

**Survey among Patients / Consumers**  
**Draft Questionnaire**

*Sample to include:*

- 250 U.S. diabetes patients
  - 250 U.S. cardiovascular disease patients
  - 250 U.S. cancer patients/cancer survivors
  - 500 U.S. adults ages 65+
  - 250 U.S. caregivers (those who provide care and/or make health care decisions for at least one adult - e.g., parent, spouse, etc.)
  - 500 U.S. parents of child(ren) under age 18, who are in the household; parent must be primary decision maker for child's health care
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Screeners

Screening questions as necessary to define segments outlined above

**Diabetes Patients**

Has a physician or other health care provider diagnosed you with diabetes?

- Yes
- No [TERMINATE]

Which type of diabetes do you have?

- Type 1
- Type 2

How long have you been diagnosed with diabetes?

- Less than one year
- 1-3 years
- 4-5 years
- More than 5 years

**Cardiovascular Disease Patients**

Has a physician or other health care provider diagnosed you with heart disease or hypertension? This may include coronary heart disease, heart failure, congenital heart disease, stroke, hypertension, heart valve disease, or atrial fibrillation.

- Yes
- No [TERMINATE]

How long have you been diagnosed with heart disease or hypertension?

- Less than one year
- 1-3 years
- 4-5 years
- More than 5 years

**Cancer Survivors/Patients**

Has a physician or other health care provider ever diagnosed you with any of the following types of cancer: prostate, breast, colon, lymphoma (Hodgkins or non-Hodgkins), non-melanoma skin cancer, or thyroid cancer?

- Yes

- No [TERMINATE]

Which type of cancer do you have?

- Prostate
- Breast
- Colon
- Lymphoma
- Non-melanoma skin cancer
- Thyroid

How long ago was your diagnosis?

- Less than one year
- 1-3 years
- 4-5 years
- More than 5 years

Are you currently in remission?

- Yes
- No

### **Seniors/Medicare Beneficiaries**

[Confirm age 65+]

Are you eligible for or do you currently receive Medicare benefits?

- Yes
- No [TERMINATE]

### **Caregivers**

Do you provide care for a friend or family member who has been diagnosed with a chronic health condition such as diabetes, heart disease, high blood pressure, atrial fibrillation, stroke, cancer, asthma, Alzheimer's, or arthritis? Providing care may include helping the patient make decisions about treatments and other aspects of health care. It may also include helping the patient take medications and follow doctor's instructions for treatment.

- Yes
- No [TERMINATE]

### **Moms**

Are you the mother of a child or children under age 18, who live(s) in your household?

- Yes
- No [TERMINATE]

### Demographics

Standard demographics provided by Ipsos:

- Gender
- Age
- Education
- Race / Hispanic ethnicity
- Employment status
- Marital status

*FINAL, June 27, 2013*

- Household size / number of children
- Household income
- Additional regional information

ADD language preference and rural/urban designation, if possible [check with Ipsos]

**QUESTIONNAIRE FOR DIABETES PATIENTS, CARDIOVASCULAR DISEASE PATIENTS, CANCER PATIENTS/CANCER SURVIVORS, SENIORS/MEDICARE BENEFICIARIES**

Topic: Experience and Satisfaction with Health System

1. How many different health care providers have you visited in the past 12 months? (e.g., such as family physician, dentist, eye doctor, cardiologist or other specialist, nurse, midwife, nurse practitioner, etc.) Please select one response.
  - 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None [SKIP to Q3]
  
2. Altogether, how many total visits did you make to health care providers in the past 12 months? Please select one response.
  - 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None
  
3. How would you rate your health compared to the average person your age?
  - Excellent
  - Very good
  - Good
  - Fair
  - Poor
  
4. Have you obtained information from any of the following sources in the past 12 months to help you make decisions about health care? **[RANDOMIZE AND READ LIST]**

