, more satisfied patients, and a more rewarding practice,^{24,25} and it is feasible in many primary care settings.^{8,9}

Social Determinants of Health and Disease. It is well established that social factors affect health to a greater extent than clinical factors do,²⁶⁻²⁹ but in the past few years we have begun to see models of comprehensive care that include actionable approaches to addressing the social determinants of health.³⁰⁻³³

Advances in Digital Technology. Beyond the electronic health record (EHR), we are beginning to benefit from wearable biosensors, telemonitoring, patient-directed self-management, and behavior-change apps, as well as the integration of genetic, medical, social, environmental, and behavioral data into “big data sets” that aid individual and population health.¹⁰⁻¹³

Complexity Science. Primary care is increasingly being understood as a complex, adaptive system, bringing into focus the ever-changing nature of the clinical setting, the importance of the dynamic context in which patients live, and the need for adaptability to improve health.^{13,34}

A New Management Support System

Our proposed ACTS system rests on a platform of advanced primary care and integrates the advances just described. Table 1 summarizes the key

Table 1. Characteristics and Key Components of ACTS Health Management Plans: What Is Possible for Chronic Illness Care and Likely Challenges to ACTS Implementation

Characteristics	What Is Possible Today	Barriers and Challenges to ACTS Implementation
<i>Adaptive</i>	<ul style="list-style-type: none"> ● Action plans are often adjusted based on patient progress during clinic visits and objective clinical lab data collected during/between visits. In addition, plans are sometimes updated between clinic visits based on phone calls or asynchronous online narrative communications between patients and clinic team. ● Although biometric technology that is increasingly being tracked by patients can be integrated with the electronic health record (EHR) (eg, wearable pedometers, downloadable blood pressure cuffs, glucometers, and scales), patients' actual upload/integration of biometric data to clinic usually lags behind the system's capacities 	<ul style="list-style-type: none"> ● Burnout for clinicians is highly prevalent and rising—the ACTS system must be implemented with care team support so as to not overburden clinicians. ● Lack of reimbursement for chronic disease management between visits has been a major barrier to asynchronous updates of care plans, but Medicare and other payers now provide reimbursement for clinicians' time spent between clinic visits. However, this new reimbursement also requires patients' copayments.

Continued

Table 1. *Continued*

Characteristics	What Is Possible Today	Barriers and Challenges to ACTS Implementation
<i>Contextual</i>	<ul style="list-style-type: none"> ● Pragmatic and actionable: Both patients’ report measures of key social determinants and geocoded data to identify high-risk neighborhoods are available. 	<ul style="list-style-type: none"> ● Not all contextual factors can be modified. ● Clinicians may feel contextual factors are outside their purview.
<i>Technology-Aided</i>	<ul style="list-style-type: none"> ● Some web- or app-based assessment and feedback portals and systems are being used. ● Emerging capacity for patient telemonitoring integration of biometric data with the EHR (eg, flowsheets of multiple raw data points not typically graphed or reportable as “percentage in target range”). ● Potential neighborhood community resources to assist patients are automatically printed following a clinic visit. 	<ul style="list-style-type: none"> ● When data are integrated with one type of EHR, that integration must currently be rebuilt, even in other health systems that use the same EHR. ● Third-party vendors that can simplify integration will be necessary for patient-level data to stream bidirectionally with EHRs in a digestible fashion.

Continued

Table 1. *Continued*

Characteristics	What Is Possible Today	Barriers and Challenges to ACTS Implementation
<i>Integrated, Patient-Directed</i>	<ul style="list-style-type: none"> ● Goals are based on patients' values and preferences elicited during clinic visits and draw on a therapeutic rapport between clinicians and patients. ● Whole person-focused, cross-disease and cross-provider plans consider all of a patient's illnesses, and treatments. 	<ul style="list-style-type: none"> ● There is limited time for clinicians to spend with patients to develop this highly personalized care plan, and this will likely require the use of care managers, peer coaches, and/or patient portals as supplements in setting appropriate goals.
<i>Shared with Other Clinicians and/or Caregivers</i>	<ul style="list-style-type: none"> ● Goals and plans developed by a patient and a clinician are often documented in the clinician's notes to share with the larger health care team, and are sometimes shared by the patient with his/her family/caregivers 	<ul style="list-style-type: none"> ● EHRs' current care plan templates are not optimal or set up to facilitate sharing with others.
<i>Health Management</i>	<ul style="list-style-type: none"> ● Wellness-focused plans that integrate mental health and multiple conditions address both prevention and treatment. 	<ul style="list-style-type: none"> ● Care plans typically address one illness at a time for simplicity. User-centered design approaches are needed to identify methods to link plans for multiple illnesses.

