## Multimedia Appendix 10: Respondents' concern about scenarios described in vignettes with a focus on study disease and entity that monitors social media user activity.

| CONCERN EXPRESSED IN RESPONSE TO VIGNETTES |  | N (\%) |
| :--- | :--- | :--- |
| Cancer vignette: A cancer research team at a major research university is looking for participants to take part in a <br> clinical trial. They use a software tool that automatically search the past 2 years of Twitter activity to locate accounts <br> that mentioned "cancer" anywhere within the text of a Twitter message. Once a relevant message is identified, the <br> research team sends a public "@reply" to the original message, asking if the user is interested in participating in the <br> clinical trial. |  |  |
| Concern about users' Twitter activity being monitored as described <br> above for the purpose of recruitment into a clinical trial |  |  |
|  | Very concerned | $110(18.2 \%)$ |
|  | Somewhat concerned | $190(31.5 \%)$ |
|  | Not too concerned | $181(30.0 \%)$ |
|  | Not concerned at all | $102(16.9 \%)$ |
| Factors that most impacted level of concern about the above scenario <br> (respondents could select up to 2) | $20(3.3 \%)$ |  |
|  | Nature of the disease/medical condition being <br> monitored for | $163(27.0 \%)$ |
|  | Whether the text of a Twitter message was <br> monitored vs. a hashtag | $152(25.2 \%)$ |
|  | How far back in your Twitter history the <br> researchers might look | $167(27.7 \%)$ |
|  | Who is doing the research | $162(26.9 \%)$ |
|  | Whether a human being or a computer | $148(24.5 \%)$ |


|  | researchers contacted you |  |
| :---: | :---: | :---: |
| Comfort level if a researcher approached them in person at a relevant medical facility |  |  |
|  | More comfortable in-person | 176 (29.2\%) |
|  | Neither more or less comfort | 209 (34.7\%) |
|  | Less comfortable in-person | 137 (22.8\%) |
|  | Don't know | 81 (13.4\%) |
| Obesity vignette: Scientists at a pharmaceutical company are looking for participants to take part in a clinical trial to test a drug designed to treat obesity. They use a software tool that allows them to automatically search the past 6 months of Twitter activity to locate accounts that mentioned "obesity", "overweight" or "lose weight" within the text of a Twitter message. Once a relevant message is identified, the scientists send a public "@reply" to the original message, asking if the user is interested in participating in the clinical trial. |  |  |
| Concern about users' Twitter activity being monitored as described above for the purpose of recruitment into a clinical trial |  |  |
|  | Very concerned | 112 (18.6\%) |
|  | Somewhat concerned | 187 (31.0\%) |
|  | Not too concerned | 181 (30.0\%) |
|  | Not concerned at all | 99 (16.4\%) |
|  | Don't know | 24 (4.0\%) |
| Factors that most impacted level of concern about the above scenario (respondents could select up to 2) |  |  |
|  | Nature of the disease/medical condition being monitored for | 169 (28.0\%) |
|  | Whether the text of a Twitter message was monitored vs. a hashtag | 149 (24.7\%) |
|  | How far back in your Twitter history the researchers might look | 147 (24.4\%) |
|  | Who is doing the research | 286 (47.4\%) |


|  | Whether a human being or a computer program is analyzing your Twitter messages | 123 (20.4\%) |
| :---: | :---: | :---: |
|  | Use of Twitter as a method in which the researchers contacted you | 187 (31.0\%) |
| Comfort level if a researcher approached them in person at a relevant medical facility |  |  |
|  | More comfortable in-person | 161 (26.7\%) |
|  | Neither more or less comfort | 225 (37.3\%) |
|  | Less comfortable in-person | 144 (23.9\%) |
|  | Don't know | 73 (12.1\%) |
| HPV vignette: A health officer at a state public health office is looking for participants to take part in a study to understand adoption of the HPV vaccination against cervical cancer. The health officer uses a software tool that allows them to search 2 years of Twitter activity to locate accounts that ever included the hashtag "\#HPV" or "\#HPVvaccine" or "cervical cancer prevention" in a Twitter message. Once identified, the health officer sends a public "@reply" to the original message, asking if the user is interested in participating in the clinical trial. |  |  |
| Concern about users' Twitter activity being monitored as described above for the purpose of recruitment into a clinical trial |  |  |
|  | Very concerned | 123 (20.4\%) |
|  | Somewhat concerned | 175 (29.0\%) |
|  | Not too concerned | 175 (29.0\%) |
|  | Not concerned at all | 101 (16.8\%) |
|  | Don't know | 29 (4.8\%) |
| Factors that most impacted level of concern about the above scenario (respondents could select up to 2) |  |  |
|  | Nature of the disease/medical condition being monitored for | 202 (33.5\%) |
|  | Whether the text of a Twitter message was monitored vs. a hashtag | 162 (26.9\%) |
|  | How far back in your Twitter history the | 126 (20.9\%) |


|  | researchers might look |  |
| :---: | :---: | :---: |
|  | Who is doing the research | 271 (44.9\%) |
|  | Whether a human being or a computer program is analyzing your Twitter messages | 122 (20.2\%) |
|  | Use of Twitter as a method in which the researchers contacted you | 173 (28.7\%) |
| Comfort level if a researcher approached them in person at a relevant medical facility |  |  |
|  | More comfortable in-person | 169 (28.0\%) |
|  | Neither more or less comfort | 233 (38.6\%) |
|  | Less comfortable in-person | 136 (22.6\%) |
|  | Don't know | 65 (10.8\%) |
| HIV/AIDS vignette: A research team at a major research university is looking for participants to take part in a clinical trial investigating treatment options for HIV/AIDS. A team member manually searches Twitter activity to locate accounts that used the hashtags "\#HIV", "\#AIDS", or "\#SexwithMen" within the last 3 months. Once identified, the researchers send a public "@reply" to the original message, asking if the user is interested in participating in the clinical trial. |  |  |
| Concern about users' Twitter activity being monitored as described above for the purpose of recruitment into a clinical trial |  |  |
|  | Very concerned | 174 (28.9\%) |
|  | Somewhat concerned | 175 (29.0\%) |
|  | Not too concerned | 132 (21.9\%) |
|  | Not concerned at all | 96 (15.9\%) |
|  | Don't know | 26 (4.3\%) |
| Factors that most impacted level of concern about the above scenario (respondents could select up to 2) |  |  |
|  | Nature of the disease/medical condition being monitored for | 243 (40.3\%) |
|  | Whether the text of a Twitter message was | 154 (25.5\%) |



|  | Nature of the disease/medical condition being <br> monitored for | $163(27.0 \%)$ |
| :--- | :--- | :--- |
|  | Whether the text of a Twitter message was <br> monitored vs. a hashtag | $146(24.2 \%)$ |
|  | How far back in your Twitter history the <br> researchers might look | $143(24.7 \%)$ |
|  | Who is doing the research | Whether a human being or a computer <br> program is analyzing your Twitter messages |
|  | Use of Twitter as a method in which the <br> researchers contacted you | $173(28.7 \%)$ |
| Comfort level if a researcher <br> medical facility | More comfortable in-person | $269(44.6 \%)$ |
|  | Neither more or less comfort them in person at a relevant | $126(26.7 \%)$ |
|  | Less comfortable in-person | $122(20.3 \%)$ |
|  | Don't know | $52(8.4 \%)$ |

