Patient Engagement in Clinical Data Research Networks: The 2015 Greater Plains Collaborative Health and Medical Research Family Survey

**NOTICE:**

Dear Co-Authors:

This document incorporates all the latest data updates/fixes into the tables and into the parts of the text where values from those tables are referenced. This has two goals:

1. Being able to see the tables all in one place, in the same order they are referenced in the text.
2. To have one place from which to copy-paste the version of the text that has the up-to-date numbers.

However, please note this is **not** the official draft of the HMRFS paper. Currently, not all sections are included here. Moreover, this document is automatically generated by scripts and will be updated on a regular basis so any edits you make to it will be lost. Please continue treating the document [Updated GPC Outcomes paper 12 27 17.docx](https://cmh.box.com/s/y1yyzvr4jnzf2dy5s1l1tp797z70yn6i) as the working draft.

– Sincerely, Alex F. Bokov

# Abstract

**Objective:** The aim of this paper is to report on the initial obesity project from the Greater Plains Collaborative (GPC), a Clinical Data Research Network (CDRN) that is part of the Patient Centered Outcomes Research Institute (PCORI) National Patient Centered Clinical Research Network (PCORNet).

**Materials and Methods:** The electronic health records of 10 academic medical centers in 8 Midwestern states were coordinated in order to allow for a prospective multi-site obesity focused research project to be conducted. A survey was designed to assess participant willingness for themselves, and their children (if appropriate) to participate in research, as well as the use of their health record data for research.The survey was composed of 7 questions regarding interest in medical research, as well as basic demographic and health related information. Each site had a goal of 1,000 initial positive survey responses and 100 completed surveys.

**Results:** A cohort of 54,269 patients was created across the participating sites. The eligible patient population was 57.02% female, 89.33% Caucasian, 28.37% self-pay, with mean age of 27.5 (18) years with 27.19% overweight and 30.36% obese. In general, a third of respondents had participated in research previously and were positive about being contacted for additional research both for themselves and for their children. Responses did vary by site.

# Background and Significance

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## GPC Member Sites

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# Objective

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|  | Table 1, Survey Questions |
|  | (placeholder) |

# Materials and Methods

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## Institutional Review Board Process

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## Data Harmonization

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## Cohort Identification

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|  | Table 2, Eligibility Query |
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## Contacting Participants

Potential participants were contacted through one of three means: the United States Postal Service (USPS), email (EMAIL), or through the patient portal feature of the electronic medical record systems (PORTAL). The method of contact was selected by each HMRFS site PI based on logistics and local policy requirements. For a detailed list of site and contact method see Table 3. Whether adult patients, pediatric patients, or both were contact for the current study also varied by site (Table 3).

Table 3: Detailed list of site, adult/pediatric cohort, and contact method.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | WISC | UMN | KUMC | MCW | IOWA | UNMC | MCRF | UTHSCSA | CMH | UTSW |
| Cohort Makeup1 | A | P | P | A | P | A | P | P | P | P |
| Contact Method2 | Patient Portal | USPS | Email | Email | USPS | Email | Email | USPS | Email | Email |

1 Cohort makeup: A = adult only, P = pediatric only.

2 Contact method: USPS = United States Postal Service, Email = electronic mail on file, Portal = patient portal feature of the electronic medical record system.

Table 4a: Counts, Age, and BMI: Adult Index Patients

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | n | Responders = TRUE (%) | Completers = TRUE (%) | Age (mean (sd)) | pat\_bmi\_raw (mean (sd)) |
| MCW | 6000 | 560 (9.3) | 560 (9.3) | 36.15 (7.74) | 28.98 (7.29) |
| UNMC | 9849 | 360 (3.7) | 360 (3.7) | 35.37 (8.40) | 30.02 (7.82) |
| WISC | 4999 | 728 (14.6) | 728 (14.6) | 47.82 (15.10) | 30.35 (7.27) |

Table 4b: Counts, Age, and BMI: Pediatric Index Patients

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | n | Responders = TRUE (%) | Completers = TRUE (%) | Age (mean (sd)) | pat\_bmi\_raw (mean (sd)) |
| CMH | 3411 | 235 (6.9) | 222 (6.5) | 9.86 (5.14) | 21.99 (6.04) |
| KUMC | 6705 | 396 (5.9) | 396 (5.9) | 14.83 (5.91) | 22.63 (6.40) |
| MCRF | 5010 | 405 (8.1) | 404 (8.1) | 9.47 (5.01) | 20.30 (5.24) |
| IOWA | 5016 | 205 (4.1) | 178 (3.5) | 11.61 (5.97) | 23.12 (6.82) |
| UMN | 4992 | 81 (1.6) | 81 (1.6) | 11.27 (5.91) | 22.01 (6.20) |
| UTHSCSA | 4328 | 174 (4.0) | 115 (2.7) | 12.33 (4.75) | 22.21 (6.23) |
| UTSW | 3959 | 95 (2.4) | 95 (2.4) | 12.02 (4.85) | 24.10 (7.84) |

