UCSF
UC San Francisco Previously Published Works

Title
Genetics workforce: distribution of genetics services and challenges to health care in California

Permalink
https://escholarship.org/uc/item/9g49n198

Journal
Genetics in Medicine, 22(1)

ISSN
1098-3600

Authors
Penon-Portmann, Monica
Chang, Jiyoo
Cheng, Mira
et al.

Publication Date
2020

DOI
10.1038/s41436-019-0628-5

Peer reviewed

eScholarship.org Powered by the California Digital Library
University of California

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

HHS Public Access
Author manuscript
Genet Med. Author manuscript; available in PMC 2023 May 26.

Published in final edited form as:
Genet Med. 2020 January ; 22(1): 227–231. doi:10.1038/s41436-019-0628-5.

Genetics Workforce: Distribution of Genetics Services and Challenges to Healthcare in California

Monica Penon-Portmann, MD[1], **Jiyoo Chang, BA**[2], **Mira Cheng**[2], **Joseph T. Shieh, MD, PhD**[1,2]

[1]Department of Pediatrics, Division of Medical Genetics, University of California San Francisco, CA, USA.

[2]Institute for Human Genetics, University of California San Francisco, CA, USA.

Abstract

Purpose: Access to genetics healthcare services is often complicated by the distance to hospitals, workforce shortages, and insurance coverage. Despite technological advances and decreasing costs of genetic sequencing, the benefits of personalized medicine may be inaccessible to many patients. To assess potential disparities in care, we examined the genetics workforce in California and geographical issues that people encounter in seeking care.

Methods: Data on all board-certified genetics providers were analyzed including Medical Geneticists (MG) and Genetic Counselors (GC) in California. To assess distance traveled for care, we computed the distance patients traveled for n=288 visits to UCSF Medical Genetics. We performed geographic optimization to minimize the distance to genetics providers.

Results: The provider-to-patient ratio in California is 1:330,000 for MG, 1:100,000 for GC, and 1:1,520,000 for biochemical MG. Genetics providers are concentrated in major metropolitan areas in California. People travel up to 386 miles for genetics care within the State (mean=76.6miles).

Conclusion: There are substantial geographic barriers to genetics care that could increase disparities. Our findings highlight a challenging genetics workforce shortage. The shortage may be even greater due to care subspecialization or lack of full-time equivalency and staffing. We are currently promoting efforts to increase remote healthcare options, training, and modified models of care.

Keywords

workforce; provider shortage; telehealth; telegenetics; disparities

Users may view, print, copy, and download text and data-mine the content in such documents, for the purposes of academic research, subject always to the full Conditions of use:http://www.nature.com/authors/editorial_policies/license.html#terms

*Correspondence to: Joseph T. Shieh, Institute for Human Genetics, Division of Medical Genetics, Department of Pediatrics, Benioff Children's Hospital, University of California San Francisco, Box 0706, 550 16th St., San Francisco, CA 94143, Phone: 415-476-2757, Fax: 415-476-9305, joseph.shieh2@ucsf.edu.

Penon et al. GIM

Conflict of interest statement:
The authors declare no conflict of interest.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

PURPOSE

Genetic evaluations and testing have rapidly expanded into many areas of medicine as genomic tools have become more robust.[1] Technological advances such as high-throughput sequencing have decreased the cost and contributed to a massive upsurge in genetic testing since the completion of the Human Genome Project.[1,2] To illustrate, the number of sequenced exomes in one lab has increased from 3000 exomes in 2014 to 100,000 as of 2018.[3]

This rapid growth in technology has outpaced the growth of the genetics workforce. Previous medical genetics workforce studies have demonstrated an already critical shortage, which could increase in the coming years as genetic knowledge and clinical applications continue to expand.[4,5] A workforce shortage could delay the widespread adoption of sequencing, because trained providers in medical genetics and genomics are essential for test interpretation and clinical care.

Despite rapid technological advances, the benefits of personalized medicine may be unequally distributed among patients. Access to genetics healthcare services can be complicated by a number of factors including distance to medical centers, workforce shortages, and insurance coverage and networks.[6]

Previous groups have examined the genetics workforce in an effort to project supply and demand in the coming years.[2,5,7–10] As genomic technologies are increasingly used in medicine, it becomes challenging to determine the demand for genetics services and establish a workforce shortage threshold. The Royal College of Physicians estimated a minimum requirement of 1:250,000, MG-to-patient ratio and the U.K.-based Association of Genetic Nurses and Counsellors set a threshold of 1:75,000–100,000 GC-to-patient ratio.[2,11] Importantly, these estimates predate the advent of high throughput sequencing.[12]

To assess the number of genetics providers and potential patterns in care, we examined the genetics workforce in California and the distances people traveled for in-person care. We hypothesize there is an overall workforce shortage and challenging distribution of providers in direct patient care. We also investigate the potential impact of the workforce shortage on vulnerable sociodemographic populations in California.

METHODS

Data on Genetics Providers in California

Data on board-certified genetics providers were extracted from the American Board of Medical Genetics and Genomics, the American Board of Genetic Counselors and the National Society of Genetic Counselors. We compiled lists of Medical Geneticists (MG), Biochemical Medical Geneticists (BMG) and Genetic Counselors (GC) in the state of California. The list of MG includes individuals with board-certification in Medical Genetics and Genomics. Each list was curated to confirm the primary practice locations and that providers were involved in direct patient care, which we also refer to as clinically active. Practice locations were then geocoded, meaning their geographical coordinates

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

were calculated. Provider-per-population ratios were estimated using U.S. Census Bureau population data and the curated list of clinically active MG, BMG and GC.

Minimum Travel Distance for Genetics Care in the State of California

We obtained a database of postal codes in the State of California from the U.S. Postal Service and U.S. Census Bureau Data (n = 2654 postal codes). Postal codes were geocoded. Distance from each postal code to each provider was computed to find the minimum geospatial distance to a provider in California.

Clinical Visits to Genetics Care

To assess the real distance that patients traveled for genetics care, we examined how far patients traveled for 288 consecutive outpatient visits to Medical Genetics at the University of California, San Francisco (UCSF). Ground travel distance was estimated from the centroid of each county to UCSF using Google Maps (https://www.google.com/maps). The shortest option for each county was selected in terms of both time and distance. International and out-of-state visits were excluded from the analysis. For a subset of consecutive visits (n = 111 of 288 visits), data including the type of insurance (private vs. public) and ethnicity were also analyzed. The Urban-Rural Classification Scheme from the National Center for Health Statistics (NCHS) was used to group counties on an urban to rural scale.[6] The six categories given by the NCHS Urban-Rural Classification Scheme were aggregated into three groups as follows: large-central and fringe-metro into large metropolitan, medium and small metro into small-medium metro, and micropolitan and non-core into micropolitan.

Statistical Analyses

Descriptive statistics, geocoding, histograms and maps were performed with R software v.3.4.4 (https://www.r-project.org/), ggplot2 (http://ggplot2.org/), and ggmap (http://cran.r-project.org/web/packages/ggmap/).

RESULTS

Genetics Providers in California

There are 871 board-certified genetics providers listed in the state of California including both MG and GC (MG = 197; GC = 674) (Figure 1). Of these, 515 or 59.1% of providers are currently involved in direct patient care (MG = 119; GC = 396). Providers who are not directly involved in patient care per traditional hospital models, work in other settings such as industry, public health, education or are dedicated to research. A total of 26 providers (MG = 8, GC = 18) were employed in a different state. Industry employs 208 of the 871, or 24% of the certified providers in the State. A small subset of 117 or 13.4%, of providers do not have online presence, which may indicate they are currently retired or working in a different area. We identified 52 providers who are board-certified in Clinical Biochemical Genetics or Medical Biochemical Genetics.[7] Physicians comprised 41 of the 52 certified individuals, of which 26 or 63.4%, are currently clinically active. The additional boarded individuals (n = 11) have a PhD training background without an MD and are board-certified in Biochemical Genetics working primarily in laboratory settings and subspecialize in inborn errors of metabolism.[7] Twenty-one BMG are also board-certified as MG.