	Yes	No
Health insurance company		
Health-related Internet site		
Online patient support group or social media forum		
Doctor		
Nurse or other health provider		
Pharmacist		
Place of worship		
Friends or relatives		
Prescription drug company		
Television or radio		
Newspapers or magazines		
Other: please describe		

Topic: Use of Internet for Health Information

5. How often do you use the Internet through a computer or mobile phone? Please select the single best response.

- Through a computer (e.g., desktop, laptop or tablet computer)
- Through a mobile phone
  
- Several times a day
- Several times a week
- Several times a month
- Several times a year
- Less frequently than several times a year
- Never
  
- If NEVER to both technologies: Do you not use the Internet because you do not want to use it, because it is difficult to use, or because you don't have access?
  - Do not want to use the Internet
  - Difficult to use the Internet
  - Don't have access to the Internet

6. Within the past 12 months, have you...

	Yes	No
Searched online for information about a disease or medical condition?		
Participated in an online support group for a disease or medical condition?		
Looked at any of your medical test results online?		
Looked at your medical record online?		
Sent or received an email message from your health care provider?		
Sent or received a text message from your health care provider?		
Renewed a prescription online?		

Topic: Experience with EHRs and other Forms of Health IT

7. A "health app" is a program on a cell phone, mobile device or computer that can help you manage your health. Examples of health apps include calorie counters, sleep monitors, heart monitors, exercise trackers, and tools to help you manage your medications.

	Yes	No
Do you currently use a health app?		
Have you ever used a health app?		

- [If yes to either]: How many health apps have you used or tried in the past year?
  - 1-2
  - 3-5
  - 5 or more
- [If yes to either]: Please briefly describe the health app you have used the most [open-ended].
  - How effective was this health app in helping you manage your health and/or health care?
    - Extremely effective

- Very effective
- Somewhat effective
- Not too effective
- Not at all effective

8. If there was a health app that could help you gather all your health records and/or your family's health records so you could have them in one place – such as on your mobile phone, home computer, tablet or laptop – how likely would you be to use it?

- Extremely likely
- Very likely
- Somewhat likely
- Not too likely
- Not at all likely

9. If there was a health app that could help you share your health records and/or your family's health records with others you trust (e.g., doctors, other care providers or family), if they need it while providing care, how likely would you be to use it?

- Extremely likely
- Very likely
- Somewhat likely
- Not too likely
- Not at all likely

10. As far as you know, is your health care provider required by law to let you view and get a copy of your medical record?

- Yes
- No
- Not sure

11. Have you heard of Blue Button?

- Yes
- No
- Not sure

[If yes] – Please describe what Blue Button is. [open end]

12. Blue Button is a way for patients to get easy, secure online access to view their own personal health information online such as their insurance claims and medical records. Using Blue Button, patients can download their personal health information in a text file or PDF that can be read, printed or saved on any computer.

	Yes	No
Have you used Blue Button to download your medical record?		
Do you know of any friends or family members who have used Blue Button?		

- [If yes to used]: How effective was this Blue Button in helping you manage your health/health care?
  - Extremely effective
  - Very effective

- Somewhat effective
  - Not too effective
  - Not at all effective
- 
- [If no to used]: Based on the description of Blue Button, do you think you'd use it if it were available to you?
    - Yes
    - No
13. Some doctors and health care organizations use computers or mobile devices to record their patients' medical and health information. These electronic health records – or 'EHRs' – contain notes from your doctor or other medical personnel about your visits, diagnoses, test results, prescriptions, lifestyle and other elements of your medical history. As far as you know, do any of your health care providers maintain your medical record in an electronic system?
- Yes
  - No
  - Not sure

