

# Use of Narrative Data to Explore Disparities in Patient Experience

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## Attachment E

### Ipsos Confidentiality Agreement

(last updated 02/23/2017)

KnowledgePanel<sup>®</sup> Members have been invited to take part in a major national research effort. Members may complete surveys to provide feedback and opinions on a range of political, lifestyle, advertising and other questions, and may contribute other types of data along with other Panel Members. Active Panel Members receive certain benefits from Ipsos Custom Research, LLC in exchange for participating in surveys.

#### OUR PRIVACY COMMITMENTS

Ipsos Custom Research, LLC ("Ipsos") respects the privacy of every Panel Member. This Privacy Statement outlines the information Ipsos will collect and how we will use that information you provide on our web site: [www.knpanel.com/participate](http://www.knpanel.com/participate). This Statement will also tell you how you can verify the accuracy of your Personal Information (defined below) submitted to Ipsos and how you can request that we delete or update your Personal Information.

We've developed our privacy policy from industry guidelines and standards, and local, national, and international laws and requirements. All privacy practices and methods described in this policy apply only insofar as permitted by the applicable standards, laws and requirements.

Thanks again for placing your trust in Ipsos.

If you have an unresolved privacy or data use concern that we have not addressed satisfactorily, please contact our U.S.-based third party dispute resolution provider (free of charge) at <https://feedback-form.truste.com/watchdog/request>.

#### INFORMATION COLLECTED AND HOW WE USE IT

##### WHAT WE COLLECT:

##### A) PERSONAL AND DEMOGRAPHIC INFORMATION

During the KnowledgePanel<sup>®</sup> recruitment process, Ipsos collects personal information that is information that could personally identify you, such as your name, address, email address and the names and ages of members of your household (such personally identifiable information being referred to as "Personal Information"); Personal Information excludes Demographic Information, as defined below). In addition, Ipsos frequently asks Panel Members for characteristics that will not generally by themselves personally identify you (such as health problems or consumer habits), attributes, and demographic information (such as age, income, gender) (collectively, "Demographic Information") via online surveys.

## **B) OPERATING INFORMATION**

Ipsos may, in the course of interacting with Panel Members, gather other types of information from Panel Members ("Operating Information"). For example, as a KnowledgePanel® Member, you will receive surveys from Ipsos on a regular basis. These surveys will ask questions about your interests, needs, and attitudes. We will receive your responses to these surveys. If we offer features, services, or programs in which you explicitly agree to participate, then Ipsos will receive information from those features, services, or programs.

## **C) LOG FILES**

As is true of most websites, we gather certain information automatically and store it in log files. This information includes internet protocol (IP) addresses, browser type, internet service provider (ISP), referring/exit pages, operating system, date/time stamp, and clickstream data.

We use this information, which does not identify individual users, to analyze trends, to administer the site, to track users' movements around the site and to gather demographic information about our user base as a whole.

We do not link this automatically-collected data to Personal Information.

## **D) COOKIES AND TRACKING TECHNOLOGIES**

Technologies such as: cookies, beacons, tags, scripts and similar technologies are used by Ipsos and our partners for market research purposes.

A cookie is a small text file that is stored on a user's computer for record-keeping purposes. We use persistent cookies on the Ipsos panel member site. Persistent cookies are used when you register as a Panel Member or log into our site, and are used to store information such as your email address and password. We use these cookies to recognize Panel Members when they participate in surveys and to record information about the survey, such as when the survey is completed and how much of the survey has been completed. A persistent cookie remains on your hard drive for an extended period of time. You can remove persistent cookies by following directions provided in your Internet browser's "help" file. If you reject cookies, you may still use our site, but your ability to use some areas of our site, such as contests or surveys, will be limited.