Continued

Table 1. Continued

Characteristics	What Is Possible Today	Barriers and Challenges to ACTS Implementation
<i>Action Plan</i>	<ul style="list-style-type: none"> Integrates aforementioned inputs into a SMART,* goal-related action plan for key challenges. Despite the emerging capacity for health systems to prompt patients periodically between clinic visits to update these goals, it is incompletely utilized. 	<ul style="list-style-type: none"> Current care plans in EHRs are not agile. This type of plan will require investment by EHR companies in developing this functionality or in linking this feature to other mobile health vendors.

* SMART goals: specific, measurable, achievable, relevant, and timely.

features that produce an integrated, adaptive, contextual, technology-assisted, patient-directed, and shared health management action plan.

This system can accommodate multiple conditions and *integrate* input from the contextual factors that impact health. To be effective, the care plan must be *patient driven* and must adjust to individuals over time. Life, family, social, economic, and other factors are equally as important as the biomedical factors and can be addressed in rapid, adaptive ways via digital technologies (see Table 1).¹⁰⁻¹³ The care plan is developed through *shared health management* rather than self-management. Its success depends on the interaction of all the elements, and therefore failures cannot be blamed on the patient.

Rapid *adaptation* is made possible by its *technology-assisted* nature. For example, Tung and colleagues³⁵ loaded key community diabetes self-management resources and their locations into their EHR and programmed it to print resources specific to each patient’s zip code into

their after-visit plan. Gold and colleagues used a multidisciplinary team to add patient-reported outcomes to the EHR for both clinical and research use.³⁶ We used this enhanced clinical informatics capacity to incorporate relevant and dynamic local data from multiple sources into the care plan.

Support Triangle Influences

Figure 1 shows the “expanding” triangles surrounding a patient’s action plan. The inner triangle represents proximal or direct factors, and the outer triangle represents more distal contextual factors. Key inner triangle influences are (1) family and home (ie, daily life in which most of the work implementing an action plan occurs); (2) work, school, or volunteer life in which patients spend many hours each week; and (3) the primary health care team.

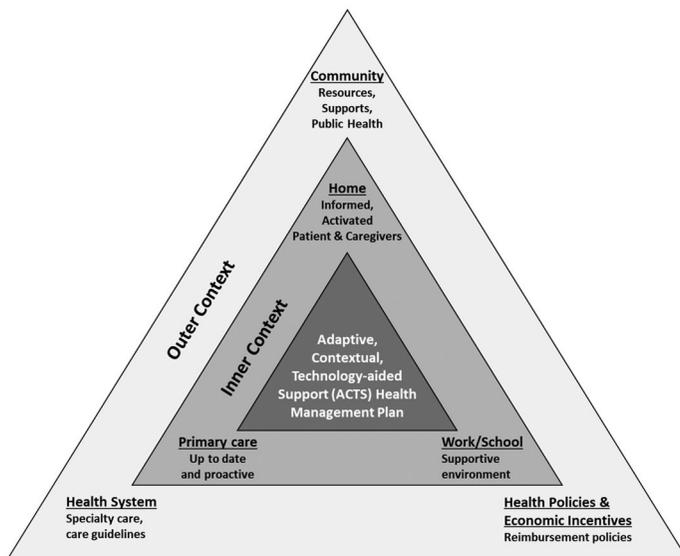
Home

Successful health management plans must consider home and family factors. Persons with chronic illnesses are not just patients but also life partners, parents, breadwinners, and caretakers, whose roles strongly affect their adherence to a medical regimen.²⁰ Even basic elements like taking medications risk failure if they do not address the patient’s schedules, resources, and competing demands. Strong data support the cost-effectiveness of follow-up^{37,38} during which a clinician can assess goal attainment and patient-reported data, download information from wearable devices, and discuss the plan with a family member, all of which help reinforce or adapt the plan as needed.^{11,12,37}

Work/School/Volunteer Environment

Many people with chronic illnesses work, volunteer, or attend school, and management plans should take this into consideration, as these people often need help understanding and negotiating work health benefits, coverages, flexibility, and accommodations. Some employers offer workplace prevention and support programs. Health privacy rules limit timely communication about a patient’s health information with his or her work or school, but shared management plans are already commonplace and patients can determine who receives what elements of their health information. For example, students with type 1 diabetes, seizure

Figure 1. Adaptive, Contextual Technology-Aided Support (ACTS) System



All elements must align with one another and adapt over time. Integrated, adaptive technology for self-management support is centered in the three key environments where patients need support: at home and work and in the health care setting. An adaptive action plan and effective technology lead to informed, activated patients and caregivers; an up-to-date proactive primary care team; and a supportive work/school/home environment. Collectively, ACTS ensures high, equitable reach, addresses key social-environmental influences, enables effective self-management, can be scaled to complex patients, and changes with context.

disorders, or asthma have detailed care plans that school nurses act on while the students are in school.