Topic: Attitudes about EHRs and Health IT

14. Would you prefer that your health care providers use electronic, computer-based medical records or paper-based records?
- Strongly prefer electronic
  - Somewhat prefer electronic
  - Neutral – no preference
  - Somewhat prefer paper
  - Strongly prefer paper
15. If your health care provider made your medical records and personal health information (such as medications and doctor's instructions) available to you online, how likely would you be to go online to view those records and information?
- Extremely likely
  - Very likely
  - Somewhat likely
  - Not too likely
  - Not at all likely

[If not at all/not too likely]: Which of the following are reasons you would be unlikely to access your medical records online? Please select all that apply. [RANDOMIZE]

- Concerned about cost
- Don't have access to a computer
- Don't have access to my medical records online
- Don't have time
- Don't understand medical terms
- Concerned about the privacy or security of my medical records
- Don't know how to access it
- Not comfortable with technology
- Would rather have my doctor keep track of my health care

- Not interested
- Afraid to know what's in my record
- Other: Please describe [open end]

16. The following are benefits and features associated with electronic or computer-based medical records and other forms of health information technology. Please indicate how useful you think each would be to you in your health care.

- Extremely useful
  - Very useful
  - Somewhat useful
  - Not too useful
  - Not at all useful
- 
- Send and refill prescriptions electronically
  - Receive electronic reminders to take medications
  - Receive electronic reminders for appointments, preventive screenings and tests
  - Communicate with health providers through secure email or secure text messaging
  - View lab and test results online
  - Have access to your health information during an emergency
  - Have a summary of each visit with your health care provider
  - Send medical information from a device that helps you monitor indicators of your health (such as blood glucose, weight, heart rate or other indicators)
  - Share your health information with other people—doctors or family caregivers-- you trust
  - Withhold sensitive health information from selected health care providers (such as mental health information, HIV status, substance abuse or other sensitive health information)
  - Add or change information in your medical record
  - Correct inaccurate information in your medical record
  - Use tools that can help you and your doctor make decisions together about your health care
  - Manage or keep track of your family's medical records
  - Monitor and manage health-related expenses
  - Keep track and manage medications in one list
  - Keep track of immunizations



**QUESTIONNAIRE FOR CAREGIVERS**

Topic: Experience and Satisfaction with Health System

1. Thinking about the person for whom you provide care, how many different health care providers has this person visited in the past 12 months? (e.g., such as family physician, dentist, eye doctor, cardiologist or other specialist, nurse, midwife, nurse practitioner, etc.) Please select one response.
- 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None [SKIP to Q3]

2. Altogether, how many total visits did this person make to health care providers in the past 12 months? Please select one response.
- 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None

3. How would you rate the health of the person for whom you provide care compared to the average person his or her age?
- Excellent
  - Very good
  - Good
  - Fair
  - Poor

4. Have you obtained information from any of the following sources in the past 12 months to help the person for whom you provide care? **[RANDOMIZE AND READ LIST]**

	Yes	No
Health insurance company		
Health-related Internet site		
Online patient support group or social media forum		
Doctor		
Nurse or other health provider		
Pharmacist		
Place of worship		
Friends or relatives		
Prescription drug company		
Television or radio		
Newspapers or magazines		
Other: please describe		

Topic: Use of Internet for Health Information

5. How often do you use the Internet through a computer or mobile phone? Please select the single best response.

- Through a computer (e.g., desktop, laptop or tablet computer)
- Through a mobile phone
  
- Several times a day
- Several times a week
- Several times a month
- Several times a year
- Less frequently than several times a year
- Never
  - If NEVER to both technologies: Do you not use the Internet because you do not want to use it, because it is difficult to use, or because you don't have access?
    - Do not want to use the Internet
    - Difficult to use the Internet
    - Don't have access to the Internet

6. Within the past 12 months, have you done any of the following activities on behalf of the person for whom you provide care?

	Yes	No
Searched online for information about a disease or medical condition?		
Participated in an online support group for a disease or medical condition?		
Looked at any medical test results online?		
Looked at a medical record online?		
Sent or received an email message from a health care provider?		
Sent or received a text message from a health care provider?		
Renewed a prescription online?		

