Privacy Concerns vs. Personalized Health Content: Two Sides of Social Media Use for Pregnant Individuals

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Table of Contents

Original Manuscript **4**
Supplementary Files **22**
0 ..... **22**
Figures **23**
Figure 1 ..... **24**
Figure 2 ..... **25**

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Abstract

Background: Frequently lacking immediate access to care providers, pregnant individuals often seek information online to address their evolving physical and mental health needs.

Objective: Given social media's increasing prominence as a source of news and information, this study investigated the extent to which patients may be willing to disclose personal health information to social media companies in order to obtain personalized health content.

Methods: We designed and deployed a survey to pregnant patients worldwide electronically in 2023. We utilized the classical Internet Users' Information Privacy Concerns (IUIPC) model to examine how privacy concerns modulate pregnant individuals' behaviors and beliefs about risk and trust while using social media for health purposes.

Results: Among 317 respondents who initiated the survey, 265 respondents remained in the study providing complete responses. Among them, 55% indicated willingness to provide their personalized health information in exchange to receiving personalized health content via social media, while 26% were uncertain and 19% opposed. Parallel to pregnant individuals' willingness to share, we find that they have more heightened privacy concerns and their use of social media for information seeking is largely impacted by their trust with the platforms. Our estimated IUIPC model results are statistically significant and qualitatively align with the classic IUIPC model for the general population previously found in an e-commerce context.

Conclusions: We find that more than half of the pregnant individuals are open to sharing their personal health information to receive personalized content about health via social media, although they have more privacy concerns than the general population. This study emphasizes a needed policy around protection of health data on social media for the pregnancy population and beyond.

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ABSTRACT

Background: Frequently lacking immediate access to care providers, pregnant individuals often seek information online to address their evolving physical and mental health needs. Given social media's increasing prominence as a source of news and information, this study investigated the extent to which patients may be willing to disclose personal health information to social media companies in order to obtain personalized health content.

Methods: We designed and deployed a survey to pregnant patients worldwide electronically in 2023. We utilized the classical Internet Users' Information Privacy Concerns (IUIPC) model to examine how privacy concerns modulate pregnant individuals' behaviors and beliefs about risk and trust while using social media for health purposes.

Findings: Among 317 respondents who initiated the survey, 265 respondents remained in the study providing complete responses. Among them, 55% indicated willingness to provide their personalized health information in exchange to receiving personalized health content via social media, while 26% were uncertain and 19% opposed. Parallel to pregnant individuals' willingness to share, we find that they have more heightened privacy concerns and their use of social media for information seeking is largely impacted by their trust with the platforms. Our estimated IUIPC model results are statistically significant and qualitatively align with the classic IUIPC model for the general population previously found in an e-commerce context.

Interpretation: We find that more than half of the pregnant individuals are open to sharing their personal health information to receive personalized content about health via social media, although they have more privacy concerns than the general population. This study emphasizes a needed policy around protection of health data on social media for the pregnancy population and beyond.

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Key Words (MeSH): Privacy concerns; trust; pregnancy; social media, health information seeking

INTRODUCTION

Background

Modern internet technology has brought tremendous promise as a health platform for social support and information exchange.[1,2] The trend of searching for health information online has gained momentum,[3–5] particularly since the COVID-19 pandemic where healthcare services were over-burdened to address individual questions.[6,7] Instead, patients gathered online, using social media in particular, for appropriate tools and resources to empower themselves, cope with stress, and strengthen positive interactions. This health seeking behavior is particularly true among pregnant patients.[8] Pregnancy is a vulnerable period that exposes patients to heightened anxiety, depression, and stress, leading to adverse maternal, infant, and family outcomes, disproportionately affecting disadvantaged families.[9,10] The negative impact can be mitigated by interventions from healthcare providers.[11,12] However, disparities in the distance to healthcare, health literacy, socioeconomic status, and neighborhood characteristics strangulate equitable access to clinical interventions.[12–14] As a result, many patients resort to online information seeking and social support to relieve stressors and resolve individual needs during pregnancy.[15] In fact, people of childbearing ages are one of the most active members in the digital space in the U.S,[16,17] with estimated three-quarters of the US pregnant population seeking pregnancy and birth information online.[18] Social media is an overwhelmingly popular source for pregnancy information, with myriad social media account and influencers distributing a wide range of information and offering venues for discussion.[8,19] For example, research showed that online support and interventions improved health outcomes of pregnant patients with gestational diabetes mellitus (GDM), and individualized health interventions resulted in lower odds of GDM.[20]