In addition, we use cookies to measure certain advertisements that are displayed on your computer. We may invite you to participate in surveys that ask whether you recalled seeing certain advertisements online. By detecting these cookies, we may also track certain information regarding your activity on our or a third party's website, which we use to conduct research on Panel Members' demographics, interests, and behavior. We do not link the information we store in cookies to any Personal Information you submit while on our site. We do not have access to, or control over, cookies that may exist on your hard drive that were placed by third parties. We cannot control how they may be used by third parties or otherwise have any control over the type of content that may be included with any tags incorporated in those cookies.

## **E) WEB BEACONS**

A web beacon (also known as a tag, clear gif or 1x1 pixel), consists of a small string of code that is embedded within a web page or email. There may or may not be a visible graphic image associated with the web beacon, and often the image is designed to blend into the background of a web page or email.

We use web beacons in our email messages to help determine whether our messages are opened and to verify any clicks through to links within the email. We may use this information to determine which of our emails are more interesting to users, to improve the quality of the emails that we send and to query users who do not open our emails as to whether they wish to continue receiving them. The web beacon is deleted when you delete the email.

We also use web beacons that interact with our audience measurement cookies to inform us when a Panel Member has viewed certain ads and other online content that we are measuring. We and our authorized service providers may link personally identifiable information to web beacons for operational and research purposes.

If you would prefer not to have web beacons in the emails that you receive, you should adjust your email program to receive messages in plain text rather than HTML. It is also possible to detect and control web beacons that are present on web pages by downloading a plug-in for your browser.

#### **BROWSER DO NOT TRACK SETTINGS**

Your browser offers a Do-Not-Track (DNT) privacy setting. Enabling it may result in your browsing history not being used by some advertising networks to serve targeted ads to you. The cookies that we use to measure advertising effectiveness may tell us which websites you visited where certain ads were displayed. Enabling or disabling the DNT setting in your browser has no impact on our use of cookies that measure exposure to ads or other online content on third party websites. For more information about DNT privacy settings, visit [www.allaboutdnt.com](http://www.allaboutdnt.com).

#### **HOW WE USE YOUR INFORMATION:**

##### **A) PERSONAL AND DEMOGRAPHIC INFORMATION**

Personal Information is used to set up e-mail accounts for each household member who is 13 years of age or older (if you do not have Internet access at the time of recruitment), to communicate with you and your household members, and to assist you with questions that you may have about the KnowledgePanel procedures. It may also be used for panel recruitment, contest entry processing or delivery of free gifts to KnowledgePanel Members, and delivery of our quarterly newsletter, which you are automatically enrolled to receive via email.

(To opt out of the newsletter, follow the unsubscribe instructions included in these emails, accessing the email preferences in your account settings page or you can go to: [members.knowledgepanel.com](http://members.knowledgepanel.com).)

Personal Information concerning location or address is also used to ensure that our panel accurately represents the country's population as a whole.

Panel Members are asked for Demographic Information in order to pre-qualify members or households for surveys that target specific groups. We also use this information to ensure that our panel accurately represents the country's population as a whole.

Ipsos uses Personal Information and Demographic Information solely in the conduct of its research business. Personal Information or Demographic Information may be combined with information collected about you by Ipsos or third parties with your express permission, with information that is collected about you from public records, or with information that Ipsos may acquire from third parties that have a legal right to provide such information to Ipsos.

If you provide us with your mobile phone number, Ipsos and/or its agents may contact you periodically using an automatic telephone dialing system, interactive voice response technology or SMS text message for purposes related to your participation in KnowledgePanel. For example, we may use interactive voice response technology and SMS text messages to notify or remind panel members when a survey is available for completion. You may revoke your consent to be contacted by an automatic telephone dialing system or interactive voice response technology on your mobile phone by contacting Ipsos. See the ACCESS TO YOUR INFORMATION AND COMPLAINTS section below. If you no longer want to receive SMS text messages from Ipsos or our agents, please reply to our or their SMS text messages by writing STOP.

Please refer to “Accessing, Correcting, Updating and Preventing Use of Your Personal Information or Demographic Information” below for information regarding your ability to control and manage your Personal Information and Demographic Information.