Topic: Experience with EHRs and other Forms of Health IT

7. A “health app” is a program on a cell phone, mobile device or computer that can help you manage your health. Examples of health apps include calorie counters, sleep monitors, heart monitors, exercise trackers, and tools to help you manage your medications.

	Yes	No
Do you currently use a health app to help the person for whom you provide care?		
Have you ever used a health app to help the person for whom you provide care?		

- [If yes to either]: How many health apps have you used or tried in the past year?
  - 1-2
  - 3-5
  - 5 or more
- [If yes to either]: Please briefly describe the health app you have used the most [open-ended].

- o How effective was this health app in helping you manage the health of the person in your care?
  - Extremely effective
  - Very effective
  - Somewhat effective
  - Not too effective
  - Not at all effective
  
- 8. If there was a health app that could help you gather all the health records of the person for whom you provide care so you could have them in one place – such as on your mobile phone, home computer, tablet or laptop – how likely would you be to use it?
  - o Extremely likely
  - o Very likely
  - o Somewhat likely
  - o Not too likely
  - o Not at all likely
  
- 9. If there was a health app that could help you share the health records of the person for whom you provide care with others you trust (e.g., doctors, other care providers or family), if they need it while providing care, how likely would you be to use it?
  - o Extremely likely
  - o Very likely
  - o Somewhat likely
  - o Not too likely
  - o Not at all likely
  
- 10. As far as you know, is your health care provider required by law to let you view and get a copy of your medical record?
  - o Yes
  - o No
  - o Not sure
  
- 11. Have you heard of Blue Button?
  - o Yes
  - o No
  - o Not sure

[If yes] – Please describe what Blue Button is. [open end]

- 12. Blue Button is a way for patients to get easy, secure online access to view their own personal health information online such as their insurance claims and medical records. Using Blue Button, patients can download their personal health information in a text file or PDF that can be read, printed or saved on any computer.

	Yes	No
Have you ever used Blue Button to download a medical record?		
Do you know of any friends or family members who have used Blue Button?		

- o [If yes to used]: How effective was this Blue Button in helping you manage health care?

- Extremely effective
  - Very effective
  - Somewhat effective
  - Not too effective
  - Not at all effective
- [If not used]: Based on the description of Blue Button, do you think you'd use it if it were available to you?
- Yes
  - No

13. Some doctors and health care organizations use computers or mobile devices to record their patients' medical and health information. These electronic health records – or 'EHRs' – contain notes from your doctor or other medical personnel about your visits, diagnoses, test results, prescriptions, lifestyle and other elements of your medical history. As far as you know, do any health care providers maintain the medical record of the person whom you provide care in an electronic system?
- Yes
  - No
  - Not sure

Topic: Attitudes about EHRs and Health IT

14. Would you prefer that health care providers use electronic, computer-based medical records or paper-based records?
- Strongly prefer electronic
  - Somewhat prefer electronic
  - Neutral – no preference
  - Somewhat prefer paper
  - Strongly prefer paper
15. If a health care provider made the medical records of the person for whom you provide care available to you online, how likely would you be to go online to view those records and information?
- Extremely likely
  - Very likely
  - Somewhat likely
  - Not too likely
  - Not at all likely

[If not at all/not too likely]: Which of the following are reasons you would be unlikely to access medical records online? Please select all that apply. [RANDOMIZE]

- Concerned about cost
- Don't have access to a computer
- Don't have access to my medical records online
- Don't have time
- Don't understand medical terms
- Concerned about the privacy or security of medical records
- Don't know how to access it
- Not comfortable with technology

- Would rather have my doctor keep track of health care
- Not interested
- Afraid to know what's in the record
- Other: Please describe [open end]

16. The following are benefits and features associated with electronic or computer-based medical records and other forms of health information technology. Please indicate how useful you think each would be as you help the person for whom you provide care.