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## Analysis Plan

# Results

|  |  |
| --- | --- |
|  | Figure 1, Consort Diagram |
|  | (placeholder) |

Table 5: Cohort, Survey 1 and Survey 2 demographics

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Cohort | Survey 1 or 2 | Survey 2 | p |
| n | 54269 | 54269 | 3139 |  |
| Sex = Male (%) | 25169 (46.5) | 25169 (46.5) | 1349 ( 43.0) | \* |
| Race (%) |  |  |  | \* \* |
| Caucasian | 40434 (76.6) | 40434 (76.6) | 2753 ( 89.3) |  |
| African   American | 4437 ( 8.4) | 4437 ( 8.4) | 72 ( 2.3) |  |
| Native   American | 250 ( 0.5) | 250 ( 0.5) | 11 ( 0.4) |  |
| Asian | 1396 ( 2.6) | 1396 ( 2.6) | 62 ( 2.0) |  |
| Other | 4552 ( 8.6) | 4552 ( 8.6) | 139 ( 4.5) |  |
| No Answer | 1730 ( 3.3) | 1730 ( 3.3) | 45 ( 1.5) |  |
| Hispanic = TRUE (%) | 5290 ( 9.7) | 5290 ( 9.7) | 118 ( 3.8) | \* \* |
| Financial.Class (%) |  |  |  | \* \* |
| Unknown | 5030 ( 9.5) | 5030 ( 9.5) | 289 ( 9.4) |  |
| Medicare | 1018 ( 1.9) | 1018 ( 1.9) | 87 ( 2.8) |  |
| Medicaid | 9031 (17.1) | 9031 (17.1) | 284 ( 9.2) |  |
| Self-Pay | 11210 (21.2) | 11210 (21.2) | 875 ( 28.4) |  |
| Private   Insurance | 25206 (47.7) | 25206 (47.7) | 1511 ( 49.0) |  |
| Other | 1385 ( 2.6) | 1385 ( 2.6) | 38 ( 1.2) |  |
| Income (mean (sd)) | 58.20 (25.03) | 58.20 (25.03) | 61.97 (23.98) | \* \* |
| Age (mean (sd)) | 22.04 (15.43) | 22.04 (15.43) | 27.50 (18.35) | \* \* |
| BMI (%) |  |  |  | NS |
| Underweight | 130 ( 0.2) | 130 ( 0.2) | 7 ( 0.2) |  |
| Normal | 22360 (41.7) | 22360 (41.7) | 1292 ( 42.2) |  |
| Overweight | 15107 (28.2) | 15107 (28.2) | 832 ( 27.2) |  |
| Obese | 15978 (29.8) | 15978 (29.8) | 929 ( 30.4) |  |
| Responders = TRUE (%) | 3239 ( 6.0) | 3239 ( 6.0) | 3139 (100.0) |  |
| Completers = TRUE (%) | 3139 ( 5.8) | 3139 ( 5.8) | 3139 (100.0) |  |

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Table 6a: Participant demographics by site (Cohort)