Author Manuscript

Considering only providers in active clinical practice, the provider-to-patient ratio in California is 1:330,000 for MG, 1:100,000 for GC, and 1:1,520,000 for BMG, based on U.S. Census data (Figure 1). This provider-to-patient ratio assumes all providers have their time fully dedicated to clinical care, however the actual clinical full-time-equivalent (FTE) is <1. Providers in active practice are distributed across 44 institutions for MG and 66 institutions for GC. BMG are distributed within 13 of these institutions. Providers are concentrated almost exclusively in larger metropolitan areas in the State. There is geographic overlap between the distribution of MG and GC (Figure 1).

Minimum Travel Distance for Genetics Care in the State of California

As with a number of states and countries, California is challenged by care provision over geographical distance. By calculating the minimum travel distance from each postal code centroid to the nearest genetics provider in California, we were able to visualize areas that are very far from genetics providers, or “desert areas” (Figure 2). The heat map demonstrates that individuals who reside outside large metropolitan areas need to travel farther for in-person genetics care. The average geospatial distance traveled from all postal codes is 34.2 miles, median 13.2 miles, and distances ranged up to 265 miles (Figure 2b). Individuals from 22% of postal codes in California would have to travel a long distance to care (>50 miles) and individuals from 9.2% of postal codes would need to travel >100 miles to their nearest genetics provider (Figure 2b).

Consecutive Visits to UCSF Medical Genetics

To compare theoretical distances to real travel distance, we looked at n=288 consecutive outpatient visits to UCSF Medical Genetics in San Francisco. People traveled up to 386 miles for genetics care within the state (mean = 76.6 miles, median = 59.0 miles) (Figure 2d). Calculated travel time for visitors ranged up to 6.9 hours (mean = 1.63 hours, median = 1.31 hours). Geographic distribution of visits extended across 30 different counties of the 58 in California (Figure 2c).

The average real travel distance was increased when compared to the theoretical minimum by 42.4 miles and the median distance increased by 45.8 miles. These data suggest that some people visited UCSF from counties that have a provider located closer to them.

To determine other factors that may be contributing to the increase in travel distance from the theoretical minimum, we examined demographic data of UCSF Medical Genetics patient visits (n=111, Table S1). Sociodemographic data showed that non-Caucasian individuals were twice as likely to be publicly-insured and that the ratio of publicly insured individuals increases as rurality increases. The median of the real travel distance was similar regardless of ethnicity (Figure S1). Nonetheless, visitors with public insurance had a longer median travel distance than those with private insurance (median distance = 69.3 miles and 45.2 miles, respectively) (Figure S1). The maximum travel distance increased by 92 miles for non-Caucasian individuals compared to Caucasian (Figure S1).

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

CONCLUSION

California's current genetics workforce supply of 1:330,000 for MG and 1:100,000 for GC is less than the recommended threshold according to previous workforce studies.[2,5,7–9,11,12] Although the genetics workforce shortage is a known issue, we posit the workforce shortage to be even greater since previous surveys report that professionals allocate between 27.4% to 54.3% of their time to patient care.[10,13] Providers often do not have a full 1 FTE since work time is distributed among other duties such as training the workforce, teaching, lab direction, administrative duties, and research.[13] The estimated workforce shortage was marked for BMG, with a provider-to-patient ratio of 1:1,520,000. Expansion of newborn screening programs to detect a growing number of treatable disorders and the possible inclusion of genomic sequencing to newborn screening may overwhelm the MG workforce. The growing demand for genetics providers in other healthcare services, like testing companies, contributes further to the workforce shortage (Table S2).

Developing a U.S.-based model to estimate the demand for the medical genetics workforce may be particularly difficult since the need for providers is dependent on numerous variables including access to services, awareness, referral patterns, and geographic location.[2] With the advent of genomic sequencing and increasing knowledge in genetics, more conditions are being discovered. Genetics providers now care for a larger spectrum of patients including those with conditions that are not rare and conditions that are not "monogenic."[14] These trends will likely increase the workforce needs. The fact that medical genetics is a newer, developing field and that there is an ongoing discussion on the evolving roles of medical genetics providers only adds to the difficulty of calculating demand.[2,8]

However, in the U.S., there is clear evidence for an increasing demand for genetic services and ongoing efforts to alleviate the workforce shortage.[1,2,4,15] In late 2018, continued advocacy led to the 2019 Appropriations Bill, which permits a nationwide analysis of the medical genetics workforce.[16] Through these efforts, the ACMG and other entities hope to "more clearly identify workforce needs, implement programs and tools to fill workforce gaps and incentivize students to enter the field."[16] Several studies have also looked at innovating healthcare delivery models, such as providing remote healthcare and helping primary healthcare providers with the delivery of genetics services.[17–19] Medical and laboratory genetics experts will also play key roles in facilitating care of a diverse population.

To gauge potential disparities in access to genetics care, we identified desert areas with minimal access to genetics services. Genetics services tend to be limited to large metropolitan areas. Genetics healthcare deserts tend to be in smaller towns or rural centers, in the periphery of large cities. People who reside in rural areas of California have more limited access to genetics services due to distance. This limitation could lead to differences in health outcomes for underserved populations.

The average, median, and range of real distances that patients traveled are greater than the minimum theoretical distances calculated. People often travel farther than their nearest genetics provider. Factors like insurance limitations, provider sub-specialization, wait times

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

for appointments, and patient preference may contribute to the increase in travel distance. Our findings highlight a challenging geographic distribution of services in addition to a genetics workforce shortage. Regardless of insurance type or ethnicity, travel distances to genetics care in the State are substantial. This may indicate that the genetics workforce shortage is so significant that it is impacting people of all backgrounds, regardless of their sociodemographic characteristics.

The data shows that 71.4% of people coming to UCSF Medical Genetics care from healthcare deserts or micropolitan/rural areas are publicly insured. Publicly-insured individuals have to travel a longer median distance by 24.1 miles compared to those with private insurance. It is possible that residents from more rural areas with public insurance are declined access to their closest center, thus creating a significant leap in distance to the next nearest genetics provider. Sociodemographic data from visits to UCSF Medical Genetics are consistent with data on health disparities, showing that minorities are more likely to be underinsured, a known social determinant of health.[20,21] Despite these challenges to the healthcare services, a high volume of visits at the center were provided to publicly-insured individuals and minorities. Vast access to services can contribute to narrowing the existing gaps in health disparities.

CONCLUSIONS

In this study, we propose a model that identifies the distribution of genetic services and areas of need or desert areas. Distance can be used as an objective measure to help visualize the geographic barriers to genetics care that can lead to increased disparities. As groups continue to work on novel tools, models of delivery, training and programs in order to alleviate the workforce gap, it is crucial to create models that integrate these advances and innovations for the population. We are currently promoting efforts to increase remote healthcare options, education, and modified models of care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGEMENTS

We thank ABMGG, ABGC and NSGC. We thank Colleen Carlston for her helpful suggestions. This research was supported in part by the Marcus Program in Precision Medicine Innovation at the University of California San Francisco.

REFERENCES

1. Phillips KA, Deverka PA, Hooker GW, Douglas MP. Genetic test availability and spending: Where are we now? Where are we going? Health Aff. 2018;37(5):710–716. doi:10.1377/hlthaff.2017.1427
2. Hoskovec JM, Bennett RL, Carey ME, et al. Projecting the Supply and Demand for Certified Genetic Counselors: a Workforce Study. J Genet Couns. 2018;27:16–20. doi:10.1007/s10897-017-0158-8 [PubMed: 29052810]
3. GeneDx. https://www.genedx.com. Published 2000. Accessed March 1, 2019.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

4. ACMG Board of Directors. Clinical utility of genetic and genomic services: A position statement of the American College of Medical Genetics and Genomics. Genet Med. 2015;17(6):505–507. doi:10.1038/gim.2015.41 [PubMed: 25764213]