- Extremely useful
  - Very useful
  - Somewhat useful
  - Not too useful
  - Not at all useful
- 
- Send and refill prescriptions electronically
  - Receive electronic reminders to take medications
  - Receive electronic reminders for appointments, preventive screenings and tests
  - Communicate with health providers through secure email or secure text messaging
  - View lab and test results online
  - Have access to health information during an emergency
  - Have a summary of each visit with a health care provider
  - Send medical information from a device that helps you monitor indicators of health (such as blood glucose, weight, heart rate or other indicators)
  - Share health information with other people—doctors or family caregivers-- you trust
  - Withhold sensitive health information from selected health care providers (such as mental health information, HIV status, substance abuse or other sensitive health information)
  - Add or change information in a medical record
  - Correct inaccurate information in a medical record
  - Use tools that can help you and a doctor make decisions together about health care
  - Manage or keep track of medical records
  - Monitor and manage health-related expenses
  - Keep track and manage medications in one list
  - Keep track of immunizations

## QUESTIONNAIRE FOR MOTHERS

### Topic: Experience and Satisfaction with Health System

1. How many different health care providers have you taken your child(ren) to in the past 12 months? (e.g., such as family physician, dentist, eye doctor, cardiologist or other specialist, nurse, midwife, nurse practitioner, etc.) Please select one response.
  - 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None [SKIP to Q3]
  
2. Altogether, how many total visits to health care providers have you taken your child(ren) to in the past 12 months? Please select one response.
  - 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - None
  
3. Have you obtained information from any of the following sources in the past 12 months regarding your child(ren)'s health or health care? [**RANDOMIZE AND READ LIST**]

	Yes	No
Health insurance company		
Health-related Internet site		
Online patient support group or social media forum		
Doctor		
Nurse or other health provider		
Pharmacist		
Place of worship		
Friends or relatives		
Prescription drug company		
Television or radio		
Newspapers or magazines		
Other: please describe		

### Topic: Use of Internet for Health Information

4. How often do you use the Internet through a computer or mobile phone? Please select the single best response.
  - Through a computer (e.g., desktop, laptop or tablet computer)
  - Through a mobile phone
  - Several times a day
  - Several times a week

- Several times a month
  - Several times a year
  - Less frequently than several times a year
  - Never
- If NEVER to both technologies: Do you not use the Internet because you do not want to use it, because it is difficult to use, or because you don't have access?
    - Do not want to use the Internet
    - Difficult to use the Internet
    - Don't have access to the Internet

5. Within the past 12 months, have you done any of the following activities for your child(ren)'s health or health care?

	Yes	No
Searched online for information about a disease or medical condition?		
Participated in an online support group for a disease or medical condition?		
Looked at any medical test results online?		
Looked at a medical record online?		
Sent or received an email message from a health care provider?		
Sent or received a text message from a health care provider?		
Renewed a prescription online?		

Topic: Experience with EHRs and other Forms of Health IT

6. A "health app" is a program on a cell phone, mobile device or computer that can help you manage your health. Examples of health apps include calorie counters, sleep monitors, heart monitors, exercise trackers, and tools to help you manage your medications.

	Yes	No
Do you currently use a health app to help you manage the health or health care of your child(ren)?		
Have you ever used a health app to help you manage the health or health care of your child(ren)?		