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **CMH** | **KUMC** | **MCRF** | **MCW** | **IOWA** | **UMN** | **UNMC** | **UTHSCSA** | **UTSW** | **WISC** | **p** |
| **n** | 3411 | 6705 | 5010 | 6000 | 5016 | 4992 | 9849 | 4328 | 3959 | 4999 |  |
| **Sex = Male (%)** | 1727 (50.6) | 3252 (48.5) | 2535 (50.6) | 2999 (50.0) | 2508 (50.0) | 2496 (50.0) | 3523 (35.8) | 2393 (55.3) | 1911 (48.3) | 1825 (37.7) | \* \* |
| **Race (%)** |  |  |  |  |  |  |  |  |  |  | \* \* |
| Caucasian | 1876 (63.4) | 4584 (68.4) | 4587 (91.6) | 5070 (84.7) | 3875 (77.3) | 3589 (71.9) | 7483 (76.7) | 2744 (64.3) | 2108 (64.4) | 4518 (93.4) |  |
| African   American | 518 (17.5) | 772 (11.5) | 50 ( 1.0) | 331 ( 5.5) | 324 ( 6.5) | 532 (10.7) | 1280 (13.1) | 129 ( 3.0) | 393 (12.0) | 108 ( 2.2) |  |
| Native   American | 14 ( 0.5) | 17 ( 0.3) | 32 ( 0.6) | 28 ( 0.5) | 10 ( 0.2) | 57 ( 1.1) | 56 ( 0.6) | 2 ( 0.0) | 13 ( 0.4) | 21 ( 0.4) |  |
| Asian | 44 ( 1.5) | 126 ( 1.9) | 136 ( 2.7) | 251 ( 4.2) | 172 ( 3.4) | 227 ( 4.5) | 218 ( 2.2) | 43 ( 1.0) | 85 ( 2.6) | 94 ( 1.9) |  |
| Other | 492 (16.6) | 1063 (15.9) | 119 ( 2.4) | 295 ( 4.9) | 537 (10.7) | 62 ( 1.2) | 601 ( 6.2) | 1352 (31.7) | 26 ( 0.8) | 5 ( 0.1) |  |
| No Answer | 14 ( 0.5) | 136 ( 2.0) | 86 ( 1.7) | 9 ( 0.2) | 98 ( 2.0) | 525 (10.5) | 121 ( 1.2) | 0 ( 0.0) | 648 (19.8) | 93 ( 1.9) |  |
| **Hispanic = TRUE (%)** | 290 ( 8.5) | 602 ( 9.0) | 160 ( 3.2) | 239 ( 4.0) | 363 ( 7.2) | 200 ( 4.0) | 612 ( 6.2) | 1576 (36.4) | 1154 (29.1) | 94 ( 1.9) | \* \* |
| **Financial.Class (%)** |  |  |  |  |  |  |  |  |  |  | \* \* |
| Unknown | 46 ( 1.6) | 3170 (47.3) | 81 ( 1.6) | 0 ( 0.0) | 9 ( 0.2) | 0 ( 0.0) | 776 ( 7.9) | 604 (14.1) | 0 ( 0.0) | 344 ( 7.1) |  |
| Medicare | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 82 ( 1.4) | 0 ( 0.0) | 0 ( 0.0) | 468 ( 4.8) | 3 ( 0.1) | 23 ( 0.7) | 442 ( 9.1) |  |
| Medicaid | 1300 (43.9) | 1177 (17.6) | 1624 (32.4) | 204 ( 3.4) | 554 (11.0) | 194 ( 3.9) | 1073 (10.9) | 1509 (35.3) | 1294 (39.5) | 102 ( 2.1) |  |
| Self-Pay | 216 ( 7.3) | 0 ( 0.0) | 1 ( 0.0) | 3195 (53.4) | 2665 (53.1) | 400 ( 8.0) | 1233 (12.5) | 125 ( 2.9) | 390 (11.9) | 2985 (61.7) |  |
| Private   Insurance | 1310 (44.3) | 2351 (35.1) | 3304 (65.9) | 2456 (41.0) | 1764 (35.2) | 4398 (88.1) | 5530 (56.2) | 1685 (39.5) | 1442 (44.1) | 966 (20.0) |  |
| Other | 86 ( 2.9) | 0 ( 0.0) | 0 ( 0.0) | 47 ( 0.8) | 24 ( 0.5) | 0 ( 0.0) | 760 ( 7.7) | 344 ( 8.1) | 124 ( 3.8) | 0 ( 0.0) |  |
| **Income (mean (sd))** | 55.79 (26.66) | 63.01 (27.63) | 42.77 (15.32) | 62.89 (22.86) | NaN (NA) | 67.02 (24.34) | 55.69 (24.34) | 51.69 (27.07) | 63.06 (26.69) | 65.30 (22.84) | \* \* |
| **Age (mean (sd))** | 9.86 (5.14) | 14.83 (5.91) | 9.47 (5.01) | 36.15 (7.74) | 11.61 (5.97) | 11.27 (5.91) | 35.37 (8.40) | 12.33 (4.75) | 12.02 (4.85) | 47.82 (15.10) | \* \* |
| **BMI (%)** |  |  |  |  |  |  |  |  |  |  | \* \* |
| Underweight | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 1 ( 0.0) | 23 ( 0.5) | 0 ( 0.0) | 16 ( 0.2) | 0 ( 0.0) | 76 ( 1.9) | 14 ( 0.3) |  |
| Normal | 1275 (37.4) | 4629 (69.0) | 2633 (52.6) | 2000 (33.3) | 1737 (34.6) | 1664 (33.3) | 2893 (29.4) | 2598 (60.0) | 1877 (47.4) | 1054 (24.5) |  |
| Overweight | 1060 (31.1) | 1061 (15.8) | 1377 (27.5) | 2001 (33.4) | 1554 (31.0) | 2282 (45.7) | 2832 (28.8) | 763 (17.6) | 828 (20.9) | 1349 (31.3) |  |
| Obese | 1076 (31.5) | 1015 (15.1) | 1000 (20.0) | 1997 (33.3) | 1700 (33.9) | 1046 (21.0) | 4108 (41.7) | 967 (22.3) | 1176 (29.7) | 1893 (43.9) |  |
| **Responders = TRUE (%)** | 235 ( 6.9) | 396 ( 5.9) | 405 ( 8.1) | 560 ( 9.3) | 205 ( 4.1) | 81 ( 1.6) | 360 ( 3.7) | 174 ( 4.0) | 95 ( 2.4) | 728 (14.6) | \* \* |
| **Completers = TRUE (%)** | 222 ( 6.5) | 396 ( 5.9) | 404 ( 8.1) | 560 ( 9.3) | 178 ( 3.5) | 81 ( 1.6) | 360 ( 3.7) | 115 ( 2.7) | 95 ( 2.4) | 728 (14.6) | \* \* |

Table 6b: Participant demographics by site (Responders)

