

Privacy and Confidentiality Challenges in Health Survey Research



Douglas Williams – Westat



Three Challenges Related to Assurances In the Digital/Social Media Era

Challenges Related to Assurances

- > Respondent beliefs
 - Widespread belief that government shares FSS data (Gerber, 2003)
 - Belief in confidentiality of data in FSS by ~50% (Childs et al, 2018)
 - Belief that government tracking (privacy) unavoidable ~60% (Pew, 2019)
 The gov't already knows a lot about me
- Contrasting protections (Social Media, Technology, Apps)
 - Informed Consent vs Terms of Service & Privacy Policies
 - IC driven by protecting respondent / ethics in research
 - TOS/PP driven by protecting company / legal requirements
 - About 20% read privacy policies (Pew, 2019)

Terms of Service

Please review the surroup of changes and updated Terms bette. You can find the earlier Terms in our entities. Effective: 18 September 2018

Distriction Terms of Service

1. READ OUR PRIVACY POLICY

2. LISE OF THE RITRIT SERVICE.

Persons under the age of TL, or any higher informum age in the jurisdiction where that person resides, are not persitted to access or use the TSIs harvier wines their person has consented in accordance with applicable line. Additionary, you cannot access or use the TSIS therwise if you are better from resolving services under applicable into or have previously been suppended or network from TSIS Service.

context Customer Support If you discover or suspect my security breach related to the Fitst Service of your account.

4. NECESSARY EQUIPMENT

5. POSTING YOUR CONTENT ON THE FITBIT SERVICE

& PITRIT'S PIGHTS

7. WHAT YOU CAN DO ON THE FITBIT

You will not use, sufficients, copy, edged, modely, commiss, set, rest, sees, see suggest entered, publishing disting, publishing services, set, rest, sees, seeings, trender, publishing disting, publishing performance of the commission of the supervision of the commission of the supervision of the commission of the c

8. HYPERLINKS

9. OUR ENFORCEMENT RIGHTS

10. USE THE FITBIT SERVICE AT YOUR OWN

If you rely on any FBSS Content or the FBSIt Service, you do so solvely of your own risk.

11. CONSULT YOUR DOCTOR BEFORE USING THE FITBIT SERVICE

Eith's respects the Intellectual property of others and espects its users to do the some. It is Titath's parity, it represents discussed to do the some. It is Titath's parity, it represents deductions said of our discussion, and of expectedly, biftings the lights of copyright holders. Person see Titath's DACLACTORPHY Platty.

13 TERMS OF SALE DETURNS AND

Pitit's Tarres of Sale and Deluns and Warramy Pit's apply to durintered project goods from Flats. The Terms of Sale are incorporated that and are mode a part of these Terms. At orders, pieced are subject to Pitit's acceptance. We may accept, decline or since prints are only and for any accept, decline or since pitits are only accepted for any accept.

Paid Services

Your purstone and use of any of our pold services are subject to the Plate Terms for their Services, which are incorporated into these Terms.

14. FEEDBACK AND SUBMISSIONS POLICY

15. CONTESTS AND GIVEAWAYS

Additional terms and conditions may apply to surveys, contests, gluesawys, and other promotions appropriate light or its partners. It is your responsibility to carefully review those terms

16. ALERTS AND NOTIFICATIONS

No. Amount of the result of the Trails Barding, and representations, but resemples, earlier, sends on the send of the Trails Barding, and of these selections of the send of the selections of the send of the sen

18. CHANGES TO THE FITBIT SERVICE

19. TERMINATION

We were the right to however in destroyer purposes a modern to the work of the work of the work of the second to t

20 DISCLAIMERS

THE TITLE SERVICE AND PRISE CONTENT ARE PROVINCE. AS INTHE THE MEMORY OF ANY PRISE AND WITHOUT MEMORY.

THE PROSECUTION OF DIVISION OF THE PROSECUTION OF THE PROSE

21 INDEMNITY

22. LIMITATION OF LIABILITY

SOME JURISDICTIONS DO NOT ALLOW THE EXCLUSION OR LIMITATION OF LIABILITY FOR CONSEQUENTIAL OR INCIDENTIAL DAMAGES, SO THE ADOVE LIMITATION MAY NOT APPLY TO YOU.

