Opinion

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Genomic data gone wild?: navigating the final frontier

Abstract

An opinion piece about the wonders and dangers of genomic data. There are challenges to genomic data for both clinician and patient, and these challenges need to be addressed for precision medicine to continue to grow in a responsible way. Genomic data is data that is the result of a genetic test, the term refers to data of a genetic nature.

Keywords: electronic health record, genomic data, personalized medicine, precision medicine, cancer genomics

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Introduction

A continuing challenge in the practice of personalized medicine is the training of physicians to use this data. Medical schools provide physicians with a well rounded education for providing patient care, but this education is often lacking in genomics in the electronic health record (EHR).[1] Part of this deficiency comes from a lack of understanding of the use of genomic data in a broader sense, and that gap is starting to close. Another reason for this deficiency is the EHR vendors still need to do a lot of work to integrate genomic data into the EHR in a meaningful way. When genomic data is available to a physician, it is typically in the form of a narrative report with result and treatment recommendations, it is not structured for integration into the EHR.[2] This creates challenges for clinical applications, if clinicians are both lacking the access to the data as well as the training to properly interpret the data. Another challenge in dealing with EHRs and genomic data, is the amount and complexity of this data.[1] The primary goal of the EHR is to improve patient care on an individual level, the EHR is also essential to enabling personalized medicine to assist patients with treatment options if they fail to respond to the standard of care as expected. As part of a personalized medicine (sometimes called precision medicine) patient experience, the EHR can assist with anything from prevention of a disease, to choice of intervention or follow up care in an unusual response case.[3] Clinical collaboration and education is vital to the development of genomic data and patient care. The combination of collaboration and education can lead to implementation of genomic medicine globally, and there are already efforts to put standards in place to facilitate such endeavors.[4] One area of medicine that is generating evidence related to the impact of genomic data on patient outcomes is Cancer research. To aid in the development of precision oncology research, a database called the NCI Genomic Data Commons (GDC) has been under development for the last 2years. This database will allow researchers and clinicians to more effectively share data, with the goal being to improve patient care through the analysis of more data. Ambiguity in data analysis has been the primary challenge in getting researchers, clinicians, and patients to embrace use of this database.[5]

Conclusion

Given all the challenges to using genomic data, one can conclude there is a long road ahead to standardization, regulation, access, and appropriately integrating genomic data into patient care. It should be noted, that patients have trouble getting access to their own medical records and adding genomic data to those records may create additional reasons for such troubles. Standards need to be brought into place that improve data access for patients and clinicians, questions such as who owns the patient data need to be addressed. There is also the question of what to do with all the data patients are now gathering themselves. Devices like fit bit and Sleep IQ can provide patients with a lot of data that few are trained to interpret, that data can then be brought into the physician who is not only responsible for treating the patient but now for data that may or may not have been properly gathered (or interpreted by a patient). Websites like 23 and me, can provide patients with certain types of genomic data about themselves, but this data can also create anxiety related to health issues and very often they are not staffed with people that are able to assist patients with medical concerns. Medical schools should examine ways to create a curriculum that allows physicians to be trained in medicine and the use of data for medical practice, especially genomic data. Most physicians are not geneticists by training and they cannot be expected to know everything about genomic data. Education programs need to be created for other health professionals on the topic of data analysis, especially genomic data as the data amounts and complexity of genomic data is quite high. It is also important that these medical professionals be equipped to create education programs for patients and the general population. Genomic data is here to stay, and the demand for genomic medicine is only going to increase as the years tick on.[6] The scientific and lay communities are going to need to learn how to manage expectations and data appropriately. There is a vast difference between having a gene that increases risk of disease and having that disease, and patients need clinicians to give them informed advice about how to handle these differences. Genomic data and all the wonders that it brings, is the last frontier of our current science endeavors. This data can be the key to unlocking

so many medical mysteries, if the data is used with responsibility and appropriate management techniques. If genomic data is allowed to go wild the results could be just as dangerous as the movie Gattaca makes it out to be.

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Conflict of interest

Author declares that there is no conflict of interest.

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