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | CMH | KUMC | MCRF | MCW | IOWA | UMN | UNMC | UTHSCSA | UTSW | WISC | p |
| **n** | 235 | 396 | 405 | 560 | 205 | 81 | 360 | 174 | 95 | 728 |  |
| **Sex = Male (%)** | 127 (54.0) | 193 ( 48.7) | 218 (53.8) | 241 ( 43.0) | 94 (45.9) | 47 ( 58.0) | 91 ( 25.3) | 95 (54.6) | 43 ( 45.3) | 255 ( 35.0) | \* |
| **Race (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Caucasian | 156 (78.8) | 319 ( 80.6) | 387 (95.6) | 515 ( 92.0) | 182 (88.8) | 69 ( 85.2) | 335 ( 93.6) | 102 (59.0) | 63 ( 81.8) | 680 ( 93.4) |  |
| African American | 18 ( 9.1) | 24 ( 6.1) | 4 ( 1.0) | 7 ( 1.2) | 7 ( 3.4) | 0 ( 0.0) | 6 ( 1.7) | 4 ( 2.3) | 2 ( 2.6) | 11 ( 1.5) |  |
| Native American | 0 ( 0.0) | 0 ( 0.0) | 1 ( 0.2) | 5 ( 0.9) | 1 ( 0.5) | 0 ( 0.0) | 0 ( 0.0) | 1 ( 0.6) | 0 ( 0.0) | 4 ( 0.5) |  |
| Asian | 2 ( 1.0) | 7 ( 1.8) | 4 ( 1.0) | 18 ( 3.2) | 4 ( 2.0) | 2 ( 2.5) | 5 ( 1.4) | 2 ( 1.2) | 2 ( 2.6) | 17 ( 2.3) |  |
| Other | 22 (11.1) | 42 ( 10.6) | 8 ( 2.0) | 13 ( 2.3) | 8 ( 3.9) | 0 ( 0.0) | 12 ( 3.4) | 64 (37.0) | 0 ( 0.0) | 1 ( 0.1) |  |
| No Answer | 0 ( 0.0) | 4 ( 1.0) | 1 ( 0.2) | 2 ( 0.4) | 3 ( 1.5) | 10 ( 12.3) | 0 ( 0.0) | 0 ( 0.0) | 10 ( 13.0) | 15 ( 2.1) |  |
| **Hispanic = TRUE (%)** | 12 ( 5.1) | 18 ( 4.5) | 10 ( 2.5) | 14 ( 2.5) | 7 ( 3.4) | 1 ( 1.2) | 8 ( 2.2) | 52 (29.9) | 7 ( 7.4) | 16 ( 2.2) | \* |
| **Financial.Class (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Unknown | 2 ( 1.0) | 189 ( 47.7) | 4 ( 1.0) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 20 ( 5.6) | 26 (15.0) | 0 ( 0.0) | 58 ( 8.0) |  |
| Medicare | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 8 ( 1.4) | 0 ( 0.0) | 0 ( 0.0) | 8 ( 2.2) | 0 ( 0.0) | 0 ( 0.0) | 71 ( 9.8) |  |
| Medicaid | 68 (34.3) | 46 ( 11.6) | 84 (20.7) | 12 ( 2.1) | 10 ( 4.9) | 0 ( 0.0) | 13 ( 3.6) | 46 (26.6) | 16 ( 20.8) | 17 ( 2.3) |  |
| Self-Pay | 16 ( 8.1) | 0 ( 0.0) | 0 ( 0.0) | 296 ( 52.9) | 110 (53.7) | 6 ( 7.4) | 26 ( 7.2) | 1 ( 0.6) | 7 ( 9.1) | 433 ( 59.5) |  |
| Private Insurance | 108 (54.5) | 161 ( 40.7) | 317 (78.3) | 241 ( 43.0) | 84 (41.0) | 75 ( 92.6) | 275 ( 76.4) | 88 (50.9) | 49 ( 63.6) | 149 ( 20.5) |  |
| Other | 4 ( 2.0) | 0 ( 0.0) | 0 ( 0.0) | 3 ( 0.5) | 1 ( 0.5) | 0 ( 0.0) | 18 ( 5.0) | 12 ( 6.9) | 5 ( 6.5) | 0 ( 0.0) |  |
| **Income (mean (sd))** | 61.84 (28.97) | 70.59 (26.33) | 44.92 (13.15) | 64.57 (22.02) | NaN (NA) | 75.49 (20.59) | 61.76 (24.13) | 55.75 (29.49) | 72.86 (27.22) | 65.32 (22.99) | \* |
| **Age (mean (sd))** | 9.69 (5.07) | 13.90 (5.67) | 9.51 (4.80) | 37.32 (7.64) | 11.22 (5.65) | 9.80 (6.29) | 37.12 (8.29) | 12.82 (4.77) | 11.81 (3.88) | 48.26 (15.00) | \* |
| **BMI (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Underweight | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 3 ( 1.5) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 1 ( 1.1) | 3 ( 0.5) |  |
| Normal | 83 (35.3) | 291 ( 73.5) | 230 (56.8) | 186 ( 33.2) | 92 (44.9) | 26 ( 32.1) | 120 ( 33.3) | 108 (62.1) | 49 ( 51.6) | 150 ( 23.1) |  |
| Overweight | 80 (34.0) | 54 ( 13.6) | 102 (25.2) | 178 ( 31.8) | 58 (28.3) | 42 ( 51.9) | 88 ( 24.4) | 34 (19.5) | 11 ( 11.6) | 207 ( 31.9) |  |
| Obese | 72 (30.6) | 51 ( 12.9) | 73 (18.0) | 196 ( 35.0) | 52 (25.4) | 13 ( 16.0) | 152 ( 42.2) | 32 (18.4) | 34 ( 35.8) | 289 ( 44.5) |  |
| **Completers = TRUE (%)** | 222 (94.5) | 396 (100.0) | 404 (99.8) | 560 (100.0) | 178 (86.8) | 81 (100.0) | 360 (100.0) | 115 (66.1) | 95 (100.0) | 728 (100.0) | \* |

Table 6c: Participant demographics by site (Completers)