23. DISPUTE RESOLUTION

We Sight Agree To Arbitrate: You and Fittit agree to readine any Disputes fromugh first and binding arbitration, workst as set forth under Especiations to Agreement to Arbitrate below.

under Exceptions to Agreement to Arbitrate below

24. GENERAL TERMS

We will notify you before on make material changes to these Terms and give you an opportunity to review the review that terms and give you an opportunity to review the review that terms continuing to use the Title Exerce. When you was the Table Service where a modification becomes effective, you are selling us that you account the modified terms. You can review previous venions of these Terms in our <u>grantises</u>.

25. ADDITIONAL TERMS MAY APPLY

PLEASE CONTACT US IF YOU HAVE ANY QUESTIONS ABOUT THESE TERMS. THESE TERMS,

THESE TERMS,

It was now yourself us at autopointment over or at our poster address below.

If you live in the European Economic Area, the United Kingdom or Switzerlandi

FITBIT PAY TERMS OF SERVICE

1. THE FITBIT PAY SERVICE

3. PRIVACY AND SECURITY

4. LIMITATION OF LIABILITY

FITBIT LIVE COACHING TERMS OF SERVICE

1. LIVE COACHING SERVICES

The Line Control Services provide retrieferm stars text had yet may be a few to be a few signs. You are joint put harts these and lead have given. You are joint put harts there are lead to the signs. You are joint put harts the period of the signs of t

3. DISCLAIMERS ABOUT THE LIVE

The Live Conching Services, are provided "sevin", without warranty of any since. Without liveling the Registry or any other services or any extensive or age are serviced as a service of a service or any extensive provided by the services of a service or any extensive or the Live Conching Services, including any warranties of methodological services or not-informative, the services of the service of the services of the service of the services of the services

4. TERMINATION

FITBIT TERMS FOR PAID SERVICES

By purchasing or using a Phild Service, you agree to be bound by the Elds familia and execute which topicated these Phild Service hasperies been an experience of the Phild Service hasperies been used to the paint supported by the paint and providing several red by you in a crain-value with your ways of the Phild Service. If you do not account these terms, do not purchase, stream or use our Phild Services.

1. PAID SERVICES

2. SUBSCRIPTIONS

Automatically Benewing Subscriptions. Your Subscriptions teaming any the assemble with modely an event advantage country and the property of the property of the assemble and the property of the property of

Subscription Cancellation. You may cancel your Subscription any time. Your cancellation will take effect at the end of the current Subscription Term.

Privacy Policy



House Information In Sharwell Your Dights for Arrass and Control Your Personal Date

- Data Retention Analytics and Automiteins Services Provided by Others
- Cour Patitions for Christians informations Today IV, Our Informational Cincentings and Data Townshire European Philosopy Christians and Carlifornia Diverse Distributions Charles on This Parity When We Acad and Time To Content Us

- INFORMATION WE COLLECT

INFORMATION YOU PROVIDE US

PAYMENT AND CARD INFORMATION

INFORMATION WE RECEIVE FROM YOUR USE OF OUR SERVICES

We also called defended the devices and computers you use to access the Services, techniques to access the Services, techniques the final content of the con

INFORMATION WE RECEIVE FROM THESE PARTIES

HOW WE USE INFORMATION

We use the information we collect for the following purposes. PROVIDE AND MAINTAIN THE SERVICES

PROVICE AND MAINTAIN THE SERVICES.
Using the tribuncation we called, we are into to deliver the Services by some inches to deliver the Services by the services of the service constant with the services of the Services, and for the service to environmental services of the Services, and for given your continues received.

