Genetics inMedicine | COMMENTARY



# What is the role of clinical genetics in the patient-centered medical home?: A commentary from the Medical Home Workgroup of the Heartland Regional Genetics and Newborn Screening Collaborative

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Much has been written about the patient-centered medical home (PCMH). In general, the focus of the PCMH has been on primary care; the center of patient services resides with a health-care provider (person or practice) that coordinates all patient-related activities. To date, however, relatively little has been written about the role of clinical genetic services in association with the PCMH. The purpose of this commentary is to focus on several aspects of the PCMH as it relates to clinical genetics. We explore specifics related to genetics—as compared with other specialties—and try and answer the question "What is the role of the medical geneticist in the PCMH?"

## THE PCMH: BACKGROUND

The American Academy of Pediatrics introduced the medical home concept in 1967 (ref. 1). The term initially referred to a central location for archiving a child's medical record. Later the medical home moved away from the idea of a single locus for care to one that is patient-centered, that is, focused on providing health services designed for an individual patient. Likewise, the medical home concept has been expanded to all ages of patients, including adult and geriatric patients.

The seven joint principles of the PCMH are:

- Personal physician
- Physician-directed medical practice
- Whole-person-oriented care, with patient engagement in his or her own care
- Care coordination and/or integration with clinical information systems that support high-quality care coordination
- Quality and safety
- Enhanced (superb) access to care
- The payment system supports the model

In addition, it is understood that PCMH activities must address the concepts of family-centered partnerships, community-based systems, and transitional care from pediatric to adult services.[2,3]

An important question is "Why have a PCMH?" The medical home was first conceptualized because it was recognized that children with special health-care needs would benefit from a delivery model that effectively coordinated the complex clinical and social services that many patients require. Studies indicate that patients who have a PCMH have a 20% decrease in hospitalizations and a 12% reduction in readmission rate. As a result, states will experience decreased per-capita costs. Also, the lack of a PCMH decreases the likelihood of receiving appropriate health maintenance.[4]

Although the role of the primary-care provider (PCP) is clearly outlined in the PCMH, it has been our observation that comparable consensus does not exist for the role of the specialist. Various types of clinical roles that a specialist can assume have been suggested, including cognitive consultation, procedural consultation, comanager with shared care, or comanager with principal care. However, concerns regarding the primary care–specialty care interface include lack of care coordination, lapses in communication between the PCP and specialists, duplicate diagnostic tests, and ambiguity regarding duties and responsibilities. In health care, specialists have traditionally operated almost autonomously. In the context of specialists providing care outside of the PCMH, they may be more likely to order tests and procedures that do not consistently result in improved clinical outcomes. An example of these dynamics is that 1 in 40 PCP visits leads to a referral to specialist.[5] In this context clinical geneticists would indeed be considered "specialists."[5,6]

To improve the PCP–specialist interface through strengthening the primary-care structure, the concept of the medical home neighbor (PCMH-N) was developed. According to the American College of Physicians, the clinical interactions between a PCMH and a PCMH-N can take the following forms[7]:

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- Preconsultation exchange, intended to expedite/prioritize care or clarify need for a referral
- Formal consultation to deal with a discrete question/procedure
- Comanagement
- Comanagement with shared management for the disease
- Comanagement with principal care for the disease
- Comanagement with principal care of a patient for a consuming illness for a limited period
- Transfer of a patient to a specialty PCMH for the entirety of care

The development of the PCMH-N as a cooperative effort between specialists and PCPs has led to the championing of innovations aimed at strengthening primary care. These innovations include telemedicine, integration of primary and specialty care, decision support, and electronic referral.

## THE ROLE OF THE MEDICAL GENETICIST IN THE PCMH

As detailed above, the PCMH is a concept that has been embraced by a myriad of professional organizations. Not surprisingly, then, there exist multiple variations as to the definition, the scope, the participants and their roles, and the focus of the PCMH. Several important questions continue to be debated, such as "Who can be the medical home?," "Who can serve in the role of a primary-care provider?," and "What is the role of specialists/subspecialists?" In this light, we have carefully considered one major question: what is the role of the medical genetics team (clinical geneticists, genetic counselors, etc.) in the PCMH?