Privacy and risk concerns are important to consider when using digital health technologies for

pregnancy.[21,22] Research has shown that individuals often possess both risk and privacy concerns when turning to social media for health information.[23–26] Pregnancy privacy concerns have heightened since the overturn of Dobbs v. Jackson by the Supreme Court in the U.S., which had protected an individual's right to abortion. This has resulted in variable state laws criminalizing certain reproductive healthcare and has amplified privacy concerns for pregnant patients seeking out online information on abortions and storing reproductive health information on personal apps.[27] However, despite significant privacy concerns, patients' overwhelming health needs remain unmet, leaving social media as a main source for seeking health information.

Objective

Given the increasing need for information and the limited access to prompt responses from healthcare providers regarding pregnancy-related inquiries, there is a notable tension between privacy concerns and the demand for personalized health communication. Despite potential privacy issues, we aim to investigate how willing pregnant individuals are to share their personal data on social media platforms in return for more tailored and customized health content that meets their specific needs.

METHODS

Study design

This is a survey study. Participants are eligible if they are at least 18 years old and are currently pregnant or were pregnant within the past 2 years of the survey. We developed and deployed a survey on the Prolific website in March 2023. Prolific is an online platform that connects researchers with a pool of pre-screened study participants globally. Earlier studies have shown that participants recruited from Prolific provide high-quality results regarding user perception about software and

digital platforms.[28,29] The survey questions were hosted on a survey software, Qualtrics®. The survey questions are listed in Appendix Table A1. Each participant received a $1 reward for answering the questions per the site's rule. Our study has been approved by IRB category II exempt, and all participants had agreed on the online consent form before they could take the online survey.

Variables and data sources

The survey draws on a conceptual model, the Internet Users' Information Privacy Concerns (IUIPC) model by Malhotra et al. (2004). The survey comprises 41 questions: 22 focus on the conceptual model, with 7-point scale Likert, and the remaining on demographic information, social media questions related to health, and three quality-check questions. IUIPC was designed to evaluate if concerns about information privacy sway an individual's intent to adopt digital technology in e-commerce context.[30] Since then, numerous studies have delved into various populations' privacy concerns across varied digital technologies based on IUIPC model.[25,31–36] However, based on our knowledge, no study has utilized the IUIPC model from the perspective of pregnant patients' privacy concerns when seeking health information on social media. We aim to uncover how information privacy concerns may influence pregnant patients' intention to reveal personal health data to receive precise pregnant health content through social media.

Figure 1 depicts the structure of the basic theoretical IUIPC model, consisting of five major constructs: collection, control, awareness, trusting beliefs, and risk beliefs.[30] Collection, control, and awareness are three first-order constructs, which are directly measured through survey items. IUIPC is a second-order construct, or a latent construct, which is estimated by the three first-order constructs. In this study, the collection construct refers to the extent of an individual's privacy concerns about whether it is worth revealing their personal information to the social media companies. The control construct measures the degree to which individuals feel they have control

over their personal data and know how the data will be collected, used, and shared. The awareness construct gauges the level of a user's privacy concern regarding their awareness of social media companies' transparency and the proper handling of their information. Trusting beliefs refer to the degree to which people believe an entity is trustworthy in protecting their personal information, whereas risk beliefs refer to the expectation of a potential loss when sharing personal information to the entity. In the present study, the personal information would be personal health information and the entity would be social media companies conscious of health. IUIPC integrates trusting beliefs and risk beliefs to elucidate why a user may have an intention to adopt a new technology for certain benefits. In the present study context, IUIPC reflects social media users' concerns about social media companies' collection of personal information, the user's control over the collected information, and the user's awareness of how the collected information is used, which in turn affects users' intention to reveal personal health information to receive customized health information through social media.

Figure 1. Internet Users' Information Privacy Concerns (IUIPC)

Research hypotheses

Previous research demonstrated that users with greater privacy concerns regarding social media tend to have lower trust towards these platforms.[34,36] Therefore, we hypothesize:

H1: For pregnant individuals, IUIPC will have a negative effect on their trusting beliefs.

There is often an inverse relationship between trusting beliefs and risk beliefs because trust implies a firm belief in the reliability of something, while risk indicates the possibility of negative outcomes. When users' exhibit higher privacy concerns towards social media, it implies they perceive a greater risk associated with its use.[34,36] Thus, we propose the following two hypotheses:

H2: For pregnant individuals, IUIPC will have a positive effect on their risk beliefs.

