ROLE OF CLINICAL GENETICS IN THE PATIENT-CENTERED MEDICAL HOME

A Concept Paper from the Medical Home Workgroup of the Heartlands Regional Genetics and Newborn Screening Collaborative

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INTRODUCTION

Why a ‘White paper’? At this point much has been written about the Patient Centered Medical Home (PCMH). While there is still much work to be accomplished in the advancement of the PCMH, the concept and the movement are well engrained into the fiber of the practice of medicine in the United States. In general, the focus of the PCMH has been on Primary Care; the center of patient services residing with a health care provider (person or practice) that coordinates all patient-related activities. Still, the best patient care may go beyond primary services. Some patients need specialized services that may include tertiary care providers; for many, quaternary integrated multi-disciplinary services are required. Recent years have seen several seminal works published that address the role and interface of specialty care with the PCMH. From these, concepts such as the ‘Medical Home Neighbor’ have emerged. To date, however, relatively little has been written about the role of clinical genetic services in collaboration with the PCMH.

The purpose of this manuscript is to focus on several aspects of the PCMH as it relates to clinical genetics - and clinical genetics in the Heartland regions in particular. We will explore specifics related to genetics – as compared to other specialties and try and answer the question: “What is the role of the medical geneticist in the PCMH?” Likewise we will consider the unique setting of these principles as applied to the eight states of the Heartlands Regional Genetics and Newborn Screening Collaborative (henceforth referred to as ‘The Heartlands’). As with all such initiatives, the ultimate goal is the best health outcomes for the patients and their family.

The Heartland Regional Genetics Services Collaborative

The ‘Heartland Region’ is comprised of the eight states of Arkansas, Iowa, Kansas, Missouri, North Dakota, Nebraska, Oklahoma, and South Dakota: this group corresponds to Health Resources and Services Administration (HRSA) Region 5 for the purposes of the Regional Genetics Services Collaboratives. In 2004, HRSA awarded grants to establish seven Genetic Service and Newborn Screening Regional Collaborative Groups and a National Coordinating Center (NCC) to develop regional approaches to address the mal-distribution of genetic resources. The Heartland Genetics Services Collaborative (formerly, the Heartland Genetics and Newborn Screening Collaborative) is focused on ensuring the best possible outcome for individuals with heritable disorders and optimizing the health of the population throughout the life cycle by improving understanding and awareness of genetics; expanding access to health care; and translating new findings to improve the quality of care within an eight-state region.

Characteristics of the Heartland region are important factors in considering the role of the medical geneticist in the PCMH. First, the Heartland is a large geographic region that is sparsely populated with an average population density of 41 persons per square mile, as compared to the U.S. average of 88 persons per square mile in 2010.¹ There are 1,774,603 square miles of frontier county in the United States and 31% of this land is located in the eight-state Heartland Region.² 1.8% of the entire Unites States population lives in a frontier county and in the eight-state Heartland Region, the average is 25%.² In the eight Heartland states there are 1795 areas / populations designated as medically underserved.³ According to the 2009/2010 National Survey of Children with Special Health Care Needs, 15.1% of the children in the United States have special healthcare needs and the eight-state region has an average of 15.9% and estimated
prevalence of 885,984 children / youth with special health care needs (CYSHCN). The birth defects rate in the region is comparable to the rest of the U.S. with an estimated 4% of all live born infants having a structural congenital anomaly.

The most recent estimates of (non-obstetrical) clinical genetics services workforce in the U.S. is 1 medical geneticist per 300,000 persons and in the Heartland region that number is only 1 in 425,000. While the overall number of medical genetics service providers in this region is indeed low, even these estimates are somewhat misleading. On average, medical geneticists only spend half of their time (0.5 FTE) in patient service. Thus the Heartlands region of 21.8 million people has access to less than 26 FTEs of medical geneticists’ clinical work (Table 1).

**The Patient Centered Medical Home**

What is the PCMH?

The American Academy of Pediatrics (AAP) introduced the medical home concept in 1967. The medical home was first conceptualized because it was recognized that children with special health care needs (CSHCN) would benefit from a delivery model that effectively coordinated the complex clinical and social services that many patients require. Initially, the medical home was referred to as a central location for archiving the 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 – focused on providing health services designed for the individual patient. In 2002 the AAP policy statement expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care. Since that time, the American Academy of Family Physicians (AAFP) in 2004, the American College of Physicians (ACP) in 2006, and others have developed their own models for improving patient care through a “medical home”.