Primary Care

Even though most patients spend less than 0.5% of their time in contact with health professionals,³⁹ the primary care setting is central to care

management and patients' outcomes.^{40,41} The features of an effective primary care relationship⁴² include accessibility, longitudinality, patient centeredness, and comprehensiveness—a whole-person approach that takes into account the physical, mental, and social dimensions of health. Primary care is essential to integrating care and helping patients navigate the ever-more-complex health care environment and new treatments.

More Distal Factors

Each point of the outer triangle in Figure 1 represents a more distal influence that corresponds to one of the inner factors. Related to the home environment are extended families, friends, and other cultural and community resources. Outside the work factors are health insurance issues, wellness incentives, work-related policies, and other employer issues that may help or hinder a management plan. Outside primary care are care guidelines, specialty care, health policy, reimbursement, and other aspects of the health care system.⁴³

These more distal factors can aid, complicate, or compromise the action plan. For example, a work schedule may conflict with a health visit, or inadequate health insurance may make it difficult to purchase a medical device. Clinicians often consider these more distal determinants beyond their control or responsibility, and thus they do not address them. But this is a missed opportunity to better inform health management plans: Patients appreciate being asked about these issues and having their health care team more fully understand the context of their life.

While it may be difficult for clinicians to change these distal factors, having this information may help guide care. For example, a clinician may not be able to lift a patient out of poverty, but knowing about financial concerns may better inform care decisions and lead to a better understanding of a patient's circumstances.^{11,44,45} The clinician may also be able to advocate for these patients and inform them about local workplace and community programs that could help.

Interactions Among the Action Plan and Triangle Components

The intersection of these diverse points of influence on an individual's health produces a complex interactive process that informs the patient's

Table 2. Types of Data Exchange to Support ACTS Management Plans

Entities Exchanging Data	Types of Data That May Be Exchanged Currently	Method of Data Exchange
<i>Patient to Health Care Team</i>	<ul style="list-style-type: none"> ● Biomarker (eg, home blood pressure readings, home weight from scale) ● Wearable data (eg, physical activity steps) ● Patient-reported data (eg, PHQ-9) ● Usually only one health behavior from one device 	<ul style="list-style-type: none"> ● Typically conveyed when it is actionable: Automated data from sensors, patient-entered data or interactive phone responses ● Less actionable (perhaps): narrative data sent via patient portal
<i>Health Care Team to Patient</i>	Care management goals	<ul style="list-style-type: none"> ● End-of-visit summaries ● Patient EHR portals
<i>Patient to Employer/School</i>	Health risk appraisals	Written or computerized risk calculators
<i>Employer to Patient</i>	Provision of wellness and environmental health resources and policies	Written or online manuals on health policies, accommodations, and wellness programs
<i>Community to Patient</i>	Lists of services and supports	Written or online lists: often incomplete, outdated, inaccurate, or inappropriate
<i>Community to Health Care Team</i>	Information on resources for patients, population health data	Nonindividualized written or web-based reports from state health departments, and CDC, on geocoded data, etc.

action plan, as summarized in Table 2. Information flows bidirectionally between the patient and the different sources in the support triangle. The second column in Table 2 displays what is possible now. EHRs

and patient portals are continually advancing and can be engineered to handle these complex information flows.^{46,47} Today, many, stand-alone interactive applications have been developed, including those collecting and summarizing patient-reported data (eg, mental states) and information from sensors (eg, for physical activity, blood glucose).^{10-13,48} These technologies are rapidly evolving and can be used to provide community and workplace resources and to reinforce patient health management. Key types of information and resources that can be shared include health policies and accommodations, availability of and participation in wellness and patients' support activities, and incentives for behavior change efforts or health risk assessments. There are, however, real challenges to implementing these care elements, as listed in the right-hand column of Table 2. For example, likely challenges include clinician time limitations and lack of adequate reimbursement.