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | CMH | KUMC | MCRF | MCW | IOWA | UMN | UNMC | UTHSCSA | UTSW | WISC | p |
| **n** | 222 | 396 | 404 | 560 | 178 | 81 | 360 | 115 | 95 | 728 |  |
| **Sex = Male (%)** | 120 (54.1) | 193 (48.7) | 217 (53.7) | 241 (43.0) | 81 (45.5) | 47 (58.0) | 91 (25.3) | 61 (53.0) | 43 (45.3) | 255 (35.0) | \* |
| **Race (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Caucasian | 148 (79.6) | 319 (80.6) | 386 (95.5) | 515 (92.0) | 163 (91.6) | 69 (85.2) | 335 (93.6) | 75 (65.8) | 63 (81.8) | 680 (93.4) |  |
| African American | 14 ( 7.5) | 24 ( 6.1) | 4 ( 1.0) | 7 ( 1.2) | 4 ( 2.2) | 0 ( 0.0) | 6 ( 1.7) | 0 ( 0.0) | 2 ( 2.6) | 11 ( 1.5) |  |
| Native American | 0 ( 0.0) | 0 ( 0.0) | 1 ( 0.2) | 5 ( 0.9) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 1 ( 0.9) | 0 ( 0.0) | 4 ( 0.5) |  |
| Asian | 2 ( 1.1) | 7 ( 1.8) | 4 ( 1.0) | 18 ( 3.2) | 3 ( 1.7) | 2 ( 2.5) | 5 ( 1.4) | 2 ( 1.8) | 2 ( 2.6) | 17 ( 2.3) |  |
| Other | 22 (11.8) | 42 (10.6) | 8 ( 2.0) | 13 ( 2.3) | 5 ( 2.8) | 0 ( 0.0) | 12 ( 3.4) | 36 (31.6) | 0 ( 0.0) | 1 ( 0.1) |  |
| No Answer | 0 ( 0.0) | 4 ( 1.0) | 1 ( 0.2) | 2 ( 0.4) | 3 ( 1.7) | 10 (12.3) | 0 ( 0.0) | 0 ( 0.0) | 10 (13.0) | 15 ( 2.1) |  |
| **Hispanic = TRUE (%)** | 12 ( 5.4) | 18 ( 4.5) | 9 ( 2.2) | 14 ( 2.5) | 4 ( 2.2) | 1 ( 1.2) | 8 ( 2.2) | 29 (25.2) | 7 ( 7.4) | 16 ( 2.2) | \* |
| **Financial.Class (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Unknown | 2 ( 1.1) | 189 (47.7) | 4 ( 1.0) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 20 ( 5.6) | 16 (14.0) | 0 ( 0.0) | 58 ( 8.0) |  |
| Medicare | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 8 ( 1.4) | 0 ( 0.0) | 0 ( 0.0) | 8 ( 2.2) | 0 ( 0.0) | 0 ( 0.0) | 71 ( 9.8) |  |
| Medicaid | 62 (33.3) | 46 (11.6) | 83 (20.5) | 12 ( 2.1) | 8 ( 4.5) | 0 ( 0.0) | 13 ( 3.6) | 27 (23.7) | 16 (20.8) | 17 ( 2.3) |  |
| Self-Pay | 14 ( 7.5) | 0 ( 0.0) | 0 ( 0.0) | 296 (52.9) | 92 (51.7) | 6 ( 7.4) | 26 ( 7.2) | 1 ( 0.9) | 7 ( 9.1) | 433 (59.5) |  |
| Private Insurance | 104 (55.9) | 161 (40.7) | 317 (78.5) | 241 (43.0) | 77 (43.3) | 75 (92.6) | 275 (76.4) | 63 (55.3) | 49 (63.6) | 149 (20.5) |  |
| Other | 4 ( 2.2) | 0 ( 0.0) | 0 ( 0.0) | 3 ( 0.5) | 1 ( 0.6) | 0 ( 0.0) | 18 ( 5.0) | 7 ( 6.1) | 5 ( 6.5) | 0 ( 0.0) |  |
| **Income (mean (sd))** | 63.83 (28.65) | 70.59 (26.33) | 45.01 (13.05) | 64.57 (22.02) | NaN (NA) | 75.49 (20.59) | 61.76 (24.13) | 60.00 (30.64) | 72.86 (27.22) | 65.32 (22.99) | \* |
| **Age (mean (sd))** | 9.68 (5.08) | 13.90 (5.67) | 9.51 (4.81) | 37.32 (7.64) | 11.42 (5.68) | 9.80 (6.29) | 37.12 (8.29) | 12.91 (4.84) | 11.81 (3.88) | 48.26 (15.00) | \* |
| **BMI (%)** |  |  |  |  |  |  |  |  |  |  | \* |
| Underweight | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 3 ( 1.7) | 0 ( 0.0) | 0 ( 0.0) | 0 ( 0.0) | 1 ( 1.1) | 3 ( 0.5) |  |
| Normal | 81 (36.5) | 291 (73.5) | 230 (56.9) | 186 (33.2) | 85 (47.8) | 26 (32.1) | 120 (33.3) | 74 (64.3) | 49 (51.6) | 150 (23.1) |  |
| Overweight | 77 (34.7) | 54 (13.6) | 102 (25.2) | 178 (31.8) | 49 (27.5) | 42 (51.9) | 88 (24.4) | 24 (20.9) | 11 (11.6) | 207 (31.9) |  |
| Obese | 64 (28.8) | 51 (12.9) | 72 (17.8) | 196 (35.0) | 41 (23.0) | 13 (16.0) | 152 (42.2) | 17 (14.8) | 34 (35.8) | 289 (44.5) |  |

Sample size and demographics varied by site (Table 6a). Sample size by site varied from a maximum of 9,849 (UNMC) to a minimum of 3,411 (CMH). The proportion of the cohort that was male at each site varied widely from 55.30% to 35.80%. The proportion of African Americans in the cohort at each site also varied widely (17.50% - 1.00%) as did the proportion of Native Americans (1.10% - 0.00%) and the proportion of Asians (4.50% - 1.00%). Insurance status type varied widely by site as well; the most common were self-pay (61.70% - 0.00%), Medicaid (43.90% - 2.10%) and private insurance (88.10% - 20.00%). *Approximated annual income ranged from $40,000-70,000/year, and mean age for the target child ranged from 9.47 years –12.33. Three sites targeted adults as they did not have children in their systems, and their average age was 36.15 (7.74) years or 47.83 (15.1) years. Finally, baseline body mass index (BMI) for the participating adult individual calculated from self-reported height and weight on the survey ranged from 20.30 (5.24) to 30.35 (7.27).* Table 6b indicates these same variables by site for responders to Survey 1, and Table 6c indicates the same variables by site for Survey 2 respondents.

## EHR Predictors of Participation

Prior to analysis the 54,269 records were randomly assigned to a development (N=10,751), validation (N=10,748), and test subsets (N=32,770) in order to avoid overfitting and bias due to within-sample testing. All analysis decisions were made based on the developmental subset. The first goal was to identify candidate predictors for survey participation from among the variables available for all members of the cohort (i.e. those listed in Table 5).

Accordingly, for each candidate predictor, a separate logistic regression model was fit to the developmental subset with responder status as the outcome. Discrete variables with multiple levels were broken up into an equal number of indicator variables. This not only informed the decision of which predictor and random-effect variables but also in some cases how condense their levels. Table 8 shows the results of these 85 tests.