IMPROVE, PERSONALISE AND DEVELOP THE SERVICES

HOW INFORMATION IS SHARED

NIMEN VOL. AREAS OF CREATE US TO PRIME
When you instant on the other party and the property and the property

We may show non-perspect information that is appropriated or de-identified on that it constant resourcing the send to identify an overland or send to be a send to be a send to be a send to perspect to the send of the send to be a send to be a send to be a perspective to the send to be a send to be a send to be a perspective to the send to be a send to be a send to be a person to be a send to be a send to be a person to be a send to be a send to be a person to be a send to be a send to be a person to be a

YOUR RIGHTS TO ACCESS AND CONTROL

We give you account entiting and spots to access and control your personned debt, no described before, regarding or of where you has 8 you had no controlling plantages, you may have legal offers with respect to your interrestion, which your proposes seet may not describe and sook with the searches, as and dedined before.

Accessing and Exporting Date. By longing this your accessor, you can expose much of part personnel information, building your destination of the second of the part of the second of the second of the part of the second of the second of the part of the part

Objecting to Date Use. We give you assumed until up and tools to careful and date use. To exemple, though your groups until the careful and date use. The exemple, though your groups until the same property of the careful and the careful a

DATA RETENTION

We want your security intermedies, they your move, annot indices as used to the control intermedies. It is since case, when you give you want to the control intermedies are small. It is control your adjusted by the control intermedies are suggested to control intermedies and the control intermedies are suggested by the second process are suggested as the control intermedies and the control intermedies are suggested as the second process are suggested as the control intermedies and the control intermedies are suggested as the control intermedies and the control intermedies are suggested as the control intermedies and the control intermedies are suggested as the control intermedies and the control intermedies are suggested and the control intermedies are the control intermedies and the control intermedies

ANALYTICS AND ADVERTISING SERVICES PROVIDED BY OTHERS

We work alth perform who provide an aith merigins and electronic services. This includes helping as witherstend from union literature of the foreign as witherstend from union literature for the foreign and with search on our literature for the foreign and the foreign an

OUR POLICIES FOR CHILDREN

Fittil inlows parents to set up accounts for their children to use with select Fibit devices ("Onlibren's Account"). Children's Accounts are subject to a separate Privacy Policy for Children's Accounts are subject to set up a separate Privacy Policy for Children's Accounts a static solution and information are collect to set up

Persons under the ape of CL, or any higher microwum ape is the jurisdictars where their person hashes, on a full permitted to create application for the person hashes, or a full person to the application for jurisdictary to the person of the person of intermetions of a shift of sight the relaxated microwum ape without intermetions of a shift of sight the relaxated microwum ape without person and personal. Therefore who because the microwim application such as personal information to a send would like to have it decided may control or of promotion to us and would like to have it decided may control or of promotions as a promotion of the person in decided may control or of promotions as a promotion of the person in decided may control or of promotions are promotions.

INFORMATION SECURITY

OUR INTERNATIONAL OPERATIONS AND DATA TRANSFERS

We very on multiple legal boxes to workly transfer paracrait data, account the world. These is house your anneas, the EU-LG and account the world. These is house your anneas, the EU-LG and account rectand classes, which require centers private and executly potentials. You may about applicable or the model contravaual potentials. You may about popular at the model contravaual school of the properties of th

Plaint line, in subject to the overlight of the US Federal Trade Commission and sensitive requirements for personal retermination who sensitive in the retermination who were traded in other within proceed in on any dentry to describe the related in the sensitive of the retermination of the retermination of the related in the Privary Street Sensitives, please contact days are retained as any other process to see all contact independent days and make a contact days are restained body 25505; and in certain street and retained any other privary Street and interesting contact and process the Privary Street and interesting contact and and interesting c

EUROPEAN PRIVACY DISCLOSURES

MEATH AND OTHER PRICIAL CATEGORES OF PRESCHAL

To be accent that information are allowed in hearth date or
manner speaked organized purposes and explored in hearth date or
manner speaked organized purposes and explored in hearth date or
first consent assembling when you have eithern seeding to our
first consent assembling when you have eithern seeding to our
first consent assembling when you have eithern seeding to our
first consent assembling when you have eithern seeding to our
first consent assembling when the formation has been proported assembling
from minimizing consent seeding and seed to seed the our
form minimized seedings, or was the format benefith manufacting desirue
memory and our requirem to accompany assembling and accompany
memory and our requirement to accompany assembling your
devices, no developing under the pre-seedings and accompany
memory and our present to a trible during services. Applicating your
devices, no developing under the pre-seedings.

