
Report on the uses and proper use of the measurement of perceived health and quality of life in France

SUMMARY OF KEY POINTS

January 18, 2022

This summary presents the key points of the report for the reader in a hurry.

I. Context and objectives of the referral

Over the last few decades, the measurement of perceived health, quality of life or well-being has become an important part of the assessment of chronic diseases, but also of population health.

The development of reliable and valid instruments has made it possible to clarify the multidimensional impact of many chronic diseases and to emphasize the importance of appropriate biomedical, psychological and social management of these diseases. Taking into account perceived health and quality of life has proven to be a useful tool for individual decision making in patients suffering from cancer, multiple sclerosis and diabetes, among others.

Regular assessment or "monitoring" of population-based quality of life has been implemented in several countries, including the United States.

Despite the "plan to improve the quality of life of people with chronic diseases" (2007-2011), which called for "operational application of the concept in routine", routine use of these measures has remained low-profile in France, both at the individual level, to help manage patients, and at the population level, for the definition and evaluation of public health actions and plans.

The objectives of the self-referral are to

- to draw up an inventory of the use of measures of perceived health, quality of life and well-being in routine practice in France
- to compare this use with that adopted in the main foreign health systems
- and to propose operational recommendations concerning their proper use.

This work was carried out by a working group composed of members of the French High Council for Public Health (HCSP) and external specialists in the field. The corpus of documentation consists of a literature review of 63 experiences and 32 interviews with researchers, professionals, user representatives and decision-makers.

II. ISSUES IN MEASURING PERCEIVED HEALTH, QUALITY OF LIFE AND WELL-BEING

A. Background, conceptual approach and operationalization

- Four main conceptual or theoretical approaches to perceived health, quality of life and well-being can be distinguished: 1) those based on theories of needs, 2) those based on theories of positive well-being and happiness, 3) those based on utilities, and 4) finally Sen's approach, based on "capabilities".
- In practice, however, most of the instruments for measuring perceived health, quality of life and well-being that have been developed over the last few decades are based on several approaches and operationalize multidimensional concepts that largely overlap, whether they are called "perceived health", "quality of life" or well-being.
- Most of the instruments allow an evaluation of the physical, psychological and social dimensions of functioning in accordance with the WHO definition of health (1946), but some, notably those of the WHO, consider other aspects of life, such as the level of independence (autonomy, power to act) or relations with the environment (place of living, noise, healthiness, access to care, etc.).
- The measurement instruments make it possible to assess numerous dimensions or facets of life experience, some of which are related to perceived health, others to quality of life or well-being, and many of which are related to both. When choosing an instrument, the potential user should of course consider the underlying theoretical or conceptual models, but above all he or she should examine the dimensions or facets that are operationalized in the instruments, and select the one or ones whose facets will be most congruent with the aspects of the problem or the characteristics of the populations he or she has to consider.

B. Specific questions posed by the use of the measures

- Older age, female gender, social and educational level, geographic origin, and a wide variety of physical and especially mental diseases or disorders are often negatively associated with perceived health, quality of life, and well-being. Several dimensions of perceived health and quality of life-which are beyond the scope of conventional biomedical measures-have been shown to be relevant for characterizing the severity of conditions and the burden of management, and useful for clinical decision making and multidimensional management of chronic diseases.
- When used to assess population health, some instruments can produce measures that are sensitive to certain social characteristics and reveal social inequalities in health in different ways.
- Condition-specific instruments facilitate the appropriation of measures of perceived health and quality of life in certain health care settings, but cannot be used exclusively, particularly when comparisons between conditions and settings are relevant within the same setting or organization.
- The development or cross-cultural adaptation of measurement instruments follows steps that are now well codified, and it is important for potential users to ensure that they do so. They also need to consider the limitations of some of these instruments when assessing them repeatedly over time.
- The length of time it takes to administer or administer certain instruments is not generally an insurmountable limit in a health care context, but it is essential that the scores be rapidly available and shared with the healthcare professionals

- Any implementation of a measure, especially in a vulnerable and dependent population such as that of patients or users of the health care system, must be the subject of prior ethical reflection, which must answer the questions of the usefulness and individual and collective benefit of this measure.

