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End-of-Life Surveys in the French Overseas Departments: Data Collection Protocol

**Sophie Pennec, Joëlle Gaymu, Efi Markou, Amandine Stephan,
Géraldine Vivier and FDVDOM Team**

Janvier 2024



End-of-Life Surveys in the French Overseas Departments

DATA COLLECTION PROTOCOL

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SUMMARY OF THE RESEARCH PROJECT

Background

A number of changes regarding the end of life have occurred in recent decades, notably legislative changes. This stage of life, which usually comes at an advanced age, is now largely medicalised and institutionalised. This research project in the French overseas departments follows on from a study conducted in metropolitan France in 2010 on the circumstances in which people spend their last months of life. From the metropolitan France study, the researchers were able to assess the implementation of the 2005 Leonetti Law, improve understanding of residential transitions prior to death, the role of carers, and people's wishes as to where they want to die. End-of-life circumstances in the overseas departments are not known. And yet the population is ageing fast, people commonly die at home, the organisation of family life is changing fast, the share of poverty is higher and there are fewer residential aged care facilities. These factors all shape end-of-life conditions in different ways, so it will be useful to acquire more data about the situation in these departments.

Aims

The purpose of this research is to give an overview of end-of-life conditions in the French overseas departments (Martinique, Guadeloupe, French Guiana and La Réunion). The aim is to see in what ways they differ from those pertaining in metropolitan France and document what public policy changes would be needed to meet these departments' particular needs.

The first research strand explores possible inequalities in medical care at this stage of life between the four overseas departments and metropolitan France: do the same individual or general situations receive the same medical care everywhere?

A second strand focuses on implementation of the two laws that grant rights to end-of-life patients in France: the law of 22 April 2005 and that of 16 February 2016. It compares medical practice with the provisions of the legislation and describes how much patients and their families know about these laws and their application.

The third strand considers the more sociological aspects regarding family and social context at this stage of life, how patient care and support is organised and who is involved. Patients' families were asked about their perceptions and expectations, with a view to improving quality of life for caregivers and hence also for people in their last stage of life.

Method

The data had to be gathered, as there were none in existence. We conducted a quantitative survey among physicians, using the broad lines of the protocol designed for metropolitan France but adapting it to local particularities to achieve a proper measure of different indicators for all topics under study and in particular medical decisions at end-of-life. We also conducted a qualitative survey in La Réunion to shed light on the context for ageing in the overseas departments and the proportion of home deaths. This comprised a series of semi-directive interviews with decedents' relatives and two focus groups, providing new information about (a) people's knowledge of the law and (b) the strengths and weaknesses of end-of-life care at home.

Prospects

This project is the first to provide scientists, the health authorities and the public with objective data on end-of-life conditions in the French overseas departments. It shows the impact of the overseas departments' sociodemographic and cultural particularities on end-of-life care and offers health professionals and the authorities some food for thought on end-of-life care policy.

Keywords : End of life, palliative care, place of death, euthanasia, medical decisions, sedation, limiting and stopping treatment, surveys, French Overseas Department

Mots-clés : fin de vie, enquête, décisions médicales, soins palliatifs, lieux de décès, limitation et arrêt de traitement, sédation, euthanasie, prise en soins, Départements d'Outre-Mer

I. GENERAL SCIENTIFIC BACKGROUND TO THE RESEARCH PROJECT

The purpose of this research is to give an overview of end-of-life conditions in Martinique, Guadeloupe, French Guiana and La Réunion, France's historical overseas departments¹. It sets out to show how sociodemographic, cultural and public health differences between departments affect patterns of end-of-life care and may create inequalities in treatment of the terminally ill. It suggests how public policy needs to change to meet the particular needs of these departments.

This project follows on from research conducted in metropolitan France in 2010 and in other countries, mainly in Europe. In the mid-1990s surveys were conducted in the Netherlands and Belgium to find out more about physicians' decision-making in end-of-life situations. That work enabled the authorities, healthcare professionals and citizens of those countries to conduct a society-wide debate based on exact, reliable information [1-15]. There had been very little research on the subject in France. The 2010 *Fin de Vie en France* (End of Life in metropolitan France) study filled the gap and provided an accurate picture of end-of-life decisions, whatever the individual characteristics of the deceased or their place of death. It was an important step forward and provided an assessment of the implementation of the Leonetti Law five years after it came into force [16-23]. More broadly, that survey also gave a description of end-of-life circumstances (residential transitions, carers, the patient's desired place of death, etc.). The analyses added to our understanding of the end-of-life process, the limitations of home care and the reasons why people are taken into hospital at this stage of life.