Table 7: Preliminary assessment of variables via univariate logistic regression.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | estimate | std.error | statistic | conf.low | conf.high | p.value |
| Adult Patient | 0.46064 | 0.082586 | 5.5776 | 0.29885 | 0.62274 | \* \* \* |
| Age | 0.01871 | 0.0024003 | 7.7948 | 0.013973 | 0.023386 | \* \* \* |
| BMI=NA | 1.1126 | 0.23568 | 4.7207 | 0.62528 | 1.5536 | \* \* \* |
| BMI=Underweight | -11.783 | 188.2 | -0.062609 | NA | -1.2353 |  |
| BMI=Normal | -0.097697 | 0.084201 | -1.1603 | -0.26364 | 0.066585 |  |
| BMI=Overweight | -0.04238 | 0.093268 | -0.45439 | -0.22762 | 0.13822 |  |
| BMI=Obese | 0.051607 | 0.089791 | 0.57475 | -0.12629 | 0.2259 |  |
| BMI percentile | -0.0043635 | 0.0020999 | -2.078 | -0.0084218 | -0.00018221 |  |
| BMI raw | 0.0092202 | 0.0051561 | 1.7882 | -0.0010283 | 0.019189 |  |
| Hispanic | -0.8766 | 0.19957 | -4.3925 | -1.2914 | -0.50599 | \* \* \* |
| Income | 6.1014e-06 | 1.8402e-06 | 3.3156 | 2.4956e-06 | 9.7114e-06 | \* |
| Insurance=Self-Pay | 0.50242 | 0.091803 | 5.4728 | 0.32043 | 0.68051 | \* \* \* |
| Insurance=Medicaid | -0.76336 | 0.14482 | -5.2709 | -1.0582 | -0.48934 | \* \* \* |
| Insurance=Other | -1.1959 | 0.45329 | -2.6382 | -2.2304 | -0.41511 |  |
| Insurance=Medicare | 0.4891 | 0.24417 | 2.0031 | -0.021753 | 0.94074 |  |
| Insurance=Unknown | -0.03698 | 0.14304 | -0.25853 | -0.32738 | 0.23436 |  |
| Insurance=Private Insurance | 0.038139 | 0.082513 | 0.46222 | -0.12383 | 0.19977 |  |
| Insurance=NA | -0.42469 | 0.3103 | -1.3686 | -1.0943 | 0.13421 |  |
| Male | 0.0078434 | 0.082635 | 0.094916 | -0.15446 | 0.16962 |  |
| Pediatric Site | -0.5204 | 0.082584 | -6.3014 | -0.6824 | -0.35851 | \* \* \* |
| Race=Caucasian | 0.78813 | 0.11888 | 6.6294 | 0.56096 | 1.0276 | \* \* \* |
| Race=African American | -1.1715 | 0.24852 | -4.7139 | -1.6977 | -0.71739 | \* \* \* |
| Race=Other | -0.54862 | 0.18484 | -2.9681 | -0.93055 | -0.20322 |  |
| Race=Native American | -12.785 | 224.57 | -0.056931 | -85.211 | -2.9035 |  |
| Race=Asian | -0.15943 | 0.27737 | -0.57478 | -0.74989 | 0.34571 |  |
| Race=No Answer | -0.56023 | 0.30946 | -1.8104 | -1.2287 | -0.0030692 |  |
| Race=NA | -0.48388 | 0.30993 | -1.5613 | -1.153 | 0.074228 |  |
| Recruitment=mychart | 1.1827 | 0.101 | 11.71 | 0.98206 | 1.3782 | \* \* \* |
| Recruitment=post | -0.68355 | 0.11181 | -6.1135 | -0.90798 | -0.46922 | \* \* \* |
| Recruitment=email | -0.14949 | 0.084518 | -1.7687 | -0.31435 | 0.017116 |  |
| Site=WISC | 1.1827 | 0.101 | 11.71 | 0.98206 | 1.3782 | \* \* \* |
| Site=UMN | -1.3875 | 0.25546 | -5.4314 | -1.9302 | -0.9219 | \* \* \* |
| Site=UNMC | -0.69134 | 0.13348 | -5.1794 | -0.96178 | -0.4377 | \* \* \* |
| Site=MCW | 0.54417 | 0.11137 | 4.8862 | 0.32131 | 0.75829 | \* \* \* |
| Site=UTSW | -1.0395 | 0.24884 | -4.1776 | -1.5663 | -0.58474 | \* \* \* |
| Site=MCRF | 0.40644 | 0.12213 | 3.328 | 0.16087 | 0.6402 | \* |
| Site=UTHSCSA | -0.4513 | 0.17996 | -2.5078 | -0.82227 | -0.11444 |  |
| Site=CMH | 0.16135 | 0.16355 | 0.98657 | -0.17283 | 0.46984 |  |
| Site=KUMC | -0.18694 | 0.13448 | -1.3901 | -0.45922 | 0.068817 |  |
| Site=IOWA | -0.19291 | 0.15267 | -1.2636 | -0.50415 | 0.095605 |  |

## HMRFS Survey

3,139 individuals completed the HMRFS survey across all sites. Of these respondents, most self-reported as female (78.17%), Caucasian (92.04%), and having private insurance (78.60%). The modal range of self-reported household income was approximately $50,000-$100,000/year and average age was 42.2 years with a baseline mean BMI of 28.85 (7.48). These data indicate the sample that responded to the HMRFS survey was similar to the overall cohort of eligible patients. Responses indicate that across all sites (Table 9A), 29.44% of respondents had participated previously in medical research. Respondents were generally open to investigators contacting them about possible participation in studies (42.71% yes; 38.93% maybe). Key factors in making the decision to participate in medical research included: topic of research (62.98%), time (48.20%), doctor recommendation (22.05%), reimbursement (17.23%), and child involvement (23.89%). Of respondents who had children (64.13%), they were also generally positive about possibly allowing their child to take part in medical research (27.21% yes; 27.21% maybe) (Table 9B). The factors for deciding whether their children could participate in research followed the same order of priority as above. Most participants were in favor of their medical information being used for research (35.32% fantastic idea, 48.61% good idea) and even more so if the data being used for medical research is de-identified (32.45% fantastic idea, 49.55% good idea).