H3: For pregnant individuals, their trusting beliefs have a negative effect on their risk beliefs.

Research has shown that trust in a specific technology positively influences individuals' intention to explore that technology.[37] A pregnant individual will share their personal information in exchange for health information through social media if they trust the companies and find the specific health content valuable enough to justify the privacy trade-off. Previous studies also showed that trust played a crucial role when adopting social media.[31,32,38] Therefore, we further hypothesize the following:

H4: For pregnant individuals, trusting beliefs have a positive effect on the intention to reveal personal health information to social media companies to receive personalized health content through social media.

A previous study on risk beliefs concerning a social networking service (SNS) suggests a perception of risk by users made them less likely to adopt social media.[36] If pregnant individuals perceive that sharing personal health information with social media companies for health purposes is risky, then this perspective will result in a lower intention to use. Thus, we hypothesize the following:

H5: For pregnant individuals, risk beliefs have a negative effect on the intention to reveal personal health information to social media companies in exchange for personalized health information through social media.

Measurement model and structural equation model evaluation

We estimated the IUIPC model and assessed the measurement model results according to the following four criteria, unidimensionality, item reliability, construct reliability, and convergent validity.[39,40] We used Stata SE 17, and Stata add-on package, plssem for the analysis. Dimensionality is the number of constructs that a group of items or a group of survey questions reflect in a formative measurement model. We conducted principal component factor analysis to examine eigenvalues and kept only the constructs whose eigen values are greater than one. Item reliability refers to the extent to which an observed item can reliably measure its corresponding

construct. We assume reliability when the standardized loading of an item on their constructs is greater than 0.7. Construct reliability refers to the degree to which the items of a construct consistently and accurately measure that construct. Two commonly used metrics to evaluate the construct reliability is Cronbach's alpha and Dillon-Goldstein's rho, and their general acceptable values are greater than 0.7. Convergent validity assesses the degree to which a set of items measure the same construct that are indeed related to each other. Average Variance Extracted (AVE) measures the average amount of variance in the items explained by the construct. AVE values should be greater than 0.5, meaning that the construct explains 50% or more of the variance in its indicators. We use the R-squared value and Goodness of Fit to evaluate the predictive power of IUIPC, which is a structural model. The acceptable threshold for Goodness of Fit is 0.36.[41] Lastly, variance Inflation Factor (VIF) values are utilized to check for multicollinearity, with a common threshold of 2.5.

RESULTS

Descriptive statistics

A total of 317 respondents answered the survey. After removing non-completed surveys and responses that did not meet our quality criteria based on the three quality check questions, 265 respondents remained in the study. Table 1 presents the socio-demographic information of the respondents. The largest racial group is White, 61.9%, and the second largest racial group is African American, 30.9%. Nearly 75% of the respondents have a bachelor's degree or above, which matches our expectation and is consistent with previous studies that surveyed participants on the Prolific website whose users have higher levels of education than the general population.[42]

Most participants (96.6%) responded that they receive their pregnancy health information from their doctors, and 69.4% mentioned internet or social media as a pregnancy health information source. Regarding specific social media platforms, 74.7% (N=198) used Instagram, 69.4% (N=184) Facebook, 55.5% (N=147) Tiktok, and 30.1% (N=81) Twitter (Now X). A small percentage, 3.4%

(N=9), responded that they used PatientsLikeMe, a health-focused online platform. There were 4.2% (N=11) who also named other SNS including Reddit, LinkedIn, YouTube, Pinterest, and WhatsApp. Lastly, 0.74% (N=2) of participants did not use social media. Overall, 99.2% of respondents used one or more SNS, and among those, 55.1% answered that they are comfortable to share their personal health information to receive customized health content on social media, whereas 26% were uncertain and 19% responded not comfortable in sharing.

Table 1. Descriptive statistics of the 265 participants

Race		Marital status	
Asian	8 (3.0%)	Married	126 (47.6%)
African American	82 (30.9%)	In a relationship	111 (41.9%)
Multi-race	5 (1.9%)	Single*	28 (10.6%)
White	164 (61.9%)	Education	
Other	6 (2.3%)	High school	23 (8.7%)
Ethnicity		Some college	44 (16.6%)
Hispanic	14 (5.3%)	Bachelor’s degree	141 (53.2%)
Non-Hispanic	228 (86.0%)	Master’s degree	47 (17.7%)
Prefer not to say	23 (8.7%)	Doctoral degree	2 (0.8%)
		Professional degree	8 (3.0%)

*Note: Single includes separated, divorced, widowed, and single.