Case Example

We developed My Own Health Report (MOHR), an online system that integrates data from a health risk assessment and a digital health monitoring device into an EHR, and makes these data immediately available to patients and care teams.⁴⁸⁻⁵⁰ We have piloted this system for improving the care of patients with out-of-control type 2 diabetes. In a rigorous cluster randomized trial, we also demonstrated the feasibility and effectiveness of an earlier version (without the monitoring device) on changes in collaborative goal setting and health behavior among general primary care patients.⁴⁸ Table 3 shows how MOHR addresses many of the ACTS issues.

MOHR gives both patients and providers real-time information on patients' physical activity, healthy eating, stress, depression, anxiety, quality of life, smoking, risky drinking, drug use, and social determinants of health.^{49,50} It helps patients both establish individualized goals and determine which identified risk factors they want to address. MOHR is effective in enhancing collaborative goal setting, improving short-term behavior changes, producing high reach (patient participation), and it is feasible for use in a variety of low-resource primary care settings and diverse populations.^{48,50} Nonetheless, MOHR still took more time than typically available for preventive care and was not sustained once research support was withdrawn.⁵¹ A qualitative

Table 3. Key Elements of Adaptive, Contextual, Technology-Aided, Support (ACTS) System Featuring Patient-Directed, Shared Health Management Action Plan Aspects of My Own Health Report (MOHR)

Issue	How MOHR Addresses This Issue
<i>Integrated</i>	Provides feedback on 11 different health risks and helps patients prioritize issues and set goals.
<i>Adaptive</i>	Ongoing assessment, feedback, and summary report shows current status and goals and is dynamic and customized for patient and clinic.
<i>Contextual</i>	Includes and addresses issues from perspective of the patient’s “support triangle” and social determinants of health.
<i>Technology-Aided</i>	Web-based platform that provides real-time feedback to the patient and health care team and is integrated with Epic EHR.
<i>Patient-Directed</i>	Patient preferences are explicitly assessed, incorporated, and reported to health care team.
<i>Shared Support</i>	At minimum, shared with patient and health care team, but patient may also choose to share it with family and/or employer.
<i>Health Management</i>	Comprehensive, whole-person care, focused on wellness and broadly addressing health, including numerous health behaviors, mental health, and social determinants of health.
<i>Action Plan</i>	SMART goals and strategies.

MOHR: My Own Health Report (myownhealthreport.org); SMART goals: specific, measurable, achievable, relevant, time-bound.

study identified practice capacity, information system capability, and community linkages as issues related to successful implementation of MOHR.⁵¹

Presently we are using MOHR with a clinic care manager who coordinates care with diabetes patients regarding their glucose readings and health risks until glycemic control is attained. The newer MOHR system can be adapted to a greater variety of settings, and we are developing dashboards and alerts tailored to individual patients as their status and needs change. MOHR is just an example. It does not contain all aspects of the ACTS system (Table 3), and a growing number of digital health technologies⁵² can provide support for triangle functions.

Discussion

This article arose because chronic medical conditions are now dominating the health and health care landscape. These conditions are ubiquitous, expensive, and disabling.¹⁻³ Many people have multiple conditions, which interact in ways that require creative, adaptive, and personalized solutions. They are caused, exacerbated, and, in some instances, alleviated by social circumstances.^{26-30,53,54} For this article, we integrated advances in several areas into a new, coherent approach to managing chronic health conditions that holds the promise of dramatically more effective care.

Our ACTS system produces an integrated, adaptive, contextual, technology-assisted, patient-directed, and shared health management action plan. It is based on a platform of advanced primary care that incorporates principles of chronic disease management (including team-based care and action plans), whole-person-centered care, modern digital technology, and systems thinking (including attention to the larger context, unintended consequences, and social determinants of health). Many primary care practices should be able to begin using many elements of this approach now, as well as plan for more comprehensive future versions.

Our preliminary results suggest that this approach is both feasible and effective.⁴⁸⁻⁵⁰ Although its further use will likely discover unanticipated difficulties, it may also find better implementation strategies. Nevertheless, this system works today. It uses adaptation principles⁵⁵ and therefore should become easier to use and more effective over time. Finally, it makes use of home, community, and employer resources, which have been grossly underutilized.