Table 8a: Survey responses.

|  |  |
| --- | --- |
|  | Overall |
| **n** | 3139 |
| **research (%)** |  |
| PreferNotAnswer | 3 ( 0.1) |
| No | 1838 (58.6) |
| Unsure | 374 (11.9) |
| Yes | 924 (29.4) |
| **possible\_research (%)** |  |
| PreferNotAnswer | 69 ( 2.2) |
| No | 504 (16.1) |
| Maybe | 1215 (38.9) |
| Yes | 1333 (42.7) |
| **PR\_Me\_DependsAbout = TRUE (%)** | 1977 (63.0) |
| **PR\_Me\_If\_Spec = TRUE (%)** | 240 ( 7.6) |
| **PR\_Me\_Time = TRUE (%)** | 1513 (48.2) |
| **PR\_Me\_Doctor\_Op = TRUE (%)** | 692 (22.0) |
| **PR\_Me\_Compensation = TRUE (%)** | 541 (17.2) |
| **PR\_Me\_Involve\_Child = TRUE (%)** | 750 (23.9) |
| **PR\_Me\_Other = TRUE (%)** | 70 ( 2.2) |
| **children\_in\_home (%)** |  |
| PreferNotAnswer | 13 ( 0.4) |
| No | 1011 (32.4) |
| None | 95 ( 3.0) |
| Yes | 2001 (64.1) |
| **res\_talk\_family (%)** |  |
| PreferNotAnswer | 35 ( 1.1) |
| No | 1102 (35.5) |
| Unsure | 967 (31.2) |
| Yes | 1000 (32.2) |
| **research\_feeling (%)** |  |
| Unsure | 331 (10.7) |
| PreferNotAnswer | 23 ( 0.7) |
| NotGoodIdea | 30 ( 1.0) |
| Fantastic | 1095 (35.3) |
| GoodIdea | 1507 (48.6) |
| Terrible | 12 ( 0.4) |
| Other | 102 ( 3.3) |
| **deid\_data (%)** |  |
| Unsure | 379 (12.2) |
| PreferNotAnswer | 21 ( 0.7) |
| Fantastic | 1004 (32.4) |
| GoodIdea | 1533 (49.5) |
| Terrible | 28 ( 0.9) |
| NotGoodIdea | 72 ( 2.3) |
| Other | 57 ( 1.8) |
| **height\_in (mean (sd))** | 66.26 (4.80) |
| **weight\_value\_lbs (mean (sd))** | 181.12 (57.02) |
| **bp\_hypten\_self (%)** |  |
| PreferNotAnswer | 9 ( 0.3) |
| No | 2479 (80.8) |
| Unsure | 64 ( 2.1) |
| Yes | 516 (16.8) |
| **chole\_triigl\_hyperlip\_self (%)** |  |
| PreferNotAnswer | 11 ( 0.4) |
| No | 2281 (74.6) |
| Unsure | 159 ( 5.2) |
| Yes | 605 (19.8) |
| **bloodsugar\_diabetes\_self (%)** |  |
| PreferNotAnswer | 9 ( 0.3) |
| No | 2670 (87.5) |
| Unsure | 95 ( 3.1) |
| Yes | 276 ( 9.0) |
| **cancer\_anytype\_self (%)** |  |
| Unsure | 80 ( 2.6) |
| PreferNotAnswer | 13 ( 0.4) |
| No | 2691 (88.8) |
| None | 95 ( 3.1) |
| Yes | 150 ( 5.0) |
| **hpb\_hprtnsn (%)** |  |
| PreferNotAnswer | 10 ( 0.3) |
| No | 888 (29.0) |
| Unsure | 200 ( 6.5) |
| Yes | 1967 (64.2) |
| **chole\_trig\_hyperlip (%)** |  |
| PreferNotAnswer | 11 ( 0.4) |
| No | 973 (32.0) |
| Unsure | 341 (11.2) |
| Yes | 1718 (56.5) |
| **elev\_bs\_diabetes (%)** |  |
| PreferNotAnswer | 10 ( 0.3) |
| No | 1488 (49.1) |
| Unsure | 188 ( 6.2) |
| Yes | 1344 (44.4) |
| **cancer\_anytype (%)** |  |
| Unsure | 140 ( 4.6) |
| PreferNotAnswer | 12 ( 0.4) |
| No | 1388 (45.7) |
| None | 95 ( 3.1) |
| Yes | 1402 (46.2) |
| **sex (%)** |  |
| PreferNotAnswer | 12 ( 0.4) |
| Male | 662 (21.4) |
| Female | 2421 (78.2) |
| Other | 2 ( 0.1) |
| **age (mean (sd))** | 42.23 (12.19) |
| **latino\_origin (%)** |  |
| 5 | 4 ( 0.1) |
| PreferNotAnswer | 25 ( 0.8) |
| No | 2880 (94.1) |
| Yes | 150 ( 4.9) |
| **White = TRUE (%)** | 2889 (92.0) |
| **Black = TRUE (%)** | 76 ( 2.4) |
| **American\_Indian = TRUE (%)** | 37 ( 1.2) |
| **Asian = TRUE (%)** | 68 ( 2.2) |
| **OtherRace = TRUE (%)** | 39 ( 1.2) |
| **PreferNotAnswer = TRUE (%)** | 28 ( 0.9) |
| **income (%)** |  |
| 0-$24999 | 274 ( 8.9) |
| $25000-$49999 | 481 (15.6) |
| $50000-$99999 | 1002 (32.4) |
| $100000-$199999 | 765 (24.7) |
| $200000+ | 182 ( 5.9) |
| PreferNotAnswer | 359 (11.6) |
| Unsure | 30 ( 1.0) |
| **insurance (%)** |  |
| Unsure | 28 ( 0.9) |
| Uninsured | 62 ( 2.0) |
| PreferNotAnswer | 55 ( 1.8) |
| MedicareMedicaid | 322 (10.4) |
| Other | 194 ( 6.3) |
| Private | 2428 (78.6) |
| **education (%)** |  |
| HighSchool | 233 ( 7.5) |
| Bachelors | 1028 (33.2) |
| Doctorate | 218 ( 7.0) |
| Masters | 559 (18.1) |
| Associates | 385 (12.4) |
| SomeCollege | 518 (16.7) |
| SomeHighSchool | 43 ( 1.4) |
| NoHighSchool | 33 ( 1.1) |
| PreferNotAnswer | 34 ( 1.1) |
| Other | 43 ( 1.4) |
| **household (%)** |  |
| I live alone | 208 ( 6.7) |
| 1-2 | 1259 (40.7) |
| 3-4 | 1200 (38.8) |
| 5-6 | 361 (11.7) |
| 7+ | 43 ( 1.4) |
| PreferNotAnswer | 21 ( 0.7) |
| **language = Yes (%)** | 179 ( 6.0) |
| **a\_bmi (mean (sd))** | 28.85 (7.48) |