OUR LEGAL BASES FOR PROCESSING PERSONAL DATA

- When you have given your consent, which you not you hishow of my fine using your arrange seeing and steer tools.
 The property of the property of the property of the you. He have not flooding and perform a control of the you. The the former of flooding and perform a control of the you. The think of the property of the performance are performed to the performance of the performance of the second of the performance of the performance of the performance which you describe an electric or the performance of the performa

HOW TO EXERCISE YOUR LEGAL RIGHTS Please teritor the Your Egits to decreas and Control Your Decision Date section for how your excess of settings and took within you to execute your rights under the COPR to access and control your personal date.

In addition to the excitors before their an extension is excited income for execution, and one transition for any exception of pro-duction of original to one provision of any original process on any states or original to one provision of the exception of the exception of the desiration of the exception of the exception of the exception of the desiration of the exception of the exception of the exception of the desiration of the exception of the exception of the exception of the provision. Provision desiration of the exception of th

CALIFORNIA PRIVACY DISCLOSURES

If you are a California resident, please review the following additional privacy discionares under the California Comunitie Privacy Act (CCPAT).

HOW TO EXERCISE YOUR LEGAL EXCHTS
The have the right to underdard have see collect, use and
the house the right to underdard have see collect, use and
the result of the see delate exchange the result to not be
discretised against for exerciting your privacy rights. You
trys searcher have rights along your account waterings and
factors as described in the Your Digital Tox
Your Searcher Office and the results.

- Dy bogging into your account and using your account surrough you may exercise you neglet to expend your purchase account your regard to expend your personal distribute. Learn more than the learn to the learn

If you need further assidence regarding your rights, please contact our Data Protection Difficer at <u>data-protection-orthanetisk now,</u> and see will consider your request to excondance with sociolicative issue.

CATEGORIES OF INFORMATION WE COLLECT, USE, AND DISCLOSE FOR BUSINESS PURPOSES

OSCLOSE FOR BUSINESS PLRFOSES.
As described in the <u>Introduction Was Called</u> section, we collect the categories of personal information listed below. We receive this information from you, your devices, you'ld use of the Services, plant cased in the product of you use out Live Concring Services. Only other than the services you have connected to While perities (the the other services por have opposed to your Filth counter, by plus a religious of man are security or your Filth counter, by plus a religious of man are compared to your Filth counter, by the counter of the coun

- Commercial information, including your payment information and records of the Services or devices you purchased, about or considered for exception. If you added them to your shopping bested on the FISSE or time store but of did not purchase them.
- storw but did not purchase them?

 Blomatric information wath my your exercise, activity, shep
 of hearth data, founding the number of wass you bride,
 distance thewards, about ourseld, within the product of the condistance through the purchase burned, within the product of the conpart of the con
 con
- Internet or other electronic network activity information, such as the usage data are receive when you occase or use our Sendree. This Intuitions information about your interactions with the Sendrees and about the devices and computers you used to access the Sendrees.
- Geologation data, including GPS signals, device sensors, Williams points, and mobile ment IDs, if you have granted as access to that information.
- . Electronic, visual or similar information, such as your profile
- Bestronce, visual to assess an interest product of the professional or employment related information, including.
 Professional or employment related information, including information or similar information of their year employee provides to us so their second information of their productions of the use of their second information of thei

described in the Analytics and Adventiony Services Provided By Others section. To learn more about how these partners object date and your options for controling the use of your information for interest-based adventising, please read our Cookie titre statement.

CHANGES TO THIS POLICY

We will notify you before we make resterial changes to this policy and give you an opportunity to review the revised policy before deciding if you would like to continue to use the Sentres. You can review previous sentions of the policy in our entities.

WHO WE ARE AND HOW TO CONTACT US

If you live in the USA, UK or Switzerland, you may also contact us

Fifth International Limited After Legal Department (Privacy Policy) 76 Lover Deppet Street Dublin 2, Ireland

Challenges Related to Assurances (2)

- > Respondent ignorance
 - Knowing when data is being collected
 - Knowing what data is being collected
 - Knowing who has data, or when shared



Thousands of Android apps can track your phone — even if you deny permissions

Even if you say "no" to one app when it asks for permission to see those personally identifying bits of data, it might not be enough: a second app ...
Jul 8 2019



ai AppleInsider

Ring's app caught spying on users, sharing data with thirdparties

The Electronic Frontier Foundation has discovered that third-party tracking software within the Ring doorbell app is sending customer data to ...

1 month ago



MarketWatch

Fitness and health apps may be sharing the most private details about your life

"Monitoring yourself with a fitness tracking app that is collecting data is like publishing your own medical autobiography online. These neat little ... Mar 5, 2019



top Washington Post

Smoking and depression apps are selling your data to Google and Facebook, study finds

Smoking and depression apps are selling your data to Google and ... The problem: Many of the apps designed to track a user's progress are ... Apr 22, 2019



Effect on Perception of Assurances

- > Respondent privacy concerns shaped by perception and experiences
- > Commercial interactions more common/influential than government
- > Lack of control over information is common experience, expectation



- Do expectations of privacy persist?
 - Use of information consequence of product or service.
 - Blurring of "protected health" data and "user health" data

Result of Experiences

- > Growing Privacy Landscape
 - EU General Data Protection Regulation (GDPR)
 Aims to give persons some control over data
 - California Data Privacy Protection Act (CDPP)
 Persons required to identify misuse/breach
 Possibly lead to incentivizing personal disclosure

Will respondents want something similar for FSS data?

Confidentiality – Differential Privacy

> Differential Privacy:

- A mathematical mechanism for ensuring <u>confidentiality</u> of collected data.
 - Permits public use of information / secure use by more data users
 - More data available to researchers?
 - Could this encourage broader collection of information overconfidence of *privacy*?
 - Doesn't eliminate the need for data security still collecting private information.
 - 55% view hacking as biggest threat to medical privacy (CHCF, 1999)

Confidentiality – Differential Privacy

> Differential Privacy:

- Challenging in assurances
 - If my data will not change findings, then why do you need it?
 - Your vital to accurate data, then we'll make it less accurate.
- Creates opposing interest: researchers want e = 1; participants want e = 0.1.
 - 31% not willing at all to risk privacy (Eggleston, HSRM)



Thank You

Douglas Williams

douglaswilliams@Westat.com

References

- California HealthCare Foundation. 1999. Medical Privacy and Confidentiality Survey Summary and Overview. Retrieved from: https://www.chcf.org/publication/medical-privacy-and-confidentiality-survey/
- Childs, J.H., Eggleston, C. & Fobia, A.C. 2018. Public Confidentiality Expectations Regarding Data Linkage. Paper Presented at 2018 Conference on Big Data Meets Survey Science (BigSurv18). Barcelona, Spain.
- Gerber, E.R. 2003. Respondents' Understanding of Confidentiality Language. Proceedings of the American Statistical Association, Section on Survey Research Methods, Alexandria, VA: American Statistical Association.
- Pew Research Center. 2019. Americans and Privacy: Concerned, confused and Feeling Lack of Control Over Their Personal Information. Retrieved from: https://www.pewresearch.org/internet/2019/11/15/americans-and-privacy-concerned-confused-and-feeling-lack-of-control-over-their-personal-information/
- Singer, E. 2003. The Eleventh Morris Hansen Lecture: Public Perceptions of Confidentiality. *Journal of Official Statistics*. 19(4): 333-341
- Singer, E., Mathiowetz, N.A., & Couper, M.P. 1993. The Impact of Privacy and Confidentiality Concerns on Survey Participation. *Public Opinion Quarterly*. 57:465-482.

HSRMC 2020: Williamsburg, VA