Outcome data

Of those who were willing to share their personal health information to receive personalized, all of them use one or more than one popular social media, such as Facebook, Instagram, Tiktok or Twitter. Of those who responded not comfortable to the question, 47% are because of privacy concerns, and equally 47% are due to lack of trust of social media companies and influencers. One respondent commented on the political environment as a concern for sharing. There were no significant differences in ethnicity, race, or education level (bachelor's or more vs. Up to high school) in the response. Among the top four SNS users, 56.1% Instagram users, 56.5% of Facebook users, 64.0% of Tiktok users, and 65.4% of Twitter (now X) users were comfortable sharing personal health

information in exchange for more customized social media content. Between people who use, and do not use Tiktok, and between those who do, or do not use Twitter (now X), the difference in their willingness was significant.

Measurement model result

The collection, control, and awareness constructs all had eigenvalues greater than one. Thus, they were kept in the model as unidimensional constructs. The loadings and constructs' AVE values are shown in Appendix Tables A2 and A3. As Appendix Table A2 shows, most of the bolded diagonal block loadings are greater than 0.7 for the corresponding constructs, which demonstrate the items' strong reliability. Although a few items on the second order construct, IUIPC, are slightly lower than 0.7, we still accept this model result because these loadings are not trivial, ranging from 0.44 to 0.58. In addition, they are still statistically significant. Furthermore, as Figure 2 shows, among the estimated coefficients for the structural model, all the path coefficients are statistically significant and are in the directions as we expected, which confirms those items are meaningful for our model. In Table A2 we can see the two commonly used metrics of evaluating the construct reliability, Cronbach's alpha and Dillon-Goldstein's rho, are greater than 0.7, above the acceptable threshold value, indicating good construct reliability of our model. As Table A3 shows, all constructs' AVE values are greater than 0.5 except for the IUIPC, the second order construct. This AVE value is lower than 0.5 because of the lower loadings of the control and awareness items on IUIPC as Table 2 shows. Lastly, the model's composite reliability scores, Dillon-Goldstein's rho of all constructs (Table A2), are higher than 0.7, indicating an internal consistency of the IUIPC model.

Structural model result

The IUIPC model's average R-squared value is 0.4146, indicating a moderate effect. The absolute Good of Fit is 0.4923, which is higher than 0.36, the acceptable threshold.[41] All VIF values were

lower than 2.5, the commonly suggested threshold value (see Table A4 in Appendix), indicating little multicollinearity concern for our structural model. As Figure 2 shows, all path coefficients are statistically significant and in the directions that we expected, and most of them are qualitatively consistent with the original IUIPC model estimates from the study by Malhotra et al. (2004) focused on the privacy concerns of general internet users in an e-commerce scenario. Our estimated IUIPC model results and the five path coefficients of the structural model supports all the five hypotheses that we constructed.

Figure 2. Internet Users' Information Privacy Concerns (IUIPC) model with estimated path coefficients

DISCUSSION

Interpretation

In the original study by Malhotra et al. (2004),[30] the coefficient between the collection construct and IUIPC was not statistically significant ($\beta = 0.75$, not significant). However, we observed significance in this coefficient in our model ($\beta = 0.849$, $p < .001$). This finding was supported by another study by Zeng et al. (2020), which examined the privacy concerns on SNS among the general population and found this coefficient to be at similar significant levels to ours ($\beta = 0.36$, $p < .001$), albeit smaller.[36] This may indicate that pregnant individuals are more careful about sharing their health related information with social media companies, reflecting their privacy concerns. In the present study, the loadings for both the control and awareness constructs are slightly lower than those in the original Malhotra et al. study. Both our study and Zeng et al. [36] have loadings of Control and Awareness that are lower than results from the classic model by Maholtra et al. This potentially indicates that today, social media users' information control and social media users' awareness of the social media company's practice have the same strong impact on their IUIPC

concerns, although quantitatively lower than previously found in the e-commerce setting in 2004.

