THE RELATIONSHIP BETWEEN HEALTH-RELATED QUALITY OF LIFE AND CLINICAL VERSUS SELF-REPORTED BODY MASS INDEX

Introduction

As healthcare research becomes more focused on a patient-centered approach, coupled with the proliferation of available “big” datasets at the patient-level, researchers are faced with the challenge of how to optimally answer their increasingly complex research questions.

- Claims and Electronic Health Record (EHR) data are extremely valuable at capturing the clinical aspects of a patient’s healthcare journey, including lab results, visits, and physician diagnoses. However, these data sources miss critical insights into a patient’s attitudes and behaviors around healthcare, including their health-related quality of life (HRQoL), which help to explain productivity, reasons for non-adherence, and, in some cases, disease severity.

- Patient-reported survey data combined with claims and EHR data help provide a more comprehensive picture of the patient. In addition, certain clinical information that is not always available in EHR or claims is often available in self-reported survey data. This integrated approach results in rich data and insights that cannot be gleaned from either data source in isolation.

- This study examines whether self-reported height and weight information can be used as a substitute for vitals that are not always available in clinical databases, such as claims data. This validation was performed by linking EHR data (with vitals) to self-report survey data at the patient-level. For linked patients, both survey and EHR data are available.

Objective

Using linked data from the patient-reported US Patient-Centered Research (PaCeR) and EHR data we seek to:

- Characterize patients with and without (refused to report) self-reported height and weight information
- Validate the use of data for BMI from nationally-representative, patient-reported survey versus EHR data by examining the correlation between values in each database
- Characterize patients with substantial differences in self-reported versus clinical BMI values
- Assess the relationship between HRQoL and BMI

Methods

Data Sources

- PaCeR (patient-reported survey data)
  - PaCeR is a self-administered, internet-based questionnaire from a sample of adults (age 18 or older)

- EHR data
  - Data from a large US ambulatory EHR database were used
  - The database comprised of: over 100,000 licensed providers, from a variety of specialties
  - Over 50 million unique patients, with over 28 million of those currently active (i.e., had at least 1 visit in the year 2016)
  - Respondents of PaCeR are recruited from an Internet panel using a random stratified sampling framework to ensure the demographic composition (with respect to age, gender, and ethnicity) is representative of the adult population based on US Census data

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Study Linkage

- Directly linking individuals in EHR and PaCeR databases was performed by comparing Protection Health Identification (PHI) from the EHR and Personal Identifiable Information (PI) from the survey in a HIPAA-compliant manner

- Information used for matching included:
  - First and last name
  - Address and zip code
  - Date of birth
  - Email (if available)
  - Phone number (if available)

- After the linking procedure was completed, BMI information was calculated for patients surveyed from 2015-2017

- The highly accurate probabilistic match yielded the study cohort with available BMI values (Figure 1)

Results

- After the linking process was completed, 9,949 PaCeR respondents were identified as having linked records in the EHR database (88% of all PaCeR respondents)

Understand the relationship between self-reported and clinical BMI values

- Characterize patients with and without (refused to report) self-reported height and weight information

- A total of 6,645 PaCeR-EHR linked patients had valid clinical BMI values from EHR: 6,235 (97.6%) with self-reported BMI from PaCeR and 210 (3.3%) without BMI (refused to report) (Table 1)

- Sociodemographic differences between those with and without self-reported BMI values showed that those who refused to report height and weight were significantly younger than those who had both self-report and clinical BMI values (0.01% vs 52.5 years, p<0.003) and more likely to be female (30.5% vs 67.7%, p<0.001).

- Among respondents who refused to provide height and weight information, the majority were obese (70%) based on their linked clinical BMI data, with an average BMI value of 35.67 (SD=5.93)

- Validable 96.7% of BMI from nationally-representative, patient-reported survey and EHR data by examining the correlation between values in each database:

- Among respondents with both sources of BMI data (n=6,235), BMI values among EHR and PaCeR cohorts were similar: 1.8% vs. 1.7% were underweight, 24.5% vs. 28.7% were normal, 26.6% vs. 23.8% were overweight, and 44.9% vs. 38.8% were obese (Table 2).

- Among the 6,235 respondents with both clinical and self-reported BMI data, a total of 4,933 respondents (79.1%) were categorized within the same BMI categories regardless of the source of data: EHR vs. PaCeR

- The average BMI value in EHR was 29.25 (SD=7.24), while the average BMI value in PaCeR was 29.25 (SD=7.24). The correlation between the two values was r=0.86, p<0.001.

- Clinical and self-reported BMI were also strongly correlated within respondents who had both values recorded within 3 months of each other. This resultant correlation was significantly stronger than when there was a lag between both values reported in PaCeR and EHR (r=0.80, p<0.001; difference between correlations r=0.06, p<0.001).

- Characterize patients with substantial differences in self-reported versus clinical BMI values

- Among the 6,235 patients with complete self-report and EHR BMI values, we assessed the relationship between both body weight reports and clinical BMI (r=0.86, p<0.001) BMI values.

- BMI was weakly and negatively associated with Physical Component Score (PCS) for both EHR (r=-0.27, p<0.001) and self-reported (r=-0.30, p<0.001) BMI values (Figure 3)

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Table 1. Characteristics of linked EHR-PaCeR cohort with versus without self-reported BMI

CONCLUSIONS

- Direct linking of PaCeR and EHR databases using HIPAA-compliant methods is successful, giving a sub-sample of linked patients for which both patient-reported data and clinical data can be used to address research questions

- Self-reported and clinical BMI data are highly correlated even within a 2-year lag, validating the use of self-reported BMI values (r=0.86; p<0.001) for research purposes

- Examination of BMI levels suggests that patients provide relatively accurate clinical information related to their health

- The datasets used in this study were large, integrated datasets by integrating objective clinical variables and patient-reported variables, is essential for addressing research questions more accurately and efficiently.

Future Directions

- Beyond validating patient-reported information, the critical value in linking syndicated survey information with EHR or claims is the potential associations between clinical outcomes and patient behavior

- From this study, further analyses may examine:
  - The relationship between patient-reported outcomes (PROs) and weight gain or loss based on longitudinal EHR data
  - The influence of socio-economic factors, such as income or number of people in the household, on these relationships.

Acknowledgments

This study is supported in part by the Commonwealth Fund, New York, NY, USA (Kantar Health, Tel Aviv, Israel, 3

Kantar Health, New York, NY, USA, and Kantar Health, San Mateo, CA, USA)

Kantar Health, New York, NY, USA

Kantar Health, San Mateo, CA, USA