

# 12-Month Participating Patient Survey

## Part 1: What you think about reading visit notes online

1. In general, making visit notes available to patients on PatientSite is a good idea.
  - Disagree
  - Somewhat disagree
  - Somewhat agree
  - Agree
  - Don't know

### Participating patients only

2. Did you look at any of your doctor's visit note(s) on PatientSite?
  - Yes → Q5
  - No → Q3 → Q4 → Q33
  - BIDMC I did not have any notes to look at because I did not see my doctor since notes were made available (June 2010). →Q33
3. What was the reason you did not look at your doctor's visit notes? (check all that apply)
  - I didn't think it would be useful
  - I forgot my notes were available
  - I tried, but I could not find my notes on PatientSite
  - I was too busy
  - I thought reading the notes would make me nervous or anxious
  - Another reason
  - No particular reason

Another reason proceed to → Q4

4. Please tell us more about why you didn't read your doctor's notes.

All Responses- blank or empty proceed to → Q33

5. Why did you read your visit notes? (check all that apply)
  - I was curious
  - I wanted to remember what happened in the visit
  - I wanted to know about my health
  - I have a right to see what's in my medical record
  - I wanted to check the notes to see if they were right
  - I wanted to be sure I understood what the doctor said
  - I wanted to know what my doctor was thinking

- No particular reason
- Other reason (please explain) \_\_\_\_\_

6. Did you show or discuss your visit notes with other people?

- Yes → Q7
- No → Q9
- Don't know/don't remember → Q9

7. With whom did you share or discuss the note? (check all that apply)

- Another doctor → Q9
- A family member/relative/friend who helps take care of me → Q8
- Another family member or relative → Q9
- Another friend → Q9
- A nurse or health professional → Q9
- Someone else (specify relationship, no names please) \_\_\_\_\_ → Q9

8. Did it help you to share your notes with family members or friends who are helping with your health care needs?

- Yes
- No

9. I would like to continue to be able to see my doctor's notes online.

- Yes
- No

## Part 2: What it was like to read your visit notes

### Participating patients AND yes to Q2

Please think about what it was like to read your doctor's notes about your office visits on PatientSite

10. How often were the doctor's notes put on PatientSite as soon as you wanted them?

- Never
- Sometimes
- Usually
- Always
- Don't know

11. How often did the note(s) accurately describe the visit?

- Never
- Sometimes
- Usually
- Always
- Don't know

12. How easy was it to understand your doctor's notes?

- Very difficult
- Somewhat difficult
- Somewhat easy
- Very easy
- Don't know

13. Did you ever mention to your doctor that you had read his/her note online?

- Yes
- No
- Don't know/don't remember

14. Did you ever contact your doctor's office about something in your notes?

- Yes → Q16 then Q17 then Q18
- No, I did not feel any need to →Q18
- I considered contacting my doctor's office but decided not to →Q15 then Q18
- Don't know/don't remember →Q18

15. If no, why not? (Check all that apply)

- I didn't want to waste my doctor's time
- I didn't think it was important
- I didn't want my doctor to be angry with me
- I worried my doctor might not take as good care of me
- I worried my doctor might get back at me
- It was too much of a bother for me
- Another reason (please explain) \_\_\_\_\_

All Responses skip to →Q18

16. Why did you contact your doctor's office about something in your notes? (Check all that apply)

- I wanted an explanation of something in my notes
- I wanted something removed from my permanent record
- I wanted to report something I thought was an error in my notes
- I wanted to discuss something I disagreed with
- Another reason (please explain) \_\_\_\_\_

All Responses proceed to →Q17

17. Were you satisfied with the doctor's or office's response to your request?

- Yes
- Somewhat
- No

18. Please briefly tell us about how you used your notes. We would appreciate any examples you have to help us understand.

19. I understand my health and medical conditions better.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

20. I remember the plan for my care better.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

21. I take better care of myself.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

22. I do better with taking my medications as prescribed.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know
- I don't take any medications

23. I feel more in control of my health care.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

24. I worry more.

- Disagree → Q26
- Somewhat disagree → Q26
- Somewhat agree → Q26
- Agree → **Q25**
- Don't know → Q26

25. Please briefly describe why you worry more in response to reading your notes.

26. I am concerned about my privacy.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

27. I felt offended.

- Disagree → Q29
- Somewhat disagree → Q29
- Somewhat agree → Q29
- Agree → **Q28**
- Don't know → Q29

28. Please briefly describe why you felt offended in response to reading your notes.

29. The notes are more confusing than helpful.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

30. I am better prepared for visits.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- Don't know

31. Did reading the doctor's note change the way you feel about your doctor?

- I feel much worse
- I feel somewhat worse
- I don't feel better or worse
- I feel somewhat better
- I feel much better

32. Did something happen (good or bad) as a result of reading your notes? Please describe your experience here:

33. Since this is a research project, the future of continued patient access to doctor's notes is uncertain. How would you feel personally if open notes were turned off?