III. EXPERIENCES IN THE FIELD OF CARE

A. FRENCH EXPERIENCES

- Several experiments on the routine implementation of quality of life measures in hospital care structures have been conducted in France, demonstrating their feasibility and clinical usefulness in high-level evaluations (randomized trial at the Nancy Regional University Hospital, large-scale cohorts in cancerology in Besançon).
- The routine collection of a short measure of quality of life (EQ-5D) for medico-economic purposes at the Assistance publique-Hôpitaux de Marseille, without any particular difficulty, has confirmed its feasibility.
- Not all professionals, depending on the chronic diseases and fields of care, are equally familiar with the use of these measures in France, and they do not all appear to be equally ready for routine use. The fields of renal failure and transplantation as well as oncology are the most advanced, with routine implementation already taking place on a regular basis. Structures caring for patients with multiple sclerosis, inflammatory rheumatism, HIV and certain mental illnesses are the next most familiar with the subject. On the contrary, research seems to be required to establish the feasibility of routine implementation in these areas: pediatrics, gerontology and end of life, for which there is no consensus yet on instruments.
- The interest of patient associations in the routine implementation of measures of perceived health and quality of life is real, and some associations such as Renaloo (kidney disease) are already very active on the issue, but the level of knowledge and familiarity with the subject remains very heterogeneous.
- The regional support structures for quality of care and patient safety (SRA) have the legitimacy and federative structuring necessary to support voluntary care structures in initiatives to implement routine measures of perceived health and quality of life.

B. FOREIGN EXPERIENCES

- The exploration of routine implementation of perceived health and quality of life measures in foreign health care systems was limited for methodological reasons. Nevertheless, it has enabled us to identify various initiatives and to highlight the difficulties of mobilizing health professionals over time.

C. ASSESSMENTS AND POSITIONS OF FRENCH INSTITUTIONS

- The General Directorate for Health Care Provision has defined a policy aimed at developing the use of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) in the health care system, including perceived health and quality of life, and would like to test their use in ten or so health care pathways as a priority.

- The French National Authority for Health (HAS), the French National Cancer Institute (INCa), and the French Biomedicine Agency (ABM) have several years of experience, some of which is extremely extensive in the case of the ABM, with the use of perceived health and quality of life measures in the healthcare system.
- The HAS is following the issue of measuring quality of life at work, in relation to the certification of health and medico-social institutions.

D. INTERNATIONAL INITIATIVES

- The OECD has developed a major initiative on the use of PROMs and PREMs in the health system, which France, having just joined, will be able to benefit from.

IV. EXPERIENCE IN POPULATION HEALTH OBSERVATION AND SURVEILLANCE SYSTEMS

A. SYSTEMS AT THE EUROPEAN AND INTERNATIONAL LEVELS

- Four European administrative surveys (EHIS, EQLS, ESS, Silc) routinely provide data related to well-being and quality of life. Perceived health is generally only measured by the three questions of the European minimodule on perceived health, chronic diseases and activity restrictions. These surveys allow France to be placed among the other countries. Eurostat is the reference organization.
- In parallel with these European surveys, many studies have sought to produce alternative indicators to the Gross Domestic Product (GDP), which represents the aggregate wealth of nations: human development index, social health index, social progress index. Based on routinely available data, they are often used to approach the quality of life in the territories.
- How's life? is an interactive tool developed by the OECD, whose particularity is to collect online the weights of individuals on several dimensions of quality of life. However, this tool has important methodological biases. Its intensive use by some countries should be monitored.
- The monitoring of the Sustainable Development Goals (SDGs) by the UN should influence the work on measuring well-being, but currently only life expectancy and life satisfaction are included in the French monitoring dashboard.

B. MECHANISMS AT THE NATIONAL LEVEL

- In France, only the measurement of perceived health by the mini-module (3 questions) is regularly implemented in the various public statistics surveys.
- The organization and relationships of health institutions in France are complex. The three institutions mainly involved in major surveys are Drees (Direction de la recherche, des études, de l'évaluation et des statistiques), Insee (Institut national de la statistique et des études économiques), and Santé publique France. These structures are represented in several international working groups (OECD, Eurostat).
- Santé publique France's Health Barometer is a key annual survey for monitoring the health behaviours, attitudes and perceptions of the French. The instability of the instruments used to measure perceived health and quality of life in the different waves of the survey has prevented its use as a routine monitoring tool.

