The Hereditary Cancer Network Database: The Journey So Far

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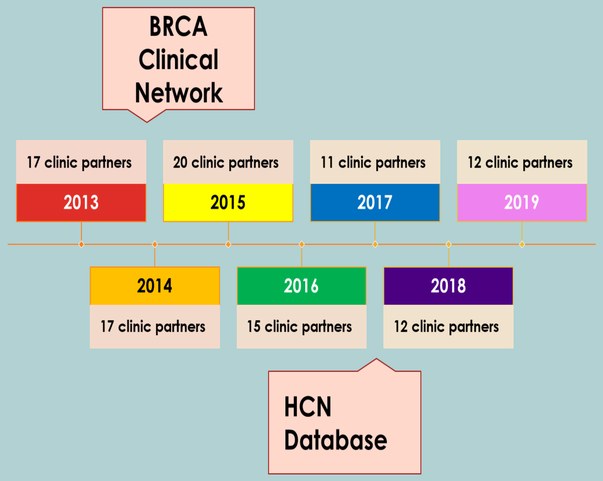
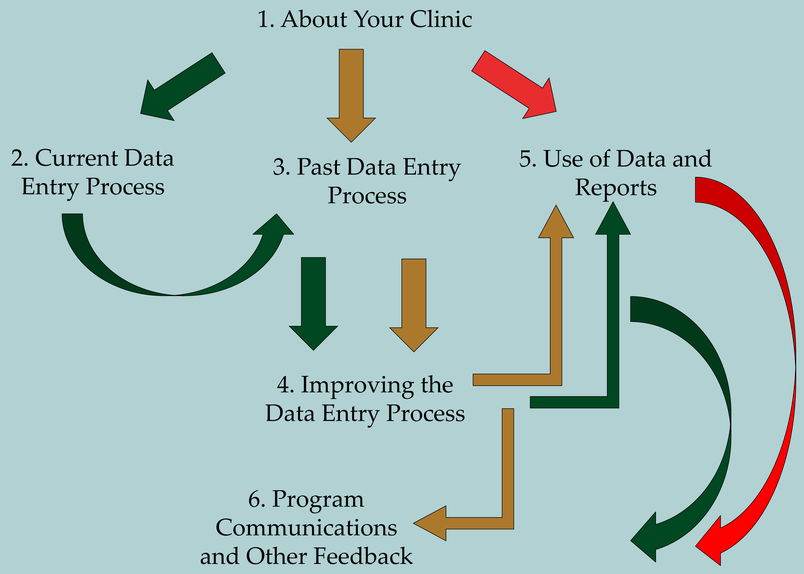
INTRODUCTION

The Hereditary Cancer Network (HCN) is a unique database that functions as a statewide surveillance network for tracking the use of cancer genetic counseling and testing services for actionable genes that are associated with Hereditary Breast and Ovarian Cancer (HBOC) and Lynch Syndrome (LS) cancers in Michigan. Beginning in 2013 as the *BRCA* Clinical Network, the database was used to assess trends in genetic counseling and testing, specifically to gather information on the population who are receiving genetic services for patients with HBOC. With the addition of LS and panel testing, the database was updated and renamed the HCN database. Multiple clinics throughout Michigan have partnered with MDHHS to enter non-identifiable patient data into the databases.



METHODS

A 40-question survey evaluation was created in Survey Monkey and was sent to our partner clinics to assess the benefits, challenges, and future directions to take regarding the database. The survey was split into sections based on if the clinic was currently entering data into the Hereditary Cancer Network (HCN) database, if the clinic had entered data into either database but had stopped in recent years, and those who have not entered data into the HCN database.



Key: Currently Entering Entered in the Past Never Entered

Response frequencies were not assessed for differences between groups due to a small sample size.

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RESULTS

Of the 20 responses, 17 (85%) were from clinics currently entering data, while the rest (3) have stopped entering data during the past few years. The main reasons these clinics stopped entering data were due to issues finding and training volunteers (15%) and having issues with grant funding (15%).

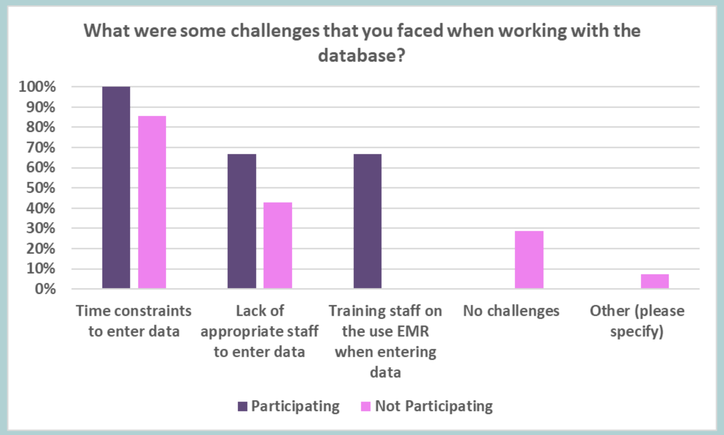
Challenges

On average, the clinics that have participated in this project see between 11 and 100+ patients each month (89%), which takes clinics between 6 and 10 hours per month to enter data into the database (64%).

The most frequently cited challenges associated with the database for both clinics currently entering data and those who are not were time constraint issues (100% vs. 86%), followed by having a lack of appropriate staff to enter the data (67% vs. 43%) (**Figure 1).**

When asked if there were any other significant challenges most responses indicated that there were no additional challenges (21%), however, some individuals expressed encountering issues with the high turnover rate for the Cancer Genomics Epidemiologist Position (21%) and issues due to the Data Sharing Agreement (DSA) process (14%).

Figure 1. Database Challenges



Benefits

The aspects of the database that the clinics felt were most helpful during the data entry process was that MDHHS was actional to feedback (31%) and provided actional changes to the format of the database (62%). Clinics also said that MDHHS provided adequate communication during the cooperative agreement (80%).

Providing clinics with aggregate data in addition to their clinic specific data was a benefit that the clinics mentioned. Clinics also mentioned interest in obtaining information on data by age of diagnosis, data by ethnicity, information on socioeconomic status, and information on why patients are not pursuing genetic testing.

Future Directions

Format Changes	Providing Help to Clinics	Clinic Reports	Increasing Clinic Participation
Clinics have suggested that auto filling the gene panels (38%) and adding more genes (15%) would make data entry more efficient. Other changes proposed by MDHHS staff include changing the race categories and making revisions for risk management strategies and reasons why genetic testing was not pursued.	Clinics have expressed interest in MDHHS either providing a data abstractor or a standardized mail-in sheet to the clinics that reflects the questions on the database to send in for data entry. Using Teleform has also been discussed as an option for data entry.	Clinics have stated that the data collected from the database is not generalizable to their entire population and have suggested that changing this would be beneficial to them. Clinics asked to have potential access to their clinic specific data as an excel file they can download from the database.	Clinics indicated that getting organizations to support Cancer Genomics could be a step towards increasing participation. Assisting clinics with data entry could also increase participation. Resolving issues with the DSA process could also increase participation.

DISCUSSION

This evaluation has allowed MDHHS to create an action plan of the steps that should be taken to make the appropriate changes to not only make the HCN database more efficient for data entry, but also to provide help to clinics who need additional resources to maintain active status with the database. Future surveillance workshops and focus groups are planned to collect further information on how we can assist clinics as we move forward with this project.

Conclusions and Future Steps:

Using the feedback from this survey and from future focus group activities, MDHHS hopes to better streamline the HCN database for more efficient data entry while expanding the surveillance efforts for HBOC and Lynch Syndrome cancers across Michigan.