- Very pleased- I would like to stop being able to read them online
- Somewhat pleased
- Would not care
- Somewhat disappointed
- Very disappointed- I do not want my online access to the notes turned off

34. In the past, have you ever requested a copy of your medical records from your doctor's office?

- Yes → Q35
- No → Q36

35. If Yes, please tell us about the experience of getting your records (was it easy, difficult, etc.)

### Part 3: The care you receive from your primary care doctor

#### Participating and non-participating patients

The following questions are about the care you receive from your primary care doctor. This is the doctor who takes care of you over time (not specialist doctors).

36. How confident are you in your ability to know what questions to ask your doctor?

Not at all										Extremely
Confident										Confident
1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>										

37. How confident are you in your ability to get your doctor to take your chief health concern seriously?

Not at all										Extremely
Confident										Confident
1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>										

38. How confident are you in your ability to make the most of your visit with your doctor?

Not at all										Extremely
Confident										Confident
1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>										

39. How confident are you in your ability to get your doctor to answer all of your questions?

Not at all										Extremely
Confident										Confident
1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>										

40. How confident are you in your ability to get your doctor to do something about your chief health concern?

<b>Not at all</b>										<b>Extremely</b>
Confident	1	2	3	4	5	6	7	8	9	Confident
	10									
	<input type="checkbox"/>									

41. In the last 12 months, how often did your doctor explain things in a way that was easy to understand?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always
- I have not communicated with my doctor in the last 12 months. → Q47

42. In the last 12 months, how often did your doctor listen carefully to you?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always

43. In the last 12 months, how often did your doctor or the staff give you clear instructions about what to do to take care of the health problems or symptoms that were bothering you?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always

44. In the last 12 months, how often did your doctor seem to know all of the important information about your medical history?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always

45. In the last 12 months, how often did your doctor spend enough time with you?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always

46. In the last 12 months, how often did you feel you could tell your doctor anything, even things that you might not tell anyone else?

- Never
- Almost never
- Sometimes
- Usually
- Almost always
- Always

47. Using any number from 1 to 10, where 1 is the **worst** doctor possible and 10 is the **best** doctor possible, what number would you use to rate your doctor?

**Worst doctor possible**

- 1    2    3    4    5    6    7    8    9    10
- 

**Best doctor possible**

48. Would you recommend your doctor to your family and friends?

- Definitely not
- Probably not
- Not sure
- Probably yes
- Definitely yes

## Part 4: Thinking about the future

**Participating:** Thank you for telling us about your experiences. In the following questions, please think about the future...

49. If you are given a choice of doctors or health plans in the future, how important would open notes be in your decision?

- Not important
- Somewhat important
- Very important

50. In the future, I should be able to add my own comments to the doctor's note.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- No opinion

51. In the future, I should be able to approve what's written in the note.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- No opinion

52. In the future, notes from hospital admissions should be available on PatientSite (Being admitted usually means that you stay in the hospital at least one night.)

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- No opinion

53. In the future, I would like the option of letting family members or friends who help me with my health care have their own access to my visit notes.

- Disagree
- Somewhat disagree
- Somewhat agree
- Agree
- No opinion

54. Do you have any other changes or suggestions about open notes?

## Part 5: About you

### Participating and non-participating patients

55. In general, how would you rate your overall health?

- Excellent
- Very good
- Good
- Fair
- Poor

56. What is the highest grade or level of school that you have completed?

- 8<sup>th</sup> grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- Some graduate school
- Masters or Doctoral degree

57. Are you of Spanish/Hispanic/Latino ethnicity?

- Yes
- No

58. What do you consider to be your racial background? (check all that apply)

- White
- Black or African American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

59. Which of the following best describes your current employment status? (check all that apply)

- Employed for wages
- Self-employed
- Homemaker
- Unemployed
- Retired
- Unable to work
- Prefer not to answer

60. If there is anything else that you would like us to know about you, or other comments you would like to make, please write them here: