

Patients' views on 'quality of life'

FREQUENTLY-ASKED QUESTIONS

WHO IS CONDUCTING THIS SURVEY?

The survey is being run by HSCNEWS International in collaboration with the QALYity Project, a recently-founded UK alliance of prestigious patient groups, doctors, academics, and journalists. PatientView, the publisher of HSCNews International, is one of the co-founders of the QALYity Project. The QALYity Project aims to develop advice that can help you (and your doctor and the NHS) improve the quality of patients' lives.

HOW WERE THE QUESTIONS FOR THIS SURVEY CHOSEN?

The QALYity Project has been told by over 270 UK-based patient and disability organisations what they think are the most important factors affecting patients' quality of life. Now we would be grateful if YOU could tell the Project what you think are the most important factors for your quality of life when you are receiving healthcare.

WHERE WILL THE RESULTS OF THIS SURVEY BE PUBLISHED?

The survey results will be posted on the PatientView website (the home site of HSCNEWS International) by the end of April 2007 [<http://www.patient-view.com>].

HOW CONFIDENTIAL WILL MY ANSWERS TO THIS SURVEY BE?

Your survey answers will be kept strictly private by the survey manager, HSCNEWS International. You do not have to supply your name or contact details. The survey results will only contain broad trends, and will not mention individuals, unless you specifically request to be named in the survey report.

WHO IS PAYING FOR THIS RESEARCH?

The survey is being paid for by HSCNEWS International.
The QALYity Project is supported by an educational grant from NovoNordisk (a Danish company that manufactures treatments for people with diabetes).

(If you wish to know more about this study, please email: info@patient-view.com)

Patients' views on 'quality of life'

[Exit this survey >>](#)

An international survey for HSCNews International

Please help make a difference by answering this questionnaire on patients' quality of life—your opinion on this subject can count.

WHY YOU CAN MAKE A DIFFERENCE BY FILLING IN THIS SHORT QUESTIONNAIRE

Do you believe that doctors and the healthcare system should take into account the quality of life of patients? Do you consider that, ideally, YOU as a patient should be able to tell doctors and the healthcare system what improves your quality of life, and what does not?

If your answer to these two questions is "Yes", you may not be too surprised to learn that many other people think similarly. Yet one reason why the situation has never really changed before is that the medical profession, healthcare managers, civil servants and politicians cannot always be expected to know what patients mean by 'quality of life'.

This survey hopes to address that problem by producing some authoritative definitions of the phrase 'patients' quality of life'. The survey is being conducted worldwide, so that patients from many countries can include their valuable thinking on the subject of quality of life. THE SURVEY RESULTS WILL HELP PATIENTS FROM ACROSS THE WORLD DETERMINE THE KEY CHARACTERISTICS BEHIND AN IMPROVED QUALITY OF LIFE.

We plan to make all of the survey's results available to the public, and we will also present them to the National Institute of Health and Clinical Excellence (NICE), the UK government-funded organisation that decides which treatments and care should be paid for by the UK's National Health System (NHS). NICE has served, and continues to serve, as an example for other countries' efforts to measure the cost-effectiveness of medicines—meaning that the results of this survey will be just as relevant to most countries around the world.

The survey's 12 questions should take ten minutes—at most—to complete.

On the next page, you will find answers to most background questions you might have about this survey.

[Next >>](#)

Patients' views on 'quality of life'

[Exit this survey >>](#)

NINE VERY BRIEF PROFILING QUESTIONS

These questions will help us understand the types of people answering the survey, and allow us to make more sense of the results.

Question 1.) Are you male or female?

- Male.
- Female.

Question 2.) Which age range do you fall into?

- Under 20
- 20 to 29
- 30 to 39
- 40 to 49
- 50 to 59
- 60 to 69
- 70 or above

Question 3.) What broad category of ethnicity do you fall into?

- Asian.
- Black.
- Latino.
- White.
- Other (please specify).

Question 4.) Which country do you live in?

Question 10.) When you are receiving medical treatment or medical care, how important are the following factors in improving your quality of life?

Please score each on a scale of 1 to 5, where ...

1 = "Very important if a treatment or care is to improve my quality of life"; and

5 = "Not important in improving my quality of life".

	1	2	3	4	5
Being satisfied with the medical treatment/ care that I am receiving.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being sure that I am getting the correct medical treatment/ care/ support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that my basic human rights are respected when I get medical treatment and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having the information that I need to manage my life successfully (including information that allows me to make choices in my treatment, and to know about my rights).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Believing that my carers/ family/ friends are getting all the information and support they need from the healthcare system to ensure that I can live as full a life as possible.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being sure that the doctor (or other healthcare professional) looking after me is sufficiently skilled and expert to do the job properly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sure that the doctor is listening to my own opinions about my treatment and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being sure that the doctor will supply the medical treatment/ care that I want (rather than just supply only the treatment/ care that the doctor thinks should be offered).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being required to pay money (and therefore possibly having financial worries) to get the medical treatment/ care/ support that I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not having to fight the system to receive the medical treatment/ care/ support that I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being relatively free of pain, or bodily discomfort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being able to lead a normal (or near-normal) life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[<< Prev](#)

[Next >>](#)

Patients' views on 'quality of life'

[Exit this survey >>](#)

SECOND OF THREE QUESTIONS ON QUALITY OF LIFE

ABOUT PRACTICAL FACTORS AND YOUR PHYSICAL WELLBEING

Question 11.) When receiving treatment/ care/ support, how important are the following factors in helping you achieve the best-possible quality of life?

Please score each on a scale of 1 to 5, where ...

1 = "Very important if a treatment or care is to improve my quality of life"; and

5 = "Not important in improving my quality of life".

	1	2	3	4	5
Feeling that I can cope with daily living in dignity, in spite of my medical condition/ disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that I can retain my independence, and can look after myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that I can accept my condition as a real fact.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not feeling as if my illness/ disability is making me an outsider to society (not feeling that I am stigmatised).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that there are no (or few) physical barriers to prevent me from taking a treatment or from getting support or care (for instance, that my medicines are easy to take; or that I can get repeat prescriptions; or that my GP practice has a car park; etc).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[<< Prev](#)[Next >>](#)

Patients' views on 'quality of life'

[Exit this survey >>](#)

LAST QUESTION ON QUALITY OF LIFE

ABOUT YOUR OUTLOOK ON LIFE

Question 12.) If a medical treatment or care is to help in improving your quality of life, how important is it that the treatment/ care brings you the following emotional benefits?

Please score each on a scale of 1 to 5, where ...

1 = "Very important if a treatment or care is to improve my quality of life"; and

5 = "Not important in improving my quality of life".

	1	2	3	4	5
Being able to face the world.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling largely in control of my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling energetic.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being able to attain personal goals and aspirations (including spiritual ones).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that little things do not get me down.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling positive about the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having peace of mind.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling broadly satisfied with life, and living a meaningful existence.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being able to take pleasure in what life has to offer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that my medical condition/ disability does not dominate my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued by my friends, family, and those around me, despite my medical condition/ disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not feeling a burden to other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling normal, and not different from other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing that scientists are working hard to find a cure for my condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Patients' views on 'quality of life'

[Exit this survey >>](#)

ADDITIONAL COMMENTS

Bearing in mind your own particular illness/ disability, does any one single definition listed in the previous 3 questions stand out as THE MOST IMPORTANT OF ALL in improving your quality of life?

Please write down your choice in the box below ...

... or select one from the list of all definitions, below

If you would like to add any comments of your own on the subject of quality of life, please feel free to do so here.

[<< Prev](#)[Next >>](#)