

# Metadata Analysis Of Consent Outcome At Two Academic Medical Centers Participating In A Cancer Biobank

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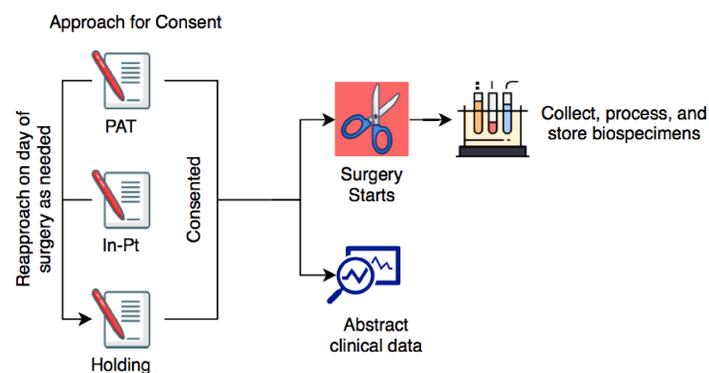
## Abstract

This project seeks to understand contributing factors in a patient's willingness to participate in a global biobanking project. To answer this question, we examined consent rates amongst adult patients undergoing surgery at two academic medical centers in the DC Metropolitan area, factoring in age, sex, tumor localization, tumor size, and location of consent approach. Our results showed that there was no statistically significant association between these factors and patients' willingness to consent. This lack of a relationship may indicate a general willingness to participate in an altruistic biobanking project among the population. Further analyses are needed to determine if other factors play a role in consent rates.

## Introduction

Global biobanking projects further scientific knowledge by establishing infrastructures that streamline cancer research.<sup>1,2</sup> Large scale analysis is made possible through the comprehensive knowledge gained from a repository of both biospecimens and clinical data.<sup>1</sup> Research on patient biobank participation rates reveals varied results with some studies reporting consent rates as low as 30%, while others report rates above 95%.<sup>2,3,4,5</sup> This discrepancy may be explained by situational variables in the consenting process and patient population differences. Minimal risk of and the altruistic nature of biobanking leads to general patient support, however, growing societal interest in how centers share patients' DNA and clinical data may be changing public and patient perceptions of biobanking.<sup>4,5,6</sup> This research seeks to understand which factors impact cancer biobank consent rates through the examination of descriptive data from an academic-linked health system in Washington, DC.

Figure 1. Summary of Research Flow



## Methods

Patients undergoing surgical procedures at two medical centers, MedStar Washington Hospital Center and MedStar Georgetown University Hospital (N=703), were approached for participation in a cancer biobank from October 2018 to October 2019. Patients were eligible if they were over 18 years of age, undergoing a solid tumor resection with a participating surgeon, and had a minimum tumor size of 1.5cm. Participation involves a one-time collection of resected tissue and blood during a planned surgical procedure, and providing access to clinical data from the electronic medical records. Patients were approached prior to surgery during pre-anesthesia testing (PAT) appointments, in pre-operative holding areas, and in-patient. Relationships between consent status, age, sex, tumor localization, size of tumor, were determined using chi-square tests.

## Results

Figure 2. Overall Consent Rate

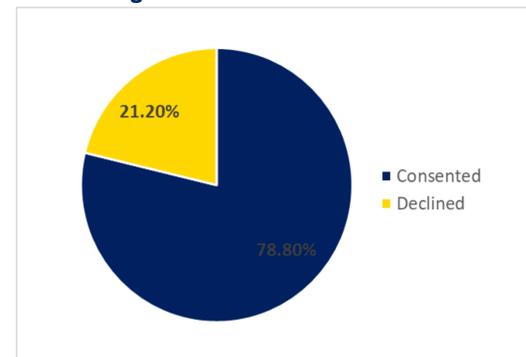


Figure 3. Consent Outcome by Location

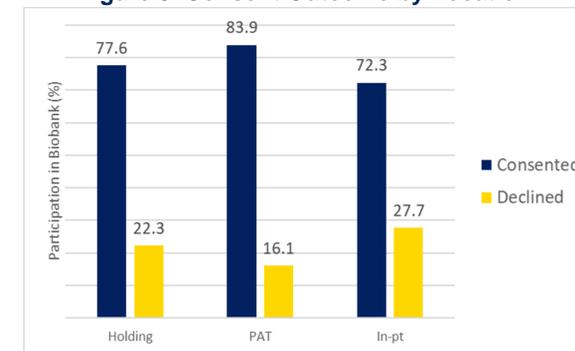


Figure 4. Consent Outcome by Age

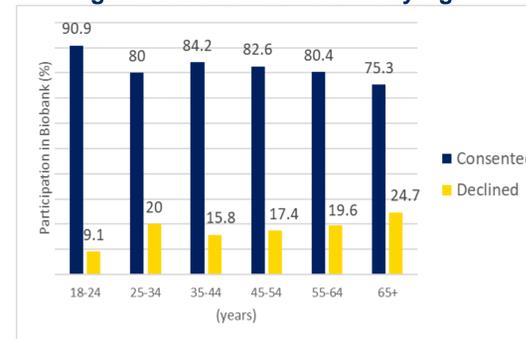
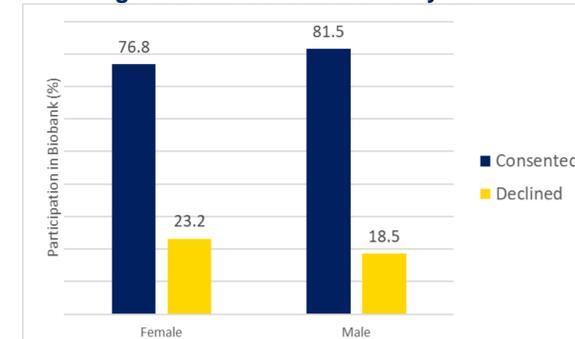


Figure 5. Consent Outcome by Sex



Note: there was no statistically significant association between patient age, sex, tumor localization, tumor size, and/or location of approach on consent status within our patient population.

## Limitations & Next Steps

This study was limited by not including more detailed demographic information and socioeconomic factors for the sampled population. Generalizability of the results is limited due to the sample size. Further research on this topic should address these limitations. Future investigation of this topic should include an examination of detailed demographic information (e.g., race and ethnicity), patient disease history, patient perception of research and biobanks, and socioeconomic factors (e.g., employment and education). A larger sample size would be beneficial in improving the accuracy of these results and minimize the impact of outliers on the analysis.

## Conclusion

While we did not find a statistically significant impact of age, sex, consent location, or tumor localization/size on consent outcome, we concluded that the majority of patients approached for enrollment were amenable to participating in a biobanking study. Further studies that extend analysis to patient demographics, disease history, and patient perceptions are needed to better understand a patient's decision to participate. Understanding the intrinsic and extrinsic motivators for participation are integral toward building sustainable models for maintaining a diverse enrollment in biobanks.

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