

Oregon Health Division Genetics Services Inventory

Availability of Services

Types of services your group provides (please check all that apply):

- sample collection for laboratory testing
- individual and family genetics counseling
- medical management for genetic conditions
- care coordination
- support services
- Other (please specify) _____

If you checked "laboratory testing" above, please indicate in which general categories of testing/screening your group provides services.

- preconception-carrier status
- prenatal screening/diagnosis
- newborn/child
- adult onset
- cancer
- other (please specify) _____

Does your organization plan to add new genetic services or to expand business in the near future?

If yes, please briefly describe what types of services you are considering adding.

Perception of need: As a genetic services provider, what services or resources do you think are in greatest need in Oregon? (Please choose your top three. Space is provided for services or resources not listed).

- Insurance coverage for genetics services
- Insurance reimbursement for genetics services
- Stricter privacy and confidentiality policies
- Weaker privacy and confidentiality policies
- Legal protection for genetic service providers
- Legal protection for genetic service consumers
- Primary care provider education about genetics and related services
- Support staff education about genetics and related services
- Public and consumer education about genetics and related services
- Additional genetic counseling services
- Additional clinical genetics services
- Additional laboratory facilities performing genetic testing
- More trained MD clinical geneticists
- More trained MS genetics counselors
- More trained genetics support staff
- Public health genetics programs
- Genetics services in rural areas or small communities
- More consumer support groups
- Other(please specify) _____

Barriers to access: As a genetic services provider, what do you believe are the greatest barriers to access experienced by patients seeking genetics services in Oregon?

(Please choose your top three. Space is provided for services or resources not listed).

- Consumers are generally unaware that genetics services are available
- Consumers are unaware of local availability of genetics services
- Consumers know services exist in general but can't find a local provider
- Too much travel involved - distance and/or time
- Families are opposed to use of genetics services
- Personal moral opposition to use of genetics services
- Consumers can't pay for services or health insurance won't cover
- Consumers can't pay for services and have no health insurance
- Concerns about potential loss of confidentiality
- Concerns about disclosure to family
- Concerns about disclosure to insurance provider- discrimination
- Concerns about disclosure to employer - discrimination
- Services are not available in the consumer's native language
- Other (please specify) _____

Please indicate the number of clients served per year in the following categories: (indicate whether numbers are *estimated* or *actual*)

Please circle one:

Total number of clients served per year: _____ estimated actual

Age distribution of clients (number of clients *or* percent of total): estimated actual

- <1 year # _____ OR _____ % of total
- 1-18 years # _____ OR _____ % of total
- 19-35 years # _____ OR _____ % of total
- >35 years # _____ OR _____ % of total
- _____ Information not available

Sex distribution of clients: estimated actual

- Female _____ % of total
- Male _____ % of total
- _____ Information not available

Ethnicity of clients (number of clients *or* percent of total): estimated actual

- Caucasian # _____ OR _____ % of total
- Hispanic # _____ OR _____ % of total
- African American # _____ OR _____ % of total
- Asian/Pacific Islander # _____ OR _____ % of total
- Native American # _____ OR _____ % of total
- Other (please specify) # _____ OR _____ % of total
- _____ Information not available

Health insurance status (number of clients *or* percent of total): estimated actual

- Not covered by insurance: # _____ OR _____ % of total
- Covered by public insurance: # _____ OR _____ % of total
(for example, Medicaid or Oregon Health Plan)
- Covered by private insurance/HMO type: # _____ OR _____ % of total
(for example, Kaiser Permanente, Blue Cross/blue Shield, etc.)
- Covered by private insurance/fee for service type: # _____ OR _____ % of total
- Other (please specify) _____ # _____ OR _____ % of total

Thank you for your participation!