Implications

ACTS has several “action principles” for planning, implementing, and sustaining success. First, a health management plan needs to be iterative, as it is unlikely to work as initially designed. Because it is impossible to anticipate all the relevant contextual factors and their interactions, close monitoring and frequent adjustment should be routine. Second, implementing an integrated, adaptive, contextual, and technology-assisted plan is a systems issue, with complex system influences and impacts, including unexpected results.^{56,57}

Third, it has been increasingly well documented that multicomponent policies and coordinated resources, as illustrated in Figure 1, drive the long-term success of action plans. For example, cigarette taxes, clean indoor air policies, accessible and affordable cessation assistance, primary care assessment and medication, and referral to smoking quit lines all combined to support individual plans and lower population smoking rates. Fourth, although the advent of precision health^{34,58,59} changes some aspects of the management plan, it will not fundamentally alter its key components. Precision health will provide more individualized information, conveyed primarily through the specialty-to-primary care-to-patient pathway. This means that more decisions may involve multiple clinicians.

Finally, the most important implication is the need for strong connections, communication, and coordination across all sectors of the support triangle. Currently, such coordination is limited and inconsistent. Responsibility for the alignment across sectors into an integrated plan is essential and cannot rest solely on the patient but must also include the health care team, workplace, family, community, and health policy leaders and organizations.

Limitations

Introducing even minor changes into a busy primary care practice risks breaking the workflow. This risk is magnified when the intervention is complex.^{5,9} ACTS thus may not be suitable for practices that have not become patient-centered health homes. But for practices already moving along this path, the improvements described are manageable, particularly if they are introduced sequentially. Some persons will claim that other models of care already use these strategies. This is true of individual or pairs of ACTS elements, and our system definitely builds on the important foundational work with the Chronic Care Model and its variants, as well as integrated care innovations.^{19,20} But this combination of multiple treatment vectors, the ACTS emphasis on rapidly available and multilevel contextual information (the support triangle), and adaptation strategies⁵⁵ have not been previously integrated in this way.

ACTS shifts the locus of initiative from the clinician and the clinic to the patient and his or her triangle of influences and thus may seem

less grounded in clinic operations. The patient initiates critical actions in his or her unique environment where the most salient variables are in play.³⁹ There is, however, still a critical role for the clinician and clinic in this model. The health care team and the patient together integrate the elements and create the action plan. A copy of this plan lives in the EHR where the health care team keeps it current and monitors and adjusts those parts in their purview. In other words, the clinician and the health care team have a full complement of responsibilities, and even though these have changed somewhat, they still fall within comprehensive primary care.^{25,42} It is also possible that ACTS could unintentionally produce negative outcomes or exacerbate health inequities. For example, several studies of patient-centered medical homes have not produced positive outcomes in terms of their impact on patients' experiences or outcomes.³⁰⁻³³ Finally, identifying social determinants of health challenges may prove frustrating or make either or both patients and clinicians feel worse if they cannot be successfully acted upon.

Future Directions

Even though the ACTS system has conceptual appeal, it has received only limited real-world testing. It needs to be further operationalized and evaluated in a variety of settings with a variety of patients. It is also possible that not all components are necessary; and cost estimates, cost effectiveness, and comparative effectiveness research on different levels and intensity of ACTS programs need to be conducted.⁶⁰ We need and expect to find more efficient and effective ways to implement ACTS. Technology will continue to change quickly, which will bring both opportunities and challenges. Providers in our MOHR example found that this "whole person perspective" program resulted in freeing up more time to counsel patients. The costs of conducting MOHR assessments, feedback, and counseling were partially compensated by reimbursement for Medicare annual wellness visits for appropriate patients, but the reimbursement did not fully cover the costs of the time devoted to MOHR. Future applications of ACTS will need to be more efficient, possibly through greater use of care managers or lower-paid staff for conducting counseling and follow-up. Greater use of user-friendly, patient-centered digital technologies may also be able to enhance the efficiency of implementing ACTS solutions. On a practical implementation note, clinic

care managers may be particularly well suited to coordinate communications among clinics, different specialties, patients, and work and school environments.

Learning collaboratives and learning communities have proved to be extremely valuable to chronic illness–care programs,^{61–63} and we expect that these networks of practices will improve ACTS even more. Finally, a number of financial and policy issues are necessary to support a full, seamless implementation of any model of health management. Policy research and actual policy changes may be required to enable widespread implementation and sustainment.

Conclusions

The prospect of patients actively and competently taking responsibility for their own health and the management of their own chronic conditions has been an aspiration just out of our reach for more than two decades.¹⁵ With recent progress in chronic disease management, patient-centered care, systems science, health technologies, and advanced primary care platforms, this aspiration is now within our reach. In this article, we proposed a means by which these elements can be integrated into a coherent management system that offers a real possibility for dramatic improvements in health care and population health.

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