Table 8b: Survey responses regarding children.

Table 8b: Survey responses regarding children.

|  |  |
| --- | --- |
|  | Overall |
| n | 2001 |
| children\_research (%) |  |
| Maybe | 797 (40.0) |
| No | 613 (30.8) |
| No\_Kids | 4 ( 0.2) |
| PreferNotAnswer | 36 ( 1.8) |
| Yes | 542 (27.2) |
| PR\_Child\_DependsAbout = TRUE (%) | 1132 (56.6) |
| PR\_Child\_If\_Spec = TRUE (%) | 133 ( 6.6) |
| PR\_Child\_TiChild = TRUE (%) | 771 (38.5) |
| PR\_Child\_Doctor\_Op = TRUE (%) | 529 (26.4) |
| PR\_Child\_Compensation = TRUE (%) | 247 (12.3) |
| PR\_Child\_Involve\_Child = TRUE (%) | 275 (13.7) |
| PR\_Child\_Other = TRUE (%) | 58 ( 2.9) |

# Discsussion

# Conclusion

# Supplementary Materials

Table S1: Participant demographics by recruitment method (Cohort)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | email | post | mychart | p |
| n | 34934 | 14336 | 4999 |  |
| Sex = Male (%) | 15947 (45.7) | 7397 (51.6) | 1825 (37.7) | \* \* |
| Race (%) |  |  |  | \* \* |
| Caucasian | 25708 (76.3) | 10208 (71.5) | 4518 (93.4) |  |
| African   American | 3344 ( 9.9) | 985 ( 6.9) | 108 ( 2.2) |  |
| Native   American | 160 ( 0.5) | 69 ( 0.5) | 21 ( 0.4) |  |
| Asian | 860 ( 2.6) | 442 ( 3.1) | 94 ( 1.9) |  |
| Other | 2596 ( 7.7) | 1951 (13.7) | 5 ( 0.1) |  |
| No Answer | 1014 ( 3.0) | 623 ( 4.4) | 93 ( 1.9) |  |
| Hispanic = TRUE (%) | 3057 ( 8.8) | 2139 (14.9) | 94 ( 1.9) | \* \* |
| Financial.Class (%) |  |  |  | \* \* |
| Unknown | 4073 (12.1) | 613 ( 4.3) | 344 ( 7.1) |  |
| Medicare | 573 ( 1.7) | 3 ( 0.0) | 442 ( 9.1) |  |
| Medicaid | 6672 (19.8) | 2257 (15.8) | 102 ( 2.1) |  |
| Self-Pay | 5035 (14.9) | 3190 (22.3) | 2985 (61.7) |  |
| Private   Insurance | 16393 (48.6) | 7847 (55.0) | 966 (20.0) |  |
| Other | 1017 ( 3.0) | 368 ( 2.6) | 0 ( 0.0) |  |
| Income (mean (sd)) | 56.33 (24.51) | 59.95 (26.75) | 65.30 (22.84) | \* \* |
| Age (mean (sd)) | 22.71 (13.71) | 11.71 (5.62) | 47.82 (15.10) | \* \* |
| BMI (%) |  |  |  | \* \* |
| Underweight | 93 ( 0.3) | 23 ( 0.2) | 14 ( 0.3) |  |
| Normal | 15307 (43.8) | 5999 (41.9) | 1054 (24.5) |  |
| Overweight | 9159 (26.2) | 4599 (32.1) | 1349 (31.3) |  |
| Obese | 10372 (29.7) | 3713 (25.9) | 1893 (43.9) |  |
| Responders = TRUE (%) | 2051 ( 5.9) | 460 ( 3.2) | 728 (14.6) | \* \* |
| Completers = TRUE (%) | 2037 ( 5.8) | 374 ( 2.6) | 728 (14.6) | \* \* |