The relationship of the interaction between the PCMH and the PCMH-N defined above seems to be consistent across all specialties. However, the question of whether the specialty of genetics may be a bit unique has been raised. In general, individual genetic conditions are rare. They are often diagnosed during childhood but require lifelong management. Because of the frequency of required genetics clinic appointments, a tight bond often develops between the family and the geneticist. Biochemical crises may result in emergency room visits and inpatient stays. In these cases it is often the geneticist who is consulted for management recommendations. Some genetic syndromes require close surveillance and serial laboratory tests or imaging. These conditions are more similar to the most complex and chronic conditions followed by other specialists. In genetics, however, almost all of the patients meet most of these criteria. Therefore, based on the nature of the specialty, geneticists may have a different role related to the PCMH than that of a "typical" specialty.

The Medical Home subcommittee of the Heartland Genetics Services Collaborative has actively addressed this issue. During this process, we have discovered that—not surprisingly—the answer to this question varies from practice to practice. Even within practices the answer is typically modified for each family. For the past 2 years, we have tried to identify possible roles that geneticists might play in a PCMH. We did this by soliciting the experience of our group via scheduled conference calls and by extracting information from national workshops on genetics in the PCMH. We have sought to validate this collective list by sending surveys and performing one-on-one interviews across the Heartland region with geneticists, genetic counselors, primary-care physicians, and patients/parents. We continue to collect this information, but to date we have received information from over 50 respondents. In doing so we have identified at least seven roles that different clinical genetic practices report as the way in which their practice interfaces with PCMHs:

1. No role or interface—in particular, some families did not see the geneticist as being a partner in the PCMH
2. PCMH-N—as defined above
3. The geneticist as the medical home—under certain circumstances (especially metabolic conditions) PCPs may sometimes "turn over" the entire care of the patient, including health-care maintenance, to the specialist
4. Educator of the PCP—in this setting the specialist does not provide actual care but provides information to the PCPs to allow them to deliver the care in an informed manner
5. Consultant/provider of quaternary care—in the traditional role of consultant, some specialists simply evaluate the patient and provide recommendations without any role in implementation of the care plan
6. Comanager of the medical home—there can be negotiations where the PCP and the specialist essentially divide up the work, with each being responsible for their own part, without much direct interaction and coordination
7. Supporter of a family-directed "PCMH"—particularly for highly mobile families (e.g., military families), the families may themselves subsume much of the role of the PCMH as they transition from place to place, taking the information—and even the medical records—with them wherever they go

(For a more detailed description of these roles that a clinical geneticist may play in the PCMH, the reader is referred to a companion article at http://www.heartlandcollaborative.org/work-groups/clinical-services/role-geneticist-medical-home.)

So which of these is the correct role? What is the best way for a geneticist to interface with the PCMH? Clearly the role of "medical home neighbor" seems to work well for many specialist– PCMH relationships and is one strong consideration. Still, in the realm of education, it has been understood for a long time that one size does not fit all. The need for clinical genetic services is likely to be strikingly different for a military family who is making multiple moves across the world compared with a family that has been living in the same remote part of the Heartland for generations.

The concept and process of the individualized education plan are based on the straightforward understanding that no

two people learn in the exact same manner. When identifying the best strategy to educate a child with special needs, the plan must be tailored to that child. We have concluded that this same principle can be successfully applied in defining the role of the geneticist in the PCMH. We agree that the traditional model of the PCMH and the role of the geneticist as an active PCMH-N may be the ideal. Still, this model simply cannot be applied in all cases. We have identified multiple models that different geneticists utilize. None will be necessarily right or wrong in all situations. In addition, some situations might seem best in theory but may be difficult to implement in actual practice.

Thus the best answer to the question "What is the role of the geneticist in the PCMH?" seems to be "Work with the PCMH in whatever role works best for the patient." Medical geneticists then need to be cognizant of the PCMH, the patient/family, and their own specific role for each individual case.[8] While this answer may seem a little oversimplified, it truly is the best framework in which to establish the optimal working relationship for patients and their families. In discussions that we have had with PCPs and patients, the most common suggestion is improved communication. In the multilayered discussions that happen between the patient, their PCP, and the geneticist, targeted discussions in which the role that the geneticist will play is formally discussed seldom occur. Perhaps simply asking the question among the three groups with joint decision making will lead to more personalized (and presumably better) care for the patient. Our workgroup is currently working on a project to obtain information from all stakeholders to identify the best strategies to accomplish this.

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## DISCLOSURE

The authors declare no conflict of interest.

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