- The use of perceived health and quality of life instruments in other thematic and population-based health surveys has remained heterogeneous. It was neither systematic nor repeated.
- The well-being observatory, run by the Centre Pour la Recherche Économique et ses Applications (Cepremap), which is linked to the INSEE household survey, carries out a quarterly survey based on four dimensions (life satisfaction, happiness, meaning of life, mental health), which is decoupled from health topics.
- In other countries, information systems and measurement tools vary from country to country, with more or less ambitious collection systems combining, for example, declared data, individual interviews and clinical examinations. Several countries have integrated routine measurement tools into inspiring schemes. Among these, the US CDC has introduced a short 4-question format in its BRFSS surveillance system several times a year. The United Kingdom publishes results twice a year. The short EQ5D scale (5 questions) is used in several European countries. The results are often used to evaluate public policies.
- One of the most striking results regularly found is the discrepancy between the evolution of GDP and that of several dimensions of quality of life.

C. REGIONAL AND LOCAL MECHANISMS

- In France, there are initiatives to measure quality of life and perceived health at fine territorial levels, but they are often small-scale and lack overall coherence. At the regional or local level, stakeholders mention the absence of representative data from major national surveys, with the exception of sporadic regional oversamples such as the Santé publique France health barometer.
- In France and abroad, some regions or cities have implemented interesting experiments over several years, which can be capitalized on. Among the most inspiring monographs are IBEST (Indicateurs d'un Bien-être Soutenable et Territorialisé) in Grenoble, the experience of Jacksonville in the United States and the IWEPs project in Belgium.

Quality of life is embraced in a broad thematic scope. These experiences are all characterized by strong political and partnership support, with the involvement of all stakeholders. The population participates in defining the indicators. Dashboards are constructed from administrative data and ad hoc surveys conducted on a routine basis. These approaches support public policy projects.

D. MEASUREMENT EXPERIMENTS FOR SPECIFIC POPULATIONS OR THEMES

- The report could not be exhaustive on all thematic or population-based approaches. The elements collected through the literature review and the hearings confirm that specific reflections should be pursued, particularly on the measurement of well-being and quality of life at school and at work. The Covid crisis has also put a very strong emphasis on quality of life in relation to the mental health of the French, at all ages of life.

E. ASSESSMENT AND EXPECTATIONS OF FRENCH INSTITUTIONS

- Regardless of the territorial level, public policies cannot simply measure traditional morbidity indicators (e.g., prevalence of obesity, tobacco consumption, incidence of heart attack, etc.). They must also set targets for quality of life and well-being and have the means to measure them. Measures to cover this field should therefore be determined at the national level and routinely applied at the territorial level.
- Some instruments for measuring perceived health or quality of life have been developed for use primarily in a health care context, with a biomedical rather than a public health vision (with a strong emphasis on

functional capacities), which limits the use of these tools in general population studies. The physical and mental aspects are often well highlighted, but other dimensions are not taken into account in these instruments (living, working and transport conditions, social life, urban and landscape environment). Instruments for measuring quality of life must evolve, as must the vision of health determinants. Used routinely, they must take into account the major determinants of well-being and can be used in health impact assessments.

- The term quality of life appears in public health planning tools. This is the case in most Regional Health Projects (PRS) and in many Local Health Contracts (CLS). However, the diagnoses and evaluation reports of these plans and contracts contain few or no indicators for measuring quality of life. And when they do, the questionnaires used in these contexts are not adapted. However, measurement instruments relating to friendships, social networks, noise perception or air quality are available.
- The use of an instrument must always be adapted to the context in which the study is being carried out and to the intended uses, which may be very local (at the scale of local catchment areas).
- The management of surveys for the collection of health data, and in particular perceived health and quality of life data, does not seem to be sufficiently coordinated between the organizations responsible for the surveys, underlining the difficulties of managing the different levels of survey for a rapid and efficient implementation in the territories.
- French institutions express a strong expectation for recommendations regarding the measurement instruments to be used in their various contexts, and for advocacy to promote them.

F. INTERNATIONAL PERSPECTIVE

- At the end of 2021, the WHO adopted the "Geneva Charter for Well-being", which calls for a global vision of well-being, including the notions of equity, inclusion and participation.