The present project aims to acquire the same information about France's overseas departments and show how far their particular demographic, social, historical, cultural and religious characteristics affect the unfolding of a person's last stage of life. End-of-life circumstances differ in a number of ways between these four departments and metropolitan France. Although life expectancy is the same as in other French departments (except for French Guiana, where it is three years shorter), mortality rates are higher at younger ages [24]. As a result, fewer people die after the age of 60 than in metropolitan France – 50% fewer in French Guiana and 73% fewer in Guadeloupe. In addition, fewer people die in institutions in the Caribbean and La Réunion: more people die at home (over 40% compared to 25% in metropolitan France in 2015), so fewer die in hospital (fewer than 50%, compared to over 60% in metropolitan France). Even fewer die in care homes (fewer than 5% compared to 13% in metropolitan France) [25-28]. In French Guiana, only 3% die in care homes, and more die in hospital than in metropolitan France.

Another aim will focus more specifically on the implementation of the provisions of the law of 22 April 2005 on the rights of the sick and the end of life, called the "Leonetti law" [29], and that of 2 February 2016, the "Leonetti–Claeys law", which created new rights for sick people at the end of life [30]. On the one hand, it will be necessary to compare medical practices with legislative provisions and, on the other hand, to describe the level of knowledge that families and patients have of the provisions regarding the patients' rights and their application.

¹ Mayotte is not included in the research owing to the poor quality of its civil registry data (deaths are significantly under-recorded).

II. THE RESEARCH TEAM

HEAD OF RESEARCH:

The research project was directed by Sophie Pennec (demographer) and until 2020 by Joëlle Gaymu (sociologist). Both are research directors at INED.

OTHER MEMBERS OF THE RESEARCH TEAM:

Family name, first name	Status	Institution	Main discipline
Aubry, Régis (until 2022)	Hospital doctor	CHU Besançon	Medicine
Pontone, Silvia	Hospital doctor	AP-HP – Robert Debré and INED	Medicine
Lépori, Mélanie (from 2021)	Demographer	Université de Strasbourg	Demography
Evin, Adrien (from 2022)	University lecturer – hospital doctor	Université de Nantes and CHU de Nantes	Medicine
Guion, Vincent (from 2022)	Hospital doctor	Besançon and St Flour	Medicine
Marie, Claude-Valentin	Overseas departments adviser to INED	INED	Political science
Breton, Didier	University professor	Université de Strasbourg	Demography
Albert, Irène (until 2020)	Training manager	IRTS La Réunion	Sociology

MEMBERS OF DEPARTMENTS ASSISTING IN DATA COLLECTION AND ANALYSIS

Family name, first name	Institution	Main discipline
Markou, Efi	INED/SES	Survey methodology survey referent from survey department
Stephan, Amandine	INED/SES	Survey methodology survey referent from survey department
Vivier, Géraldine	INED/SES	Expert for the qualitative survey
Naït-Abdellah, Kamel	INED/SES	Survey data processing/survey IT
Temine, Lamia	INED/SES	Survey technician
Laprée, Valérie	INED/SES	Survey technician/questionnaire editing
Charrance, Géraldine	INED/SES	Data collection statistics
Cochet, Paul	INED/SES	Data collection statistics
Bondon, Marine	INED/SES	Data collection statistics/response rate/weights

Baron, Julie	INED/SES	Survey documentation
Morand, Elisabeth	INED/SMS	Statistical analysis
Garnier, Bénédicte	INED/SMS	Cartography/text analysis
Muller, Arno	INED/SMS	Statistical analysis/datavizu

SES: Surveys Department; SMS: Department of Statistical Analysis and Methods

MEMBERS OF DEPARTMENTS ASSISTING IN OTHER DUTIES

Family name, first name	Department
Bailly, Marie Danielle	Administrative assistant
Wojcik, Martyna	Partnership department (for funding)
Milan, Isabelle	Design of documents/logo
Darnaud, Julien Pennanec'h Marie-Christine	Budget office

TEMPORARY STAFF FOR QUALITATIVE DATA GATHERING

The semi-directive interviews were conducted by students in social work from the Institut Régional du Travail Social, La Réunion.

