

Welcome to the University of North Carolina (UNC) Patient Advocacy Survey.

The first step is to read a FACT SHEET about this project. When you finish reading, please SCROLL DOWN to the bottom of the page, indicate whether you AGREE or DISAGREE with our terms, and then click NEXT.

Let's begin...

1. [FACT SHEET PAGE]

Thank you for taking the time to complete this survey. This questionnaire, which should take about 15 minutes to fill out, begins with a few questions about you and what you do.

2. For how long have you been interested in health-related advocacy issues?

12 years or more

9-11 years

6-8 years

3-5 years

1-2 years

less than one year

I am not interested in health-related advocacy issues

3. For how long have you worked on health-related advocacy issues?

12 years or more

9-11 years

6-8 years

3-5 years

1-2 years

less than one year

I do not work on health-related advocacy issues

4. What is your background? (Please choose only one)

business

education

government

humanities/arts and sciences

journalism

law

medicine

nursing

pharmacy

public health

social work

other (specify): _____

5. In what capacity would you say you MOST often practice health-related advocacy? (Please choose one) Do you most often practice advocacy as a:

provider of health care services

researcher/evaluator of health care services

member/leader of a non-profit organization

member/leader of a governmental agency

member/leader of an academic institution

I do not practice health-related advocacy

other: _____

6. What percentage of your work over a year's time would you say is devoted to health-related advocacy?

0-25%

26-50%

51-75%

76-100%

7. What is your major area of advocacy interest? (Please choose only one area)

advocacy by patients themselves

advocacy by parents/family members

advocacy by clinicians

e-health/Internet advocacy

education of advocates

research in advocacy-related topics (e.g., patient-provider communication)

inclusion of advocates in planning/conducting research

hospital/organizational change

consumer health advocacy

grassroots organizing

legal advocacy

legislation/policy making

media advocacy

I do not have one major area of interest

other (specify): _____

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8. People become involved in advocacy for a variety of reasons. If you had to pick just one, what would you say was the factor that most motivated you to get involved in health-related advocacy? (Please choose only one)

own experience as a patient

friend/family member's experience as a patient

own experience as a provider

interest in a particular disease

interest in certain populations (e.g., people of color, children)

interest in patient safety

interest in health communication

job opportunity

intellectual curiosity

I am not involved in health-related advocacy

other (specify): _____

9. What would you say is the one factor that most motivates you to continue to work on health-related advocacy issues? (Please choose one)

own experience as a patient

friend/family member's experience as a patient

own experience as a provider

interest in a particular disease

interest in certain populations (e.g., people of color, children)

interest in patient safety

interest in health communication

job opportunity

intellectual curiosity

I do not work on health-related advocacy issues

other (specify): _____

Advocates use a variety of terms to describe their work. This survey is about defining “patient advocacy.” In this next section, you will be asked about the people, professions, and organizations that in your opinion contribute to this kind of advocacy. Needless to say, there are no “right” or “wrong” answers to these questions. Your answers should reflect your own experiences and/or general impressions about patient advocacy.

10. How often do you think the following groups of people take on the role of patient advocate?
[often, sometimes, once in a while, practically never]

patients themselves
patients’ family members/friends
physicians
nurses
pharmacists
social workers
hospital patient representatives

11. Which groups, if any, would you like to see take on MORE of a role in patient advocacy?
(Please choose all that apply)

patients themselves
patients’ family members/friends
physicians
nurses
pharmacists
social workers
hospital patient representatives
none of these groups

12. Besides patients and providers, how much of a role do you think the following groups play in supporting the work of patient advocates?

[a big role, somewhat of a role, a small role, not really any role]

leaders of non-profit organizations
hospital administrators
legislators
attorneys
researchers
educators of patient advocates
activists/grassroots organizers

13. Besides patients and providers, which of these groups, if any, would you like to see take on MORE of a role in patient advocacy? (Please choose all that apply)

leaders of non-profit organizations

hospital administrators

legislators

attorneys

researchers

educators of patient advocates

activists/grassroots organizers

none of these groups

other: _____

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14. When you think about patient advocacy, what substantive field would you say has been MOST important in leading the way? (Please choose only one) Would you say:

HIV/AIDS

cancer

mental health

palliative care and pain management

disability rights

complementary and alternative medicine

Medicaid/Medicare rights

Other (specify): _____

15. What are some of the organizations, if any, that in your opinion have emerged as leaders in patient advocacy? (Please name them) [open]

16. Who, in your opinion, are some of the individuals, if anyone, who have emerged as leaders in patient advocacy? (Please name them) [open]

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The next section of the questionnaire asks you about the goals, methods, next steps, and competencies that are most important to patient advocacy. As before, your answers should reflect your own experiences and opinions.