V. RECOMMENDATIONS

A. CARE DOMAIN

Measures of perceived health, quality of life and well-being should be used more in the health care system, both at the individual level, in the context of care, to improve the quality of care and its impact on patients' quality of life, and at the collective level, to help improve the organization and management of the health care system

General recommendations

- Every patient with a chronic disease should have a multidimensional quality of life measurement at key moments in the course of the disease and the care pathway.
- The results should immediately generate quantified information, presented in a simple manner, and interpretable for decision making.
- Apart from areas in which professionals have experience of this measurement, such as cancer, renal failure, HIV, inflammatory rheumatism, etc., pilot tests should be planned before routine implementation.
- The choice of instruments must be made in consultation with those involved: caregivers, patients and users.

- When a specific instrument is chosen, it should be accompanied by a generic instrument, in particular to allow comparisons with the population from which the patients come.
- The use of measures for medico-economic or practice evaluation purposes should favour short, manageable instruments if their use does not obscure an important dimension of patients' lives.

Structure for supporting and monitoring implementation

The implementation of routine measures in the health care system must be encouraged but also supported and capitalized on.

- The group recommends the development of a mechanism to identify the implementation of measures carried out routinely in the care system. It would encourage the pooling of user experiences, evaluative thinking, and the convergence of operations based on good practice guides. It could be based on a platform integrating validated measurement tools as well as advice on their use, including reference values where appropriate.

Quality of life at work

An "acceptable" quality of work life for healthcare professionals is necessary for the long-term functioning of the healthcare system. Moreover, the quality of work life of healthcare professionals is a proven determinant of the quality of care. Several validated instruments, generic or specific to health care or medico-social establishments, evaluating this quality of life at work, exist in French and can be used immediately.

- Regular assessments of quality of life at work should be implemented for each profession in health care and medico-social establishments, carried out within the framework of independent systems that guarantee the necessary objectivity of the measurements and the absence of instrumentalization of the results.

Training

The large number of different tools (generic and specific) and the number of PROMS (patient-reported outcomes measures) generates confusion. The development of the use of the measurement of perceived health and quality of life therefore requires clarification of the concepts (quality of life, satisfaction, perceived health, etc.) and the issues involved in using these tools.

- The teaching of measurement sciences (psychometrics, econometrics, clinimetry) and, more broadly, of PROs must be reinforced in medical and health care studies and public health training.
- The use of these instruments by healthcare professionals requires an understanding of the instruments used, which requires training in the instruments and in the use of their results, and the use of guides for using the instruments.

Pricing experiments

Experiments should be undertaken to evaluate the efficiency - and ensure that there are no perverse effects - of financial measures that could encourage the measurement and consideration of perceived health or quality of life in the field of care.

- The measurement of perceived health or quality of life could be considered as a care act, to be carried out by a health professional (doctor, advanced practice nurse, Asalée nurse, etc.), and recorded in the medical record.

- Experiments with differential pricing based on changes in indicators should be carried out in hospitals and outpatient clinics, taking care to limit social and territorial inequalities in health as much as possible.

Research

- A call for research projects should be organized to test and evaluate pilot experiments for routine implementation. Research focused on the predictive value of these measures with respect to mortality, morbidity or loss of autonomy, and the possibility of defining alert thresholds requiring responses should be reinforced.
- Strengthening participatory research would make it possible to better take into account the perspectives of patients, their particularities (cultural and social in particular) or their perception in the design and adaptation of measurement instruments, which must evolve in the same way as the vision of health determinants evolves.
- Particular effort should be made in the areas of end of life, old age, childhood and adolescence, disability and the issue of healthcare professionals

International relations

- It is important for France to participate in international discussions and existing initiatives, such as the OECD's PaRIS.

