Case Study 2 – Mammography

Sergiy Palguyev

spalguyev3@gatech.edu

1. *What types of data do we (as a health data analyst) need to capture in order to generate better evidence regarding mammograms? Provide examples and detail how it could be used to generate better evidence?*

The data required to be analyzed to make better evidence regarding mammograms include data on the following: early and late stage cancer occurrence, information on false positive, benign, non-metastatic, and metastatic detected tumor growths as well as data on procedures ordered after each screening.

Data on cancer occurrence could show a correlation between early detection and late-stage cancer occurrence (preferably a decrease). Information on tumor-growths and post-screening procedures could provide data on unnecessary medical procedures which may have been ordered for benign growths, inducing patient stress and trauma due to biopsies and/or surgeries. Depending on the amount of unnecessary radiation, surgery, and trauma the requirement for regular screening may lead to more risk than benefit of early detection [1].

2. *PCP's may recommend a screening based on USPTF guidelines, however patients are not obliged to heed such recommendations. What types of "decision support" could help patients decide if mammograms are right for them?*

Clinical decision support may be the most underestimated stage in saving a person's life. Considering the limited time each doctor has for a patient and the decisions, prescriptions, and diagnoses made have to be done with all available data to the PCP. Clinical decision support systems filter, sift, and priorities relevant data to health professionals so decisions can be made better, quicker, and with higher confidence [2].

In the case of mammograms, a CDS system can collect, analyse, and determine if common breast cancer causes are occurring for patients, which may trigger a need to be examined by the PCP. The most common causes of breast cancer are genetic history, lifetime estrogen exposure, dense breast tissue, obesity, radiation therapy, long-term alcoholism, age and ethnicity. Considering all of these factors, a PCP could not possibly consider all of these variables in detail for all of his/her patients as effectively as a CDS system [2].

Additionally, new information about cancer detection, correlations to lifestyle, or drug interactions can be added to the CDS system, which would

provide the additional alert and information to the PCP. This reduces human dependence in assuming the PCP would obtain all necessary information themselves about all aspects of a patient's health, life and history themselves.

3. *If patients who have received mammograms (like LS) wished to share their data for research, how could they do it?*

Sharing medical data has many benefits for both the patient and society. In a similar fashion as vaccine 'herd immunity' benefits the at-risk members of our population, opting-in to share medical data can provide the necessary information to determine corollary factors which may help the at-risk members of our population to prevent disease, chronic illness, and acute distress [3].

Currently, patient records are maintained by a medical health provider entity. Most patient's health records can be shared electronically between different health providers. The only way that data is shared is if one system queries another system, one system pushed data to another system, or the patient themselves requests their own health data, and carries the physical copies to another provider. In either case, the data is maintained by the health provider and can be used by them in any manner as long as the patient did not consciously opt-out of sharing of their information [6].

Due to the all or nothing approach, patients tend to decline sharing of their data by default. Certain studies have found that given a multi-tiered choice where certain parts of medical data are shared, patients would be more willing to opt-in to divulging their information at a specific level of openness [5].

Finally, a patient can proactively seek out and participate in clinical trials which may require them to share their data. Many clinical trials are government or institutions funded, and list their proposals with those entities. For a list of studies, a patient can search ClinicalTrials.gov, clinicalstudies.info.nih.gov or researchmatch.org.

References

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