## **B) OPERATING INFORMATION**

Ipsos uses Operating Information solely in the conduct of its research business. As is the case with Personal Information and Demographic Information, Operating Information may be combined with information collected about you by third parties with your express permission, with information that is collected about you from public records, or with information that Ipsos may acquire from third parties that have a legal right to provide such information to Ipsos.

## **DATA SHARING AND TRANSFER**

### **A) HOW WE MAY SHARE INFORMATION:**

Except as detailed in this section of the Privacy Statement, Personal Information regarding Panel Members will never be shared with any third parties without your express permission. We do not sell your personal information to third parties.

We reserve the right, however, to disclose your Personal Information as required by law and when we believe that disclosure is necessary to protect our rights and/or comply with a judicial proceeding, court order, or legal process served on Ipsos or its employees or agents.

In addition, occasionally Ipsos will share contact information, such as name and mailing address, with third parties with whom we have partnered to provide specific services to Ipsos, or services on behalf of Ipsos, specifically for the purposes of panel recruitment, panel communications, contest entry processing or delivery of free gifts to KnowledgePanel Members. These partners have agreed not to share or resell this data and they are contractually obligated not to use any Personal Information except for the purpose of providing these services, unless you enter into a relationship with them that would directly allow them to do so.

Ipsos collects and shares Demographic Information and Operating Information with its research clients (“Clients”) in an anonymous form. We may share this information with our Clients on an anonymous individual basis to provide your individual Demographic Information and Operating Information (without specifically identifying you), and may provide this information on an aggregate basis with respect to a group of our Panel Members to describe group demographics or interest profiles (again, without specifically identifying any Panel Member). As discussed above under the heading “Cookies,” certain web pages that you view may be tracked by third parties using advanced cookies, and this tracking data may be provided by such third parties to our Clients, and combined by our Clients with your Demographic Information and Operating Information for market research purposes.

Our research Clients will never receive Personal Information of Panel Members, nor will they be able to identify Panel Members, without your express permission.

Ipsos is an expanding business, and like other companies, we sometimes acquire or divest business units or ourselves be acquired. As part of such transfers or mergers, we may convey the business assets of the particular business unit, or the company as a whole, including Personal Information, Demographic Information, or Operating Information of Panel Members. In that eventuality, you would be notified via email.

#### **B) DATA TRANSFERS:**

Your Personal Information, Demographic Information, and Operating Information will generally be stored in our Ipsos databases. For easier processing of e-mail communications, contests, sweepstakes, or other marketing purposes, or for panel recruitment or panel communications, however, your Personal Information, Demographic Information, or Operating Information may be sent to or accessed by Ipsos’ service providers and contractors who are obligated to keep such information confidential in countries outside the United States or the European Union. Ipsos data protection standards and those of its service providers and contractors are the same, regardless of where your information is stored.

Ipsos’s legal entities outside the European Union have entered into intra-company data protection agreements using standard contractual clauses prepared by the European Commission. Moreover, Ipsos’s U.S. entities have entered into data protection agreements with service providers and other business partners. These agreements require the contracting parties to respect the confidentiality of your Personal Information and to handle European personal data in accordance with applicable European data protection laws.

#### **CHILDREN’S PRIVACY**

Ipsos believes that it’s especially important to protect children’s privacy online and encourages parents and guardians to spend time online with their children to participate and monitor their Internet activity.

Ipsos complies with all applicable national and international children’s privacy regulations. We do not permit children who are under 13 years of age to become KnowledgePanel Members. We do not collect any Personal Information from children under 13 years of age. As part of the registration process for new Panel Members, we collect from the new Panel Member the names of each individual in the Panel Members’ household, which may include the names of children who are under 13 years of age.

Occasionally we may send a survey to a Panel Member who is a parent or guardian of a child under the age of 13 that asks that Panel Member to have his or her child who is under 13 answer the survey. We

take reasonable steps to ensure parental consent to such procedure by sending the survey to the parent or guardian's password-protected email address. The information collected in response to such surveys is not combined with identifying information about the child. In every case such survey does not collect Personal Information about the child. We comply with the Children's Online Privacy Protection Act of 1998.