B. POPULATION OBSERVATION AND SURVEILLANCE

General recommendations

- Measures of perceived health, quality of life and well-being should be included in the major health indicators monitored by French public statistics, alongside mortality and activity limitations. They should be adapted to the different territorial levels, from national to local, in consultation with health democracy bodies and organizations.
- They should be included in the diagnoses and impact assessments of national plans, regional health projects (PRS), regional health and environment plans (PRSE) and local health contracts (CLS). Monitoring their evolution over time is of major interest.
- It is preferable to use positive approaches in the wording of surveys (e.g. quality of life at work rather than psychosocial risks) and in the items measured whenever possible.
- The European minimodule should be preferred for annual monitoring of perceived health, associated with minimal sociodemographic data, but also health data. It should be associated with a generic instrument every 3 to 5 years (SF-36, WHOQoL-BREF, PROMIS-29), used over time to allow comparisons over time.
- The steering of the survey systems must be established at the national level, with better coordination. The General Directorate of Health has a central role, with DREES and Santé publique France as the main operators. Collaboration should be initiated or strengthened with organizations such as Cepremap, and the OECD Statistical Directorate.
- In the case of surveys with a local focus, specific modules can be developed using a participatory approach. For reasons of efficiency and ethics, the systematic involvement of the populations concerned is necessary, from the construction of the survey protocols to the appropriation of the results.

Measurement in case of specific exposures

- Measures must be included in the surveillance of populations affected by deleterious exposures such as environmental factors (exposure to industrial pollution, proximity to hazardous areas, etc.), social, economic and cultural factors (low level of social support, precarious employment and housing conditions, low health literacy, food insecurity, prison, etc.).
- For populations affected by environmental exposures, the use of the European minimodule should be associated with generic dimensional instruments including environmental dimensions such as the WHOQoL-BREF.

Knowledge transfer

- Effective methods of disseminating the results of surveys must be promoted, ensuring that they are readable and understandable by all. These tools will make it possible to support debates between political decision-makers and with the population, to strengthen citizen participation, to support and establish public policies, and to integrate health into all policies.
- A global advocacy for the promotion of these tools in public policies accompanied by a strategy for the use of the tools should be drafted as a result of this report.
- The creation of a platform of perceived health, quality of life and well-being tools commonly used in France would facilitate their use by local authorities, user associations and any other organization. It would allow the analysis and capitalization of experiences. User guides including an inventory of appropriate situations and examples of use of each measure could be provided to support local use.

The "cap bien vivre" resource center is a website to be promoted in this perspective of knowledge transfer. It proposes to capitalize, valorize and share experiences leading to the rethinking of good living and its measurement tools throughout the world.

Training

- The teaching of the principles of construction and use of indicators, of the methods for agreeing on what will be measured, must be reinforced in the studies of professionals in health and public health institutions.
- The use of indicators requires training in their different uses (observation, evaluation, monitoring, comparison) and awareness of their performative dimension (they describe phenomena and transform them) in order to prevent misuse (use other than that initially intended). A minimum awareness or training of all stakeholders (health, social and educational professionals, user associations) must be integrated into the training systems.

Research

- Research must be encouraged in France to identify the determinants, particularly social and territorial, of perceived health, quality of life and well-being, and their evolution. Research should encourage combined approaches to objective and perceived data, and the strengthening of collaboration between biostatistics and the human and social sciences, particularly on themes such as the equivalence of instruments and the computer-assisted administration of questions.

- An inventory of existing approaches to well-being and quality of life for observation and evaluation purposes should be drawn up. Work needs to be initiated on the issue of steering action with regard to well-being and quality of life, but also on the uses and implementation. Finally, the evaluation of public policies and programs with regard to well-being is an emerging field of research that should be supported.

National policy and international relations

- Law n°2015-411 of April 13, 2015, which aims to take into account new wealth indicators in the definition of public policies, is a first step towards integrating the issue of quality of life into national budgetary decisions. This lever should be reactivated by the government with the support of the Economic, Social and Environmental Council (CESE) and France Stratégie. The creation of a "parliamentary council for the evaluation of public policies and well-being" proposed in 2018 in the Senate could be a lever for better integrating these issues at the national level.

- France should participate in the international discussions underway (Finland, New Zealand, Bhutan, OECD, UN Sustainable Development Goals, etc.) and position itself in the relevant forums (working group on national accounts-ISWGNA, OECD, UN) to ensure that well-being and quality of life are taken into account in ways that are not reducible to monetary measures (such as GDP).

To cite this document:

Rapport relatif aux usages et bon usage de la mesure de la santé perçue et de la qualité de vie en France : synthèse des points-clés. Paris : HCSP, 2022, 10 p. En ligne : <https://www.hcsp.fr/explore.cgi/avisrapportsdomaine?clefr=1170>