

DEMOGRAPHIC CHARACTERISTICS, EDUCATION, AND TRAINING

1. Year born: 19 _ _
2. Gender:
 - a. Female
 - b. Male
3. Ethnicity:
 - a. Hispanic or Latino(a)
 - b. Not Hispanic or Latino(a)
4. Race:
 - a. American Indian or Alaskan Native
 - b. Asian
 - c. Black or African American
 - d. Native Hawaiian or Other Pacific Islander
 - e. White
 - f. Other, specify: _____
5. Professional/Doctoral Degrees
Select all that apply
Question also asks for year awarded and location of school – US, Canada, Other non- US
 - a. MD
 - b. DO
 - c. MS CGC
 - d. PhD, in: _____
 - e. Other, specify: _____
6. Medical Genetics Training: Accredited residency, fellowship and other medical genetics post-doctoral training
Mark all that apply
Question also asks for year awarded
 - a. Clinical Genetics Residency/Fellowship
 - b. PhD Medical Genetics
 - c. Clinical Biochemical Genetics
 - d. Clinical Molecular Genetics
 - e. Clinical Cytogenetics
 - f. Molecular Genetics Pathology (Subspecialty)
 - g. On the job training
 - h. No formal training
 - i. Other, specify: _____
7. Non-Genetics Graduate Medical Education (GME): MDs and DOs only
Mark all that apply
Question also asks for year completed and to specify any subspecialty training
 - a. Pediatrics
 - b. Internal Medicine

- c. Obstetrics/Gynecology
 - d. Family Practice
 - e. Pathology
 - f. Other, specify: _____
 - g. None
8. How many years have you worked in the genetics profession?
- a. Less than 2 years
 - b. 3-5 years
 - c. 6-10 years
 - d. 11-15 years
 - e. 16-20 years
 - f. 21-25 years
 - g. More than 25 years

PROFESSIONAL PRACTICE

9. What best describes your current primary workplace setting (where you work the most hours)?

Select only one response

- a. Academic medical center/university
 - b. Managed care organization/HMO
 - c. Medical practice - single specialty
 - d. Medical practice - multiple specialty
 - e. Commercial laboratory
 - f. Pharmaceutical/biotechnology company
 - g. Government agency (State/Federal - non-military)
 - h. Consulting (group or self-employed)
 - i. Hospital based
 - j. U.S. military
 - k. Other, specify: _____
10. Indicate the ZIP code of your current primary workplace setting: _ _ _ _ _
11. Estimate the average total hours that you worked in pediatric genetics care in a typical week in calendar year 20 _ _.
12. Indicate how frequently you use the following electronic resources in your professional activities:
- Select from Never, Once a month, Once a week, Once daily, More than once daily*
- a. Email
 - b. Internet (web based resources)
 - c. Personal Digital Assistant (Palm Pilot, Handspring)
 - d. Clinical applications (patient care or laboratory; e.g., electronic medical records, reports)
 - e. Medical decision support software (patient diagnosis, patient management, information resource)
 - f. Telemedicine for educational activities

- g. Telemedicine for patient care activities
- h. Other: _____

GENETICS PATIENT CARE/CLINICAL PRACTICE SECTION

Many of the questions ask about new patients – could generalize to all patients or ask separately about new and follow-up patients

13. Indicate the percentage of your patient care activities that you spend in:
Select from 0%, 1- 10%, 11- 20%, 21- 40%, 41- 60%, 61- 80%, 81- 99%, 100%
 - a. Pediatric genetics related care
 - b. Other patient care
14. Estimate the average amount of time per visit in minutes that you spend on a typical new and on a typical follow-up pediatric genetics patient:
 - a. New patient time
 - b. Follow-up patient time
15. Estimate the number of pediatric genetics patient visits (new patients and follow-up patients) you have in an average week:
 - a. New patient visits
 - b. Follow-up patient visits
16. For a typical new pediatric genetics patient, indicate the percentage of your patient care time you spend on each of the following:
Select from 0%, 1- 10%, 11- 20%, 21- 40%, 41- 60%, 61- 80%, 81- 99%, 100%
 - a. Direct “face to face” contact with patient and/or family
 - b. Other communication with patient and/or family
 - c. Case research, review data, prepare consultation notes, etc.
 - d. Administrative tasks related to clinical care
 - e. Communication with referring physician
 - f. Communication with other genetics professionals
 - g. Other
17. What is the typical waiting time (work days) for an appointment (non-emergency) to see you?
Select from 1- 2 days, 3- 6 days, 1- 3 weeks, 1- 3 months, more than 3 months, not applicable
 - a. Existing patient
 - b. New patient
18. Without making substantial changes to your current practice patterns, which response best describes your current genetics practice?
 - a. I cannot accept any more genetics patients, my genetics practice is full
 - b. I can accept some additional genetics patients, my genetics practice is nearly full
 - c. I can accept many additional genetics patients, my practice is far from full
19. Describe the staffing level at the clinical genetics site of your primary workplace setting (where you work the most hours):