- [If yes to either]: How many health apps have you used or tried in the past year?
  - 1-2
  - 3-5
  - 5 or more
- [If yes to either]: Please briefly describe the health app you have used the most [open-ended].
  - How effective was this health app in helping you manage the health or health care of your child(ren)?
    - Extremely effective
    - Very effective
    - Somewhat effective
    - Not too effective
    - Not at all effective

7. If there was a health app that could help you gather all of your child(ren)'s health records so you could have them in one place – such as on your mobile phone, home computer, tablet or laptop – how likely would you be to use it?
  - Extremely likely
  - Very likely
  - Somewhat likely
  - Not too likely
  - Not at all likely
  
8. If there was a health app that could help you share your child(ren)'s health records with others you trust (e.g., doctors, other care providers or family), if they need it while providing care, how likely would you be to use it?
  - Extremely likely
  - Very likely
  - Somewhat likely
  - Not too likely
  - Not at all likely
  
9. As far as you know, is your health care provider required by law to let you view and get a copy of your medical record?
  - Yes
  - No
  - Not sure
  
10. Have you heard of Blue Button?
  - Yes
  - No
  - Not sure

[If yes] – Please describe what Blue Button is. [open end]

11. Blue Button is a way for patients to get easy, secure online access to view their own personal health information online such as their insurance claims and medical records. Using Blue Button, patients can download their personal health information in a text file or PDF that can be read, printed or saved on any computer.

	Yes	No
Have you ever used Blue Button to download a medical record?		
Do you know of any friends or family members who have used Blue Button?		

- [If yes to used]: How effective was this Blue Button in helping you manage health care?
  - Extremely effective
  - Very effective
  - Somewhat effective
  - Not too effective
  - Not at all effective
  
- [If no to used]: Based on the description of Blue Button, do you think you'd use it if it were available to you?



- Yes
- No

12. Some doctors and health care organizations use computers or mobile devices to record their patients' medical and health information. These electronic health records – or 'EHRs' – contain notes from your doctor or other medical personnel about your visits, diagnoses, test results, prescriptions, lifestyle and other elements of your medical history. As far as you know, do any health care providers maintain your child(ren)'s health records in an electronic system?
- Yes
  - No
  - Not sure

Topic: Attitudes about EHRs and Health IT

13. Would you prefer that health care providers use electronic, computer-based medical records or paper-based records?
- Strongly prefer electronic
  - Somewhat prefer electronic
  - Neutral – no preference
  - Somewhat prefer paper
  - Strongly prefer paper
14. If a health care provider made your child(ren)'s health records available to you online, how likely would you be to go online to view those records and information?
- Extremely likely
  - Very likely
  - Somewhat likely
  - Not too likely
  - Not at all likely

[If not at all/not too likely]: Which of the following are reasons you would be unlikely to access your child(ren)'s health records online? Please select all that apply. [RANDOMIZE]

- Concerned about cost
  - Don't have access to a computer
  - Don't have access to my medical records online
  - Don't have time
  - Don't understand medical terms
  - Concerned about the privacy or security of medical records
  - Don't know how to access it
  - Not comfortable with technology
  - Would rather have my doctor keep track of health care
  - Not interested
  - Afraid to know what's in the record
  - Other: Please describe [open end]
15. The following are benefits and features associated with electronic or computer-based medical records and other forms of health information technology. Please indicate how useful you think each would be as you manage your child(ren)'s health and health care.

- Extremely useful
  - Very useful
  - Somewhat useful
  - Not too useful
  - Not at all useful
- 
- Send and refill prescriptions electronically
  - Receive electronic reminders to take medications
  - Receive electronic reminders for appointments, preventive screenings and tests
  - Communicate with health providers through secure email or secure text messaging
  - View lab and test results online
  - Have access to health information during an emergency
  - Have a summary of each visit with a health care provider
  - Send medical information from a device that helps you monitor indicators of health (such as blood glucose, weight, heart rate or other indicators)
  - Share health information with other people—doctors or family caregivers-- you trust
  - Withhold sensitive health information from selected health care providers (such as mental health information, HIV status, substance abuse or other sensitive health information)
  - Add or change information in a medical record
  - Correct inaccurate information in a medical record
  - Use tools that can help you and a doctor make decisions together about your child(ren)'s health care
  - Manage or keep track of your child(ren)'s medical records
  - Monitor and manage health-related expenses
  - Keep track and manage medications in one list
  - Keep track of immunizations