5. Cooksey JA, Forte G, Benkendorf J, Blitzer MG. The state of the medical geneticist workforce: Findings of the 2003 survey of American Board of Medical Genetics certified geneticists. Genet Med. 2005;7(6):439–443. doi:10.1097/01.GIM.0000172416.35285.9F [PubMed: 16024977]

6. Uribe-Leitz T, Esquivel MM, Garland NY, Staudenmayer KL, Spain DA, Weiser TG. Surgical deserts in California: an analysis of access to surgical care. J Surg Res. 2018;223:102–108. doi:10.1016/j.jss.2017.10.014 [PubMed: 29433860]

7. Korf BR, Blitzer MG, Demmer LA, Feldman GL, Watson MS. Report on the Banbury Summit Meeting on medical genetics training in the genomic era, 23–26 February 2014. Genet Med. 2017;19(9):1–6. doi:10.1038/gim.2017.38

8. Korf BR, Ledbetter D, Murray MF. Report of the Banbury Summit Meeting on the evolving role of the medical geneticist, February 12–14, 2006. Genet Med. 2008;10(7):502–507. doi:10.1097/GIM.0b013e31817701fe [PubMed: 18580691]

9. Korf BR, Feldman G, Wiesner GL. Report of Banbury Summit meeting on training of physicians in medical genetics, October 20–22, 2004. Genet Med. 2005;7(6):433–438. doi:10.1097/01.GIM.0000171324.58121.CF [PubMed: 16024976]

10. Cooksey JA, Forte G, Flanagan PA, Benkendorf J, Blitzer MG. The medical genetics workforce: An analysis of clinical geneticist subgroups. Genet Med. 2006;8(10):603–614. doi:10.1097/01.gim.0000242307.83900.77 [PubMed: 17079876]

11. Royal College of Physicians. Consultant Physicians Working with Patients The Duties, Responsibilities and Practice of Physicians in Medicine. Vol Revised 5t.; 2013. doi:10.1002/9781119962083.ch22

12. Summar ML, Watson MS. LDTs , Incidental Findings , and the Need for More Geneticists. Medscape. https://www.medscape.com/viewarticle/853979_print. Published 2015.

13. American College of Medical Genetics and Genomics 2017 Salary Survey Report.; 2018.

14. Korf BR. Integration of genetics into medical practice. Growth Horm IGF Res. 2004;14:146–149. doi:10.1016/j.ghir.2004.03.032

15. Maiese DR, Keehn A, Lyon M, Flannery D, Watson M. Current conditions in medical genetics practice. Genet Med. 2019;0(0). doi:10.1038/s41436-018-0417-6

16. Moran K ACMG Applauds Increase in Funding for Newborn Screening and Medical Genetics Workforce Study in FY 2019 LHHS Appropriations.; 2019.

17. Elwyn G, Edwards A, Iredale R, Davies P, Gray J. Identifying future models for delivering genetic services: A nominal group study in primary care. BMC Fam Pract. 2005;6:1–6. doi:10.1186/1471-2296-6-14 [PubMed: 15631626]

18. Greendale K, Pyeritz RE. Empowering primary care health professionals in medical genetics: How soon? How fast? How far? Am J Med Genet - Semin Med Genet. 2001;106(3):223–232. doi:10.1002/ajmg.10010

19. Kubendran S, Sivamurthy S, Schaefer GB. A novel approach in pediatric telegenetic services: Geneticist, pediatrician and genetic counselor team. Genet Med. 2017;19(11):1260–1267. doi:10.1038/gim.2017.45 [PubMed: 28471436]