Our results suggest, not surprisingly, that pregnant individuals are concerned about their personal health data being collected by social media companies, losing control of their health information collected by social media companies, and how their health information would be used. Therefore, prior to collecting personal health information, social media companies with health-related components should explain clearly that the purpose of data collection is to create personalized health content for each user's benefit. Furthermore, social media companies should guarantee that patients can easily access any information they have provided to ensure users' right to control the data. Users should also be informed of their privacy policies in clear language, including if and how their health data will be used. This transparency and control over their data may help build trust between pregnant individuals and the social media companies.

The IUIPC in our model negatively affects trusting beliefs, evidenced by a path coefficient of $\beta = -0.408$ ($p < .001$), which is consistent but stronger than the original model's path coefficient of $\beta = -0.34$ ($p < .001$). This difference may suggest that the pregnant individuals' privacy concerns on trust are more pronounced than those found in the classical model.[30] The IUIPC construct in our model positively influences risk beliefs, with a coefficient of $\beta = 0.442$ ($p < .001$) which is larger than the coefficient in the original model, $\beta = 0.26$ ($p < .001$) as well. This suggests that in addition to trust, pregnant individuals' privacy concerns also have a stronger influence on their risk beliefs than the general population in e-commerce context.

In our model, trusting beliefs negatively impact risk beliefs, with a coefficient of $\beta = -0.362$ ($p < .001$) which is stronger than the original model's coefficient of $\beta = -0.15$ ($p < .001$). This suggests that if a pregnant individual's trust in a social media company related to health increases, their

perceived risks would decrease more than general population in the e-commerce context as previously found .[30] Trusting beliefs positively influence pregnant individuals' intention to reveal health information to receive customized health content through social media with a coefficient of $\beta = 0.266$ ($p < .001$) which is larger than the original model, $\beta = 0.23$ ($p < .001$). Conversely, risk beliefs have a negative effect on this intention with a coefficient of $\beta = -0.281$ ($p < .001$), which is smaller in magnitude than the original model, $\beta = -0.63$ ($p < .001$). This is consistent with a previous study which showed that trust is positively associated with adoption intention while privacy concerns are negatively associated with the adoption intention of technology in healthcare.[43] Our model results suggest that the impact of trusting beliefs on pregnant patients' intention to adopt health related social media is greater than as found in Malhotra et al. Conversely, pregnant patients' risk beliefs have a smaller effect on this intention compared to the general population. This may indicate that in our study context, trust plays a more significant role than risk concerns in the adoption decision. Therefore, social media companies focusing on providing personalized health content should prioritize building trust among their pregnant users.

Limitations

This study has limitations. First, since we distributed the survey to participants globally, various cultural differences, religions, and government policies drive the perceptions of the participants. Second, our survey did not specify any social media or online health forum specifically but refer to a general health-conscious social media. Considering the privacy policies of various health-related social media platforms differ, users' trusting beliefs and risk beliefs may differ by social media platforms. Third, our sample size is limited to online survey participants which may be exposed to a built-in bias towards the digital space. Our sample also had a higher education level and thus potentially higher online literacy than the general population.

Conclusion

In the present study, we examined pregnant individuals' willingness to disclose personal health information in exchange for more personalized health content via social media. Based on a classical model on internet users' information privacy concerns, we designed and deployed a survey among pregnant patients. Our results indicate that pregnant individuals' social privacy concerns are more pronounced in both trusting beliefs and risk beliefs compared to the concerns identified in the classic model. Future studies should investigate additional factors such as sociodemographic moderating effects that may influence pregnant individuals' intentions to use social media or online health platforms for health information seeking or communication. The major implication of our study is that social media companies focusing on delivering personalized health content on pregnancy should prioritize building trust with their users. This involves clearly informing patients about what health data is collected, providing them with easy access to their own health data, keeping them informed about how their health data is used, and including information on privacy protection policies. Given pregnant individuals' needs for online health information seeking and the level of openness towards information sharing found from this study, we argue that more solutions are needed to mitigate users' privacy and risk concerns and protect their data against exploiting forces on social media.

Authors' contributions

HH initiated the study, designed the survey, analyzed the data, conducted model estimation and analyses, wrote and revised the manuscript.
YL provided advice on the paper's structure, assisted with revising the model and writing the paper.
MS contributed a clinical perspective, reviewed and revised the manuscript, and provided references for related healthcare studies.
QL assisted in data collection, data cleaning, literature review, and paper format polishing.
YZ initiated the study, provided funding for data collection, designed and deployed the survey, analyzed data and model, and wrote and revised the manuscript.