17. With regard to patient advocacy, would you say the following goals are:

[very relevant, somewhat relevant, a little relevant, not really relevant at all]

quality improvement/patient safety

more patient-centered care

increased patient satisfaction

improved patient-provider communication

greater cost containment

more patient-friendly insurance policies

increased access to care

more culturally sensitive care

18. Besides those listed above, what other goals, if any, do you believe are relevant to patient advocacy? (open)

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19. How often do you think patient advocates use the following methods?

[often, sometimes, once in a while, practically never]

patient/consumer education

peer-to-peer support

provider education/curriculum reform

grassroots organizing

litigation

regulation/legislation

organizational change in hospitals

media advocacy

20. Which methods should patient advocates use more often than they currently do? (Please choose all that apply)

patient education

peer-to-peer support

provider education/curriculum reform

grassroots organizing

litigation

regulation/legislation

organizational change in hospitals

media advocacy

other (specify): _____

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21. How high or low priority are the following “next steps” in patient advocacy?

[very HIGH priority, somewhat HIGH priority, somewhat LOW priority, very LOW priority]

defining patient advocacy

raising public awareness about advocacy issues

issuing a “call to arms” among professionals

coordinating advocacy efforts more effectively

training more advocates/training advocates more effectively

evaluating advocacy efforts

establishing best practices

setting a research agenda for patient advocacy

22. Besides those listed above, what other “next steps,” if any, should be given a high priority in patient advocacy? (open)

23. When training future patient advocates, do you think competence in the following areas is:
[very important, somewhat important, a little important, not really important at all]

communication skills
an understanding of the patient's perspective
knowledge of what patient empowerment entails
an understanding of advocacy ethics
media literacy
an understanding of the importance of power dynamics
self-reflection
cultural sensitivity
an understanding of how medical organizations operate
an understanding of how providers think

24. What other areas of skill and knowledge, if any, are important for future advocates? (open)

25. In terms of recruiting future patient advocates, would you say the following qualities are:
[very important, somewhat important, a little important, not really important at all]

willingness to collaborate
passion about the cause/area
empathy for others
assertiveness
vision for the future
self-awareness
self-confidence
a strong work ethic

26. What other qualities, if any, are important for future advocates to have? (open)

27. In conducting future research related to patient advocacy, how high or low priority are the following areas for research?

[very HIGH priority, somewhat HIGH priority, somewhat LOW priority, very LOW priority]

patient-provider communication
e-health/Internet advocacy
patient-centered hospital models
quality improvement measures
patient safety
influence of grassroots organizing
policy/economic analysis

28. Besides those listed above, what other areas of research, if any, should be given a high priority? (open)

The next four questions comprise the heart of our survey. We are asking you to share your own definition of patient advocacy and, if applicable, to identify the rewards and challenges associated with your work in this area.

29. [REQUIRED] In your own words, how would you define patient advocacy? (open)

30. How relevant is patient advocacy to your own work?

very relevant

somewhat relevant

a little relevant

not really relevant at all

31. What is the most rewarding aspect of your work in patient advocacy? (open)

32. What is the most challenging aspect of your work in patient advocacy? (open)

33. Is there anything else you would like to say about patient advocacy? (open)

The final three survey questions request demographic information. These questions are optional, but we ask that you answer them to help us assess the nature of our sample of respondents.

34. What gender are you?

Male

Female

35. What is your race/ethnicity?

African American or Black

Latino or Hispanic

Asian or Pacific Islander

Native American

Caucasian or White

Other (specify):_____

36. What degrees, if any, do you hold at the following levels? (Please name, specifying an area of study if applicable)

Undergraduate Level (e.g., BA, BS)_____

Master's Level (e.g., MSW, MPH in epidemiology)_____

Doctoral Level (e.g., MD, JD, PhD in psychology)_____

Other _____

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You have completed the UNC Patient Advocacy Survey, and your answers have been saved. We appreciate your time and will use what you've told us to reach a better understanding of patient advocacy.

To close this survey, please click "Done." You will be transferred to the UNC School of Public Health web site.

Thank you again for your help!

<END>