In 2007, the AAFP, ACP, American Osteopathic Association (AOA), and the AAP developed joint principles for Patient-Centered Medical Home (PCMH). The goal of a medical home is to provide a rationally organized health care system that ensures that patients who can benefit from specialty care gain timely access. However, physicians within primary care settings retain those patients who would not derive benefit from specialty services. The impetus for the joint principles for the PCMH was policymakers, managed care organizations, medical educators and the public being concerned about the amount and quality of care provided within the healthcare system. The seven joint principles of the PCMH are:

- Personal physician
- Physician directed medical practice
- Whole person oriented care – with patient engagement in their 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
- 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 form pediatric to adult services.
The definition of a Medical Home includes the following:

- “A team-based model of care led by a personal physician who provides continuous and coordinated care throughout a patient's lifetime to maximize health outcomes
- Responsible for providing for all of a patient’s health care needs or appropriately arranging care with other qualified professionals. This includes the provision of preventive services, treatment of acute and chronic illness, and assistance with end-of-life issues
- A model of practice in which a team of health professionals, coordinated by a personal physician, works collaboratively to provide high levels of care, access and communication, care coordination and integration, and care quality and safety.”

**Why the PCMH?**
The most important role for a PCP is to establish a medical home for patients. The PCP should work with patients and the care team to coordinate all health services in a quality, cost-effective and accessible manner. The pediatric care team works in partnership with a child and a child’s family to assure that all medical and non-medical needs of the patient are met. The care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community services that are important for the overall health of the child and family. Studies indicate that patients who have a PCMH will have a 20% decrease in hospitalizations and 12% reduction in readmission rate. As a result states will experience decreased per capita costs. Lack of involvement of a PCP decreases the likelihood of receiving appropriate health maintenance.

According to the ACP, a PCP should only be a physician. However, they acknowledge that the possible specialties of the physician assuming the role of the PCMH can be any of several possibilities including pediatricians, family physicians, internal medicine physicians, geriatric physicians, or obstetricians/gynecologists. Experience has demonstrated that limiting the primary care provider role to physicians is not practical. Due to managed care and manpower issues, PCPs are increasingly asked to take on expanded responsibilities in the care of their patients in order to limit expensive consultations and associated tests and procedures. In response to this, PCPs have partnered with other health care practitioners, such as nurse practitioners (NPs) and physician assistants (PAs) in their practices. In October 2010, the National Committee for Quality Assurance (NCQA) announced that they would recognize “nurse-led” primary care practices as PCMH under the PCC-PCMH recognition / accreditation program. The Joint Commission also recognizes nurse-led primary care medical homes. Between 2000 and 2006, the number of PCPs at health centers grew 57%, while the combined number of NPs, PAs and CNMs grew by 64%. Currently, more NPs and PAs are providing primary care than family physicians. Specialists and PCPs are employing NPs and PAs increasingly in their practices.

Currently, the PCMH is endorsed by many professional organizations: (Table 2) The Institute of Medicine (IOM) defines primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients and practicing in the context of family and community”. A clinician, according to the IOM, is an individual who uses a recognized scientific knowledge base and has the authority to direct the delivery of personal health care services to patients – may be a physician, nurse practitioner, or physician assistant”. A “Personal Physician” is generally referred to as a patient’s primary care provider (PCP).
PCP is considered a generalist whose medical knowledge provides them the ability to be the first contact and provide comprehensive and continuous medical care to patients.  

**Interface (roles) of specialties with the PCMH**

In the U.S., specialists provide at least 20% of the primary care to patients. A specialist is a physician with advanced and focused medical knowledge and skills in a specific organ system, class of diseases, or types of patients and who provides care for these patients with complex problems. Studies suggest that there are differences between specialists (Cardiology, Dermatology, Endocrinology, Gastroenterology, Infectious Disease, Neurology, Psychiatry, Pulmonology, Rheumatology, Orthopedic, Oncology and even Preventive Care) and generalists in terms of knowledge, patterns of care and clinical outcomes. Specialists are more knowledgeable about their area of expertise and quicker to adopt new and effective treatments than generalists. Although the role of the PCP is clearly outlined, comparable consensus does not exist for the specialist. The types of clinical roles that a specialist can assume include the following:

- **Cognitive Consultation** – provide diagnostic or therapeutic advice to reduce clinical uncertainty. The PCP will consult with the specialist regarding the patient symptoms, testing results, and etc.
- **Procedural Consultation** – perform a technical procedure to aid diagnosis, cure a condition, identify and prevent new conditions or palliate symptoms. The PCP will refer patient to the specialist for evaluation and testing.
- **Co-manager with shared care** – share long-term management with a PCP for a patient’s referred health problem
  - For all co-managed patients, the PCP provides the medical home that serves as the first contact site for new, unrelated health concerns, refills, new referrals and share responsibility for patient and family education. The specialist provides medical care and case management for the specific condition.
- **Co-manager with principal care** – assume total responsibility for long-term management of a referred health problem. In this situation, the PCP will leave responsibility for the patient’s health care in the hands of the specialist. In this scenario, the health care is physician directed; however, some concerns exist addressing the needs of the whole person.

Note: In the area of Pediatrics, 40% of the referrals to specialists are for consultations, 35% for share management, and 25% for referral with transferred care.

Patients seeing a specialist and a PCP for a particular condition are more likely to receive recommended services. However, some patient concerns with the primary care-specialty care interface include: lack of care coordination and lapses in communication between the PCP and specialists, duplicate diagnostic tests, and ambiguity regarding duties and responsibilities. Specialists also are more likely to order tests and procedures that do not consistently result in improved clinical outcomes. In this context, clinical geneticists would indeed be considered ‘specialists’.  

**The Medical Home Neighbor**

“Building a Medical Neighborhood for the Medical Home” is a new approach for the PCMH. The goal is to improve the PCP/Specialist interface through strengthening the primary care.
Some innovations aimed at strengthening the primary care include telemedicine, integration of primary-specialty care, and decision support and e-referral. An example of the medical-neighborhood interactions is that one in 40 PCP visits leads to a referral to specialist. A specialty/subspecialty practice can be recognized as a Patient Centered Medical Home – Neighbor (PCMH-N), if the practice engages in the following processes that:

- “Ensure effective communication, coordination, and integration with PCMH practices in a bidirectional manner to provide high-quality and efficient care
- Ensure appropriate and timely consultations and referrals that complement the aims of the PCMH practice
- Ensure the efficient, appropriate, and effective flow of necessary patient and care information
- Effectively guides determination of responsibility in co-management situations
- Support patient-centered care, enhanced care access, and high levels of care quality and safety
- Support the PCMH practice as the provider of whole-person primary care to the patient and as having overall responsibility for ensuring the coordination and integration of the care provided by all involved physicians and other health care professionals.”

According to the ACP, the clinical interactions between PCMH and the PCMH-N can take the following forms:

- Pre-consultation exchange—intended to expedite/prioritize care, or clarify need for a referral
- Formal consultation—to deal with a discrete question/procedure
- Co-management
- Co-management with Shared Management for the disease
- Co-management with Principal care for the disease
- Co-management with Principal care of the patient for a consuming illness for a limited period
- Transfer of patient to specialty PCMH for the entirety of care.

The ACP supports the development of care-coordination agreements with PCMH and the PCMH-N to outline the responsibilities and processes of each group based on the co-management arrangement, and these should be easily understood and acceptable to the patient. These agreements will define types of referrals and consultations and consider patient/family choices.14

Other related activities

- **AAP Genetics in Primary Care Institute**

The Genetics in Primary Care Institute is a cooperative agreement between the Health Resources & Services Administration / Maternal & Child Health Bureau and the American Academy of Pediatrics [AAP]. The AAP has engaged its established quality improvement program—Quality Improvement Innovation Networks (QuIIN)—to work with an Expert Group and 13 diverse primary care practices (serving more than 130,000 patients) on the development of a change package including strategies and tools to enhance primary care delivery of genetic medicine. The diverse group of primary care practice teams will have attended two in-person Learning Sessions prior to, and following the six-month action period, which occurred between April and
September 2013. The thirteen teams, genetic mentors, and project leadership reconvened in November to develop sustainability plans and obtain additional education. Over the six months, practices made significant strides to meet the following goals of the project:

1. Improve the assessment and identification of genetic conditions for all patients aged 0-21 years old, as part of the health supervision visit, through the collection of family health history information.
2. Improve the care and management of patients aged 0-21 years with defined genetic conditions.
3. At the practice level, improve office systems and processes to meet the first two aims.

http://www.geneticsinprimarycare.org/Pages/default.aspx

- **Center for Medical Home Improvement**
The Center for Medical Home Improvement (CMHI) provides resources and technical assistance to primary care practices that are engaging in quality improvement and transformation into a high quality medical home. The CMHI offers a “methodology for practice transformation using the CMHI Medical Home TAPPP™ (Gap) Analysis and an array of medical home resources, tools, and guidance; measurement strategies of the patient and family-centered medical home for use with practices, patients/families, state health and human service organizations, and health plans; and medical home content expertise with experience convening stakeholders towards the development of new programs and the promotion of new knowledge”.

http://www.medicalhomeimprovement.org/about/

- **Med Home Portal**
The Medical Home Portal is a web site that aims to help families, physicians, and others find reliable information and access to valuable professional and community resources to improve the care, health, and long-range outcomes of children and youth with special health care needs (CYSHCN). The Portal is unique in its focus on both primary care clinicians and families and in integrating information about local resources and service providers. This site provides content on forty-one conditions (with more being continually added) for families and primary care providers.

http://www.geneticsinprimarycare.org/Pages/default.aspx

- **National Coordinating Center Medical Home Workgroup**
The National Coordinating Center (NCC) has formed a Medical Home Workgroup, which has representation from all of the Regional Genetics Collaboratives. This workgroup is aimed at collaborating and sharing medical home activities from each region and then supporting and building upon these regional activities at the national level.

http://www.nccrcg.org/NCCRCG/Workgroups/Medical_Home/Products/NCCRCG/Workgroups/Medical_Home/Medical_Home_Products.aspx?hkey=63ec62ce-0916-4a36-8cb4-5def25f9bd63

- **National Health Care Transition Center**
The aim of this center is to “advance access to effective transition support from pediatric to adult health care for all youth, including those with special needs” http://www.gottransition.org/about-us-why-got-transition. Through funding from HRSA, the CHCTI has, among other strategies,
developed resources and learning communities to promote improvement in health care transition practices at the practice level.
http://www.gottransition.org/

KEY ISSUES

Is genetics any different from any other specialty?
The relationship defined above of the interaction between the PCMH and the PCMH-N appears to be consistent across all specialties. However, the specialty of genetics may be a bit unique. A specialist in the field of genetics treats those with genetically linked disease. This specialist may use cytogenetic, molecular, radiologic and biochemical testing to assist in diagnosis and therapeutic intervention. The genetic condition could be syndromic or biochemical in nature. A medical geneticist plans and coordinates care for those patients with syndromes, inborn errors of metabolism, chromosomal abnormalities and many are involved with the newborn screening follow-up program within the state. Additionally, the geneticist is often not just treating the patient that is attending the clinic visit, but is often providing information and counseling that impacts other members of the family and has prenatal implications. Therefore, based on the unique nature of this specialty, it may have a different role than that of a typical specialty, related to the PCMH.

In general, genetic conditions are rare. They also span a lifetime and often impact multiple body systems. Additionally, they are often diagnosed in childhood, but require lifelong management. Due to the frequency of required genetics clinic appointments, often a unique bond develops between the family and the geneticist. Biochemical crises may result in emergency room visits as well as 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. However, in genetics, almost all of the patients meet these criteria.

Adult versus pediatric care
Due to the dearth of adult genetic providers, many children that are diagnosed with genetic conditions continue to follow with their pediatric geneticists into adulthood. This is in direct conflict with the idea of transition that is recommended within PCMH. However, if there are few or no adult providers reasonably located for follow-up, then these adults with genetic conditions are left with only the option of following with a pediatric provider, or not having a specialist to manage their genetic condition in adulthood. Additionally, many of the genetic conditions require much more stringent follow-up in the pediatric phase than in the adult phase of life. Therefore, the role of the clinical geneticist may be different in different phases of life.

Multiple specialists
The PCMH-N is focused on one specialist interacting with the PCMH. However, it is not uncommon for someone with a genetic condition to follow with multiple specialists and therapists. This may be even more important in genetics because so many of the conditions impact multiple body systems. The idea of concierge medicine by a specialist has been presented as an option. This is a hybrid model of care where the specialist provides more care than just their own specialty, but this is costly and not currently prevalent in the healthcare system. Additionally, the idea of a primary specialist has been presented where they co-manage the
patient with the PCP and other specialists have less involvement. A care contract is often recommended in these relationships so that the family is clear on whom to contact for carious needs.

**Difference in setting**
It may also be that the variety of models recommended for the generalist-specialist interface might work best in different settings. A PCP in a PCMH in an outpatient clinic associated with a large teaching institution, in an urban area, might have the resources and feel comfortable with taking on a more primary role for a patient with a genetic condition. However, a more rural provider with less resources may not be able to take on this role. It is perhaps the relative distance to a genetic support system that helps to dictate the role of genetics in the PCMH.

If this is the case, then outreach plays an imperative role in managing these patients. Tele-health or tele-genetics allows for the geneticist to reach patients at greater distances. This may also play a significant role for those families that move often and have to change providers. Tele-health might allow the specific geneticist to remain involved in the patients’ care from a distance, allowing for continuity. This may also be of paramount importance in those states in the Heartland region that do not have many geneticists available. If PCMHs in the region are able to lean on the expertise and support of geneticists not in their state, patients may receive better access and care.

**Primary care lack of knowledge / comfort in providing care**
Despite these concerns though, there seems to be an imperative that the geneticist be involved in the care of a person with a genetic condition. There is a significant body of literature that suggests that primary care providers are not comfortable with integrating genetics into primary care practice. This means that they may also not feel comfortable managing a patient with a genetic condition on their own. Therefore, the role perhaps is one more of co-management where the geneticist helps devise a plan of care surrounding the patient’s genetic condition and the primary care provider is then responsible for carrying out the care plan and asking for assistance when needed. Therefore, the PCP would still be the primary PCMH for the patient, but the geneticist would be providing the support and resources to build this relationship and truly functioning as a PCMH-N.

**Information sharing**
Another imperative piece of this puzzle is also the sharing of information between the PCMH and the geneticist. Currently, newborn screening, the largest public health process, which is also genetic in nature, is required in all states. This test is collected at the birth hospital and then results are sent to the PCP, who performs follow-up as recommended and with the help of the designated tertiary care facility. This means that the process of exchanging information has been established with the public health laboratories. However, this process is much less flawless with regards to getting the information from the geneticist to the PCP. This information needs to include the clinic notes, care plan and testing results. Often times one of more of these is excluded. A process needs to be developed to support this information interface and to help support the PCMH.
SO, WHAT IS THE ROLE OF THE MEDICAL GENETICST IN THE PCMH?

As has been detailed above, the Patient Centered Medical Home is a concept that has been embraced by a myriad of professional organizations (Table 1). Not surprisingly then, multiple variations exist 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/sub-specialists”. 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?

As we have looked at this question 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. We have identified at least 7 roles that different clinical genetic practices self-report as the way in which their practice interfaces with the PCMH. These reported roles are:

1. No role or interface
2. Medical home neighbor
3. Sub-specialist as the Medical Home
4. Educator of the PCP
5. Consultant / provider of quaternary care
6. Co-manager of medical home
7. Supporter of a family-directed ‘PCMH’

Clearly coordinated medical care is a standard that the vast majority of experts and practitioners adhere to. While it is not necessarily ‘enforceable’, it is prudent to encourage all health care professionals to work in concert for the best interest of the patient – with the best possible outcome. Thus, while some may see the PCMH as yet another fad or another bureaucratic imposition, there is little rationale for recommending that the medical geneticist remain distanced from the PCMH.

The concept of the medical home neighbor is a well-established construct. Earlier in this paper we describe this in detail. This role seems to be a very good ‘fit’ for specialists interfacing with the PCMH (and in particular for specialties such as genetics where there is such a strong emphasis on extended care and family). We see this model as a particularly attractive way of taking advantage of all of the key skills that geneticists bring to the patient and family.

While many would argue that the PCMH by definition is a primary care provider, we are aware of many examples in which the medical geneticist has essentially assumed the role of the PCMH. There are many reasons that such an arrangement may exist. Sometimes this can happen by default. As geneticists follow patients over time, the more complex patients may require additional time and resources. Over the course of time a strong relationship builds between the geneticist and the patient. Often there is also a measure of uneasiness on the part of some primary care providers. In some cases, it may be such that they are even be hesitant to perform immunizations or other primary services in patients that are perceived as especially complicated or fragile. Patients with inborn errors of metabolism are an example of one group of patients in which this relationship is often seen. Other factors that may promote such a relationship would
include a limited number of providers or especially busy practices. While the ideal situation remains for a patient to have a PCMH directed by a primary care provider with the medical geneticist as a supporting professional, we opine that there are times in which this type of relationship in practical terms is the best of the patient and their family.