20. CDC. CDC Health Disparities and Inequalities Report — United States, 2013. Vol 62.; 2013.

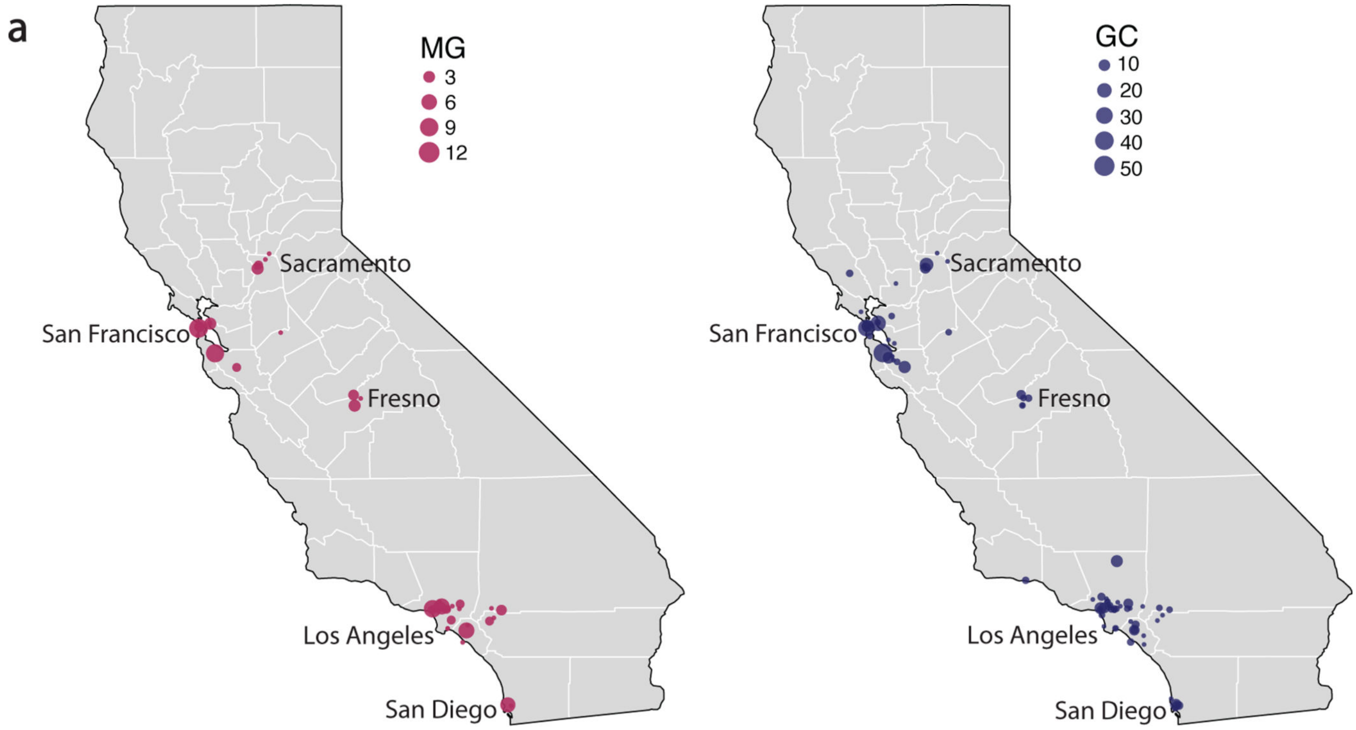
21. Fiscella K, Sanders MR. Racial and Ethnic Disparities in the Quality of Health Care. Annu Rev Public Heal. 2016;37:375–94. doi:10.1146/annurev-publhealth-032315-021439

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript



b

	Certified	Direct Patient Care	Provider-to-patient ratio
MG	197	119 (60%)	1:330,000
GC	674	396 (59%)	1:110,000
BMG	41	26 (63%)	1:1,520,000

Figure 1. Distribution and number of genetics providers in California

(**a**) Geocoded practice locations of providers in direct patient care (MG in maroon and GC in blue). **(b)** Total number of certified providers in the State by genetics specialty, subset of the workforce dedicated to direct patient care (%) and estimated provider-to-patient ratio.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