Indicate yourself in the count

Could ask specifically about FTEs here

Select from 1, 2, 3- 5, 6- 10, 11 or more, I don't know

- a. Geneticists (MD, DO, PhD)
 - b. Genetic Counselors
 - c. Nurses (RN or higher)
 - d. Other professionals
 - e. Support staff
20. Are any of the nurses on your staff formally trained in genetics?
- a. Yes
 - b. No
21. What is your assessment of the adequacy of the current staffing at your primary clinical genetics site?
- Select from Too Few, Right Number, Too Many**
- a. MD, DO geneticists
 - b. PhD geneticists
 - c. Genetic counselors
 - d. Nurses (RN or higher)
 - e. Support staff
22. How satisfied are you with the following aspects of your primary clinical genetics site?
- Select from Significantly Dissatisfied, Dissatisfied, Neutral, Satisfied, Significantly Satisfied, I Don't Know/No Opinion**
- a. Length of time you spend with a patient
 - b. Number of patients you see
 - c. Your relationships with the patients/family
 - d. Level of reimbursement for genetic services you provide
 - e. Autonomy to make decisions about patient care issues (e.g., testing decisions)
23. How many of your pediatric genetics patients are referred to you from the following:
- Select from None, Very Few, Several, Many, All**
- a. Generalist physicians (pediatricians, internists, family practitioners)
 - b. Specialist physicians (including obstetricians/gynecologists)
 - c. Genetic counselors
 - d. Managed care contracting
 - e. Patient (self-referral or family referral)
 - f. Genetic testing laboratories or programs
 - g. Other
24. How many of your pediatric genetics patients spent time with the following in their first visit:
- Select from None, Very Few, Several, Many, All**
- a. Genetic counselor
 - b. Nurse specializing in genetics

25. How many of your pediatric genetics patients receive the following from you:

Select from None, Very Few, Several, Many, All

- a. Consultation on a one-time basis
- b. Consultation over several visits
- c. Ongoing management of genetic condition(s)
- d. Ongoing management of genetics-related and other health conditions

26. Estimate the percentage of your new pediatric patients representing the following groups:

Select from 0%, 1- 10%, 11- 20%, 21- 40%, 41- 60%, 61- 80%, 81- 99%, 100%

- a. Newborns and infants (under one year of age)
- b. Children and adolescents (not pregnant)

27. Indicate the percentage of your pediatric patients with genetic disorders belonging to the following categories:

Select from 0%, 1- 10%, 11- 20%, 21- 40%, 41- 60%, 61- 80%, 81- 99%, 100%

- a. Dysmorphologies/syndromes/birth defects
- b. Developmental delay/mental retardation
- c. Chromosomal disorders
- d. Metabolic conditions
- e. Other

28. Estimate the percentage of your genetics patients in each of the following categories of health insurance:

Select from 0%, 1- 10%, 11- 20%, 21- 40%, 41- 60%, 61- 80%, 81- 99%, 100%

- a. Managed care (e.g., HMP/PPO/IPA)
- b. Traditional indemnity insurance/private insurance
- c. Medicaid
- d. Medicare
- e. Self-pay
- f. Uninsured
- g. Unknown insurance type

29. Indicate how the following items have changed in your current clinical genetics practice since 20_ _:

Select from Significantly Decreased, Decreased, Stayed the Same, Increased, Significantly Increased, I Don't Know, N/A

- a. My office hours have
- b. My genetics patient volume has
- c. The number of services I provide per visit has
- d. The clinical complexity of my genetics patients has
- e. Referrals from physicians have
- f. My use of genetic counselors has
- g. My use of nurses trained in genetics has
- h. Competition from other genetics practices has
- i. Competition from physicians (non-genetics) providing genetic services has

- j. Revenue generated by my practice has
 - k. Operational costs of providing genetics services have
 - l. Financial support from my institution has
 - m. Insurance reimbursement levels have
 - n. Insurance coverage for genetic services has
 - o. The number of managed care contracts I have has
30. How many total outreach clinic sessions did you travel to in an average month in order to provide genetic services (do not include locations within your primary patient care setting)?
- a. I do not provide outreach services
 - b. 1-2 sessions
 - c. 3-5 sessions
 - d. 6-10 sessions
 - e. More than 10 sessions
31. How many total hours (on average) did you spend in travel time to these outreach sessions in an average month?
- a. Less than 1 hour
 - b. 1-2 hours
 - c. 3-5 hours
 - d. 6-9 hours
 - e. 10-14 hours
 - f. 15-19 hours
 - g. 20-23 hours
 - h. More than 23 hours
 - i. N/A
32. How many different outreach locations/sites did you travel to in order to provide genetic services (do not include locations within your primary patient care setting):
- a. I do not provide outreach services
 - b. 1-2 locations
 - c. 3-5 locations
 - d. 6-10 locations
 - e. More than 10 locations
33. Do you travel to rural sites?
- a. Yes
 - b. No

FREE RESPONSE QUESTIONS

34. What clinical genetics services does your center, institution, program, practice or office currently provide?
35. Do you interact with or consult with other medical specialists, either informally or as part of multi-specialty or team clinic?
(Interviewer prompts: Which specialists seek you out most often? Which specialists do you seek out most often? What is/are the team clinic(s) and

its/their history(ies)? How is the clinic organized? What specialties/health professionals attend? What is your role?)

36. How do you schedule your patients?
37. Do you do a family history before visit? During the visit?
38. What is your communication model (e.g., who do you send information to, how do you communicate with referring providers)? Who does your dictation?
39. Do you use the medical home model? Do you know what it is?
40. Per clinical FTE - how many days a week are you in clinic and how many days in-patient consults?
41. What is the role of genetic counselors? Do they see patients independently?
42. Do you have a nurse practitioner? What is the nurse practitioner's focus?
43. Do you have subspecialty or multidisciplinary clinics? Which ones do you have?
44. What's your RVU per clinical FTE (relative value units - measure productivity across subspecialties) for the year?
45. I am interested in learning more about the pediatric genetic services that you provide. Please follow a representative pediatric patient with a common diagnosis for your practice.

For example, how does the patient get to you? Who else participates in his/her care? What steps are involved in the services provided by you and others? What do you discuss with the patient? What types of referrals might you make? What happens to the patient once s/he leaves you? Who do you communicate with about the patients with genetic issues?