

Von: "From PatientView " <[info@patient-view.com](mailto:info@patient-view.com)>

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An:

Betreff: Your help is needed: a survey on quality-of-life for patients (and people with a disability)

Do you believe that doctors and the healthcare system should do more to improve the quality of life of the people that your organisation represents? If you do, one problem is that the medical profession, managers, administrators and politicians have little idea what you (and everyone else) mean when you use the phrase 'quality of life'.

To help overcome this barrier to improvements in patients' quality of life, we would like to invite the members (patients or people with a disability) of your organisation to add their opinions to a worldwide study on what constitutes patients' quality of life. The results of this survey will help patients from across the world determine the key characteristics behind an improved quality of life.

The study is being conducted by HSCNews International, an independent publication for health advocates, in collaboration with the QALYity Project (a UK-based alliance of prestigious patient groups, medical professionals, academics, and journalists). The Project is trying to develop an index that can measure how effective each individual medical treatment (or form of care/ support) is at improving the quality of life of people with a long-term medical condition (or a disability)—as determined by the individuals themselves, not by clinicians. The results of this international survey, and the tools that emerge from it, will be made publicly available, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), a UK-government-funded body that decides which treatments and care should be paid for by the healthcare system in the UK. Many of the actions taken by NICE are relevant to other countries' healthcare systems.

In December 2006 the QALYity Project published the results of a survey, which had collected the views of over 270 patient/disability/ carer organisations in one country (England and Wales), see footnote to this email. These groups have kindly provided a wealth of potential definitions of the phrase 'quality of life'. But people are different, and not all of the December 2006 definitions are likely to apply to everyone. This second questionnaire which is being sent worldwide is aimed at your members and should allow individual differences to be collated.

For this reason, we would be most grateful if you could give your members a chance to input their opinions to this quality-of-life survey (the short questionnaire can be filled out online by clicking on the following hyperlink: [QUALITY OF LIFE SURVEY](#), where further details about this survey can be found.)

If you would prefer to circulate a hard copy of the questionnaire to your members, please email your contact details to the email address below, and we will send you a PDF version of the questionnaire, which can be emailed or faxed back to us .

The administrative costs of this international survey are being paid for by HSCNews International.

Please note that the QALYity Project is supported by an educational grant from NovoNordisk (a Danish company that manufactures medicines for people with diabetes).

Thank you for your assistance in this matter,

Alexandra Wyke,

CEO, PatientView

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For more information: <<http://www.patient-view.com>>

Foot note

The results of the QALYity Project's first survey into patients' quality of life can be read at <<http://www.patient-view.com/qalyity.htm>>.