If a Panel Member has provided us with Personal Information about a child in the Panel Member's household who is under the age of 13, a parent or guardian of that child may contact us at the email address or mailing address listed at the bottom of this Privacy Statement if he or she would like this information deleted from our records. We will use reasonable efforts to delete the child's information from our databases.

If you would like to contact us about your or your child's Personal Information, or to find out how you can have your child's Personal Information removed from our database, please see the "Access To Your Information and Complaints" section later in this document.

### **DATA SECURITY AND RESPONSIBILITY**

Ipsos is committed to keeping the data you provide us secure and will take reasonable precautions to protect your Personal Information from loss, misuse or alteration. Vendors, contractors, or partners of Ipsos who have access to your Personal Information in connection with providing services for Ipsos are contractually required to keep the information confidential and are not permitted to use this information for any other purpose than to carry out the services they are performing for Ipsos.

Ipsos also safeguards Personal Information, Demographic Information, and Operating Information from unauthorized access. Most Operating Information is maintained in databases that are separate from those containing Personal Information and Demographic Information. Only authorized Ipsos employees or agents carrying out permitted business functions are allowed to access these databases. In addition, each employee of Ipsos is required to sign a confidentiality agreement requiring him or her to keep confidential all Personal Information of Panel Members. Employees who violate the confidentiality agreement are subject to disciplinary actions, including termination when appropriate.

While we strive to use industry-standard security technology, procedures and other measures to help protect your Personal or Demographic Information, we cannot guarantee the security of the information you transmit.

### **LINKS TO THIRD PARTY SITES**

Our Site includes links to other websites whose privacy practices may differ from those of Ipsos. If you submit personal information to any of those sites, your information is governed by their privacy policies. We encourage you to carefully read the privacy policy of any website you visit.

### **CHANGES TO THIS PRIVACY STATEMENT**

We may update this privacy statement to reflect changes to our information practices. If we make any material changes we will notify you by email (sent to the e-mail address specified in your account) or by means of a notice on this Site prior to the change becoming effective. We encourage you to periodically review this page for the latest information on our privacy practices.

## **ACCESS TO YOUR INFORMATION AND COMPLAINTS**

### **A) Accessing, Correcting, Updating and Preventing Use of Your Personal Information or Demographic Information.**

If you have submitted Personal or Demographic Information to Ipsos through KnowledgePanel or otherwise, or if someone else has otherwise submitted your Personal or Demographic Information to Ipsos, you can:

- Access, Correct, Update Your Personal or Demographic Information, by emailing your request to: [privacy@knowledgepanel.com](mailto:privacy@knowledgepanel.com), or by sending us a letter to the address listed below. Ipsos will use reasonable efforts to supply you with the information you requested to access and to correct any factual inaccuracies in this information within a reasonable timeframe.
- Prevent Further Use of Your Personal or Demographic Information, by emailing your request to: [privacy@knowledgepanel.com](mailto:privacy@knowledgepanel.com). Alternatively, you may call us at 1-800-782-6899 or send us a letter to the address listed below. In each case, we will then use reasonable efforts to prevent further use of your Personal Information or Demographic Information in our files.
- We will retain your information for as long as your account is active or as needed to provide you services. If you wish to cancel your account or request that we no longer use your information to provide you services contact us at [privacy@knowledgepanel.com](mailto:privacy@knowledgepanel.com). We will retain and use your information as necessary to comply with our legal obligations, resolve disputes, and enforce our agreements.

### **B) Complaints**

Ipsos is committed to working with consumers to obtain a fair and rapid resolution of any complaints or disputes about privacy. Please send us your questions or comments regarding our privacy practices or requests to revoke consent to be contacted by an automatic telephone dialing system or interactive voice technology on your mobile phone by emailing us at: [privacy@knowledgepanel.com](mailto:privacy@knowledgepanel.com), or send us a letter to:

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