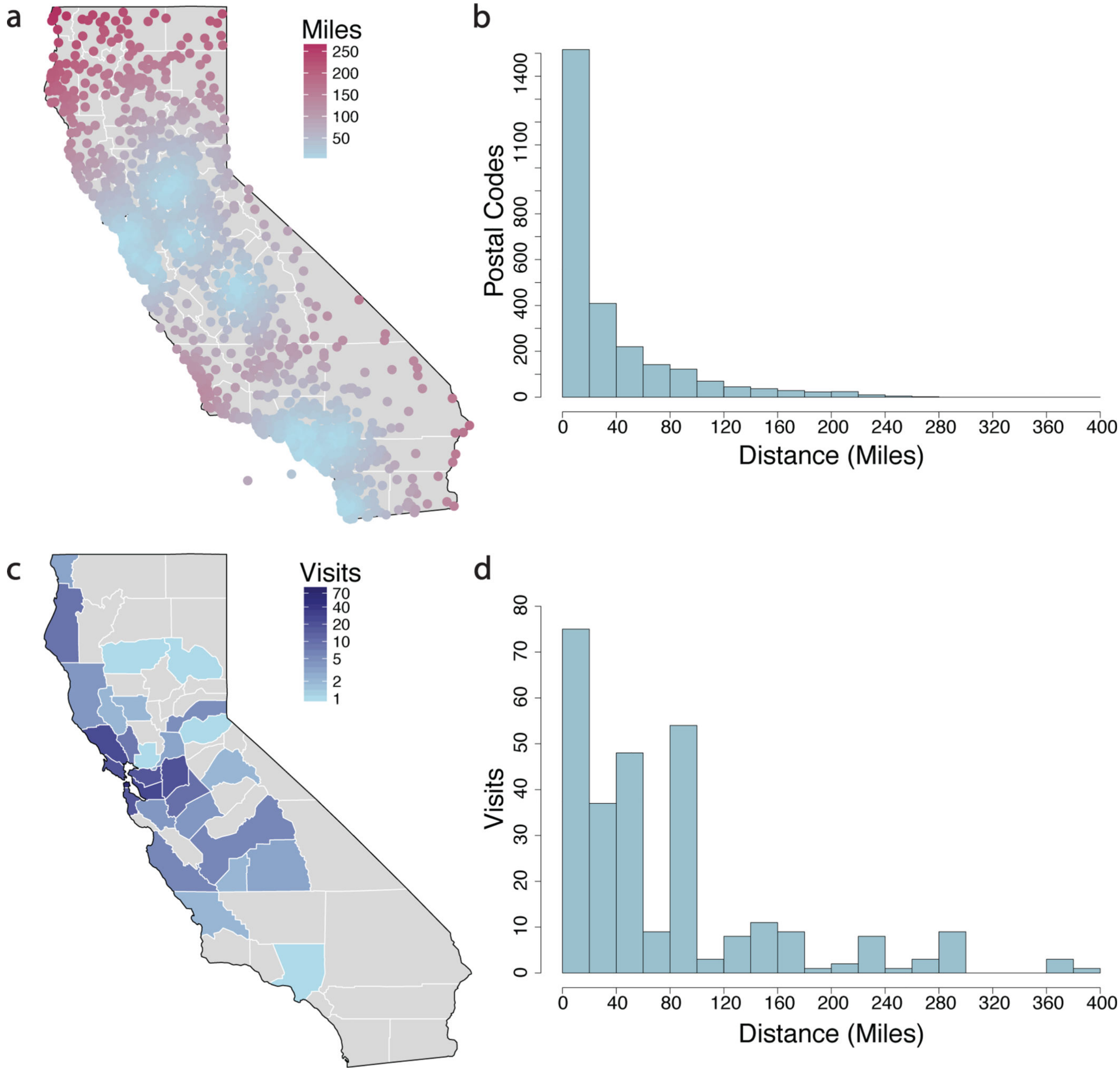


Figure 2. Distance to genetics healthcare services in California.

(a) A heat map of the minimum geospatial distance between each state postal code centroid to its nearest genetics provider. Desert areas correspond to maroon-colored dots, located >50miles away from genetics healthcare services. **(b)** Distribution of theoretical minimum travel distances from all postal codes to the nearest genetics provider. **(c)** Geographic distribution of within-state visits to UCSF (n=282). **(d)** Real travel distance of visits to UCSF (n=282).