Statement on conflicts of interest

The authors have no conflict of interest.

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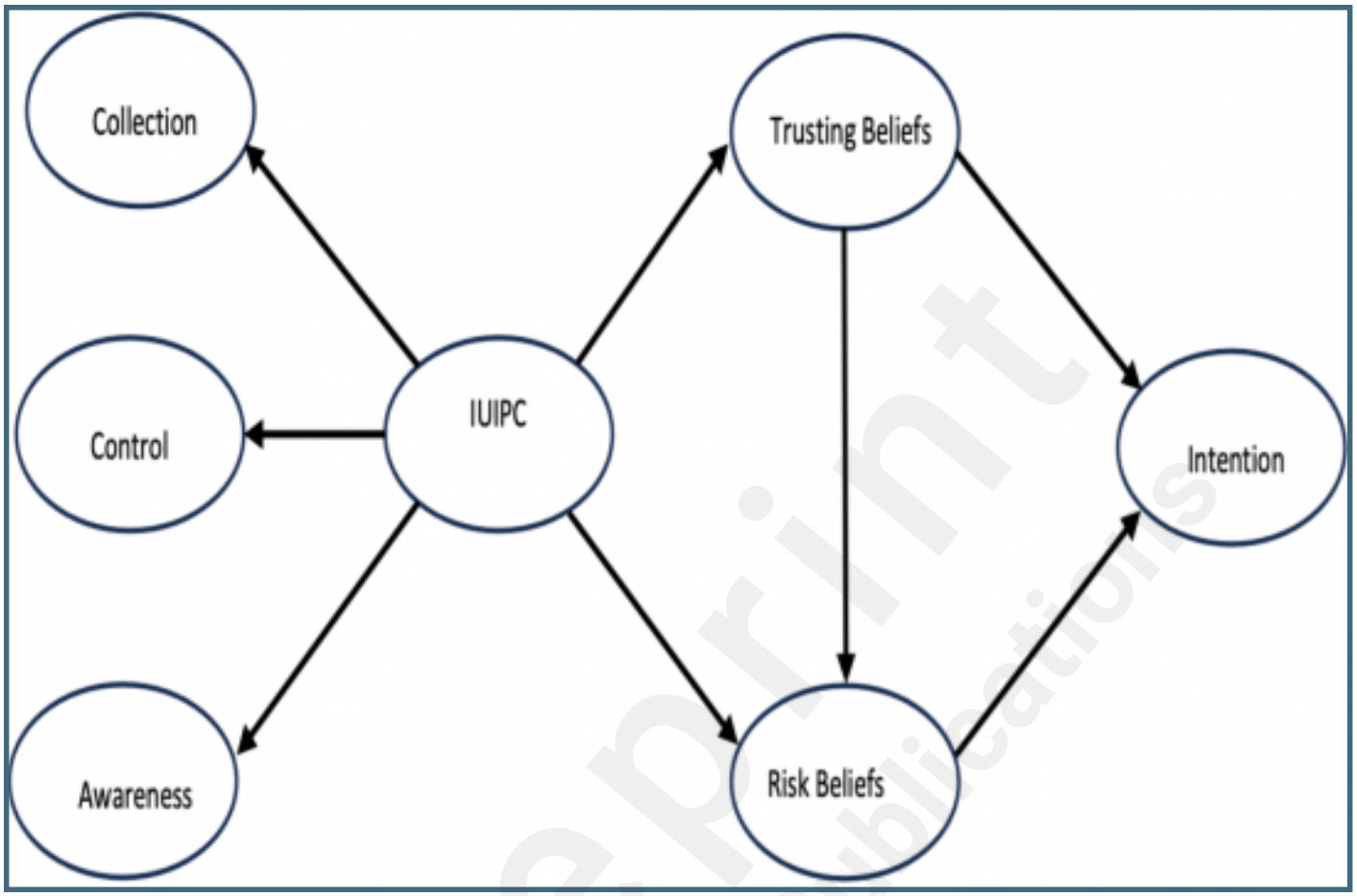
Supplementary Files

Untitled.
URL: http://asset.jmir.pub/assets/bae53b22adac6748bb8ab7095fb447ee.docx

Figures

Internet Users' Information Privacy Concerns (IUIPC).



Internet Users' Information Privacy Concerns (IUIPC) model with estimated path coefficients.