It is well understood that a major role of the specialty care provider is education. An established part of the scope of practice is to provide the patient and the primary care provider with need information about conditions that may be rare or poorly understood. There are times in which specialists reach a point in a patient’s care in which their role as a medical provider is no longer necessary (a diagnosis has been made and the patient is stable and doing well). At this juncture, the only ongoing needed role of the geneticist may be to be available to field questions and provide updated information to the PCMH. For such patients, this seems to us to be a very appropriate role for the geneticist.

At first glance, it may seem that the role of “consultant” or “provider of quaternary care” is not much different than that of educator. While the concept of a parallel activity is the same, the actual service provided is somewhat different. There are, in fact, medical geneticists who envision their role as one of providing a subspecialty level of care as a direct independent service. Likewise, this is not exactly the same as having no role in the PCMH. Rather this model espouses the geneticist as providing an independent service with information conveyed as a consultant – that is the information is provided to the requesting provider, but outside of the context of a care team. This model is not unlike the traditional relationship of the specialist as a consultant which was the prevailing standard of practice of the 1960’s and 70’s.

Many geneticists report that they and the established PCMH have struck an agreement as “co-managers” of the PCMH. Essentially this is a division of labor. The work required of the PCMH is assessed and the identified duties are then assigned to either the PCP or the geneticist. In this model, the division of duties is based upon which provider has the best resources and skills to provide that specific service. In many ways we see this logical way of “getting the work done.” Practically the major factor in making this a success is a trusting relationship and frequent communication between the primary care provider and the geneticist. Depending on the logistics of either side, this may not always be practical.

Finally, we are aware of many examples in which the role of the PCMH has essentially been assumed by the family themselves. This seems to be a decision of necessity in several extenuating circumstances. The most common setting that this is seen is in military (or other highly mobile families). This may often be necessary especially if the family must relocate to under-served or third world areas. In this context, many families literally carry their medical records with them from place to place. Typically then, they will also actually need to educate and “catch-up” the provider at their newest location. When such families have a member who has a genetic disorder, it is not uncommon for them to maintain contact with a geneticist from a past locale who knows the patient and can continue to provide some modicum of continuity by informal – and often undocumented – interactions. While this is certainly not ideal, it may indeed be the best method of ensuring informed patient care in some cases.
Customized / Individualized PCMH
In the realm of education it is been understood for a long time that ‘one size does not fit all’. The concept and process of the Individualized Education Plan (IEP) utilizes the straight-forward 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 has to be tailored to that child. We would opine that this same principle can be 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 medical home neighbor may be the ‘ideal’. Still, this model simply cannot be applied in all cases. We have presented 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 hard to execute in true practice. Thus the best answer to the question “What is the role of the geneticist in the PCMH may 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.
Table 1: Practicing medical geneticists and genetic counselors by Heartland state

<table>
<thead>
<tr>
<th>State</th>
<th>Medical Geneticists</th>
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<td><strong>TOTAL</strong></td>
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Table 2: Professional Organizations Which Endorse the PCMH

- American Academy of Family Practice
- American Academy of Hospice and Palliative medicine
- American Academy of Neurology
- American Academy of Pediatrics
- American Association of Critical Care Nurses
- American College of Cardiology
- American College of Chest Physicians
- American College of Occupational and Environmental Medicine
- American College of Osteopathic Family Physicians
- American College of Osteopathic Internists
- American College of Physicians
- American Geriatrics Society
- American Medical Association
- American Medical Directors Association
- American Nurses Association
- American Osteopathic Association
- American Society of Addiction medicine
- American Society of Clinical Oncology
- Association of Professors of Medicine
- Association of Program Directors in Internal Medicine
- Clerkship Directors in Internal Medicine
- Infectious Diseases Society of America
- National Association of Pediatric Nurse practitioners
- Society for Adolescent Medicine
- Society of Critical Care Medicine
- Society of Pediatric Nursing
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