ASSENDJE Loetitia

GIGANT Maeva

INGAR Shabbir

PANURGE Catherine

RENNEVILLE Marion

RENNEVILLE Tatiana

ROBERT Thomas

CHRISTOPHE Richard

TEMPORARY STAFF

BARI-GARNIER Thomas

EL-FAHNI RANIA

LIEVRE Julie

MELEZE Sabine

III. ORGANISATION

SCIENTIFIC COMMITTEE

The project's scientific committee was made up of members of the *Conseil national de l'ordre des Médecins* (the French medical board, Dr Jean-Marie Faroudja) and people from the End-of-Life Group at the Free University of Brussels (Joachim Cohen), CépiDc (the Inserm Centre for cause of death epidemiology-Grégoire Rey).

PARTNERSHIPS

The research team managed the project for all data collection. The quantitative data was gathered by the INED surveys department. This department, staffed by some twenty engineers and technicians, has extensive experience of conducting surveys on subjects or populations considered 'sensitive'. It was involved in the End-of-Life survey in mainland France. Statisticians from INED's statistical methods department helped analyse the data.

INED's IT department and survey department were responsible for the storage of anonymised questionnaire responses.

Qualitative data collection (interviews) involved the research team, INED's surveys department, and the Institut Régional du Travail Social (regional social work institute) in La Réunion.

Other operators involved in the survey are:

- ARS La Réunion (the regional health agency: Florence Caliez, head of data and health surveys department; Gilberte Hachim and Florence Payet, technicians) and the *Centre d'épidémiologie sur les causes médicales de Décès* (CepiDc-Inserm, centre for the epidemiology of medical causes of death) for selecting the sample;
- A service provider acting as 'trusted third party' for the management and digitisation of the questionnaires: *Centre Hospitalier Régional Universitaire* (university hospital), Besançon - Medical data department: Marie-Pierre Pequignot, head of department; Muriel Chatey, Sophie Folley, Laurence Tillati, technicians and Maryline Laurent, IT;
- A printing and dispatch provider who printed and dispatched the documents and personalised letters (Merico-Paragon, chosen by tender);
- A telephone survey provider to make reminder calls to physicians (Kantar, chosen by tender).

IV. REGULATORY ASPECTS

The methodology of both the project's data collecting strands (the quantitative survey and the semi-directive interviews and focus groups) were approved by the *Comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé* (CEREES, expert committee for health-related research, surveys and evaluations) in March 2018 and by the *Commission nationale de l'informatique et des libertés* (CNIL, the French data protection authority) in May 2018 (Cnil – DR-2018-102).

V. EXPLORATORY MISSION

In 2012 we conducted an exploratory mission in La Réunion to establish the feasibility of gathering the data and the acceptability of the research topic. The idea was to discuss with the various institutions that might be involved in the study, such as the Agence Régionale de Santé (ARS, regional health agency) and the medical authorities (*Conseil de l'ordre des Médecins*, the national medical council; Union Régionale des personnels de santé de la Réunion, the Réunion health personnel union; the president of the hospital's medical committee). Because religion is an important factor in Réunion's multicultural society, we also approached the religious authorities. Discussions showed that there was no a priori reticence to the survey, so a protocol was then drawn up.

VI. METHODOLOGY

The data needed to meet all the goals of the research had never been gathered. To collect it, we used a mixed method. A quantitative survey among physicians was conducted, broadly on the lines of the protocol used in metropolitan France [30] but adapting it to local particularities so as to obtain a good measure of incidences. We also designed a qualitative survey to shed light on the particularities of the situation regarding ageing in the overseas departments and especially the proportion of people dying at home. A series of semi-directive interviews with decedents' relatives and two focus groups with healthcare professionals in La Réunion provided new information about people's knowledge of the law and the strengths and weaknesses of end-of-life care in the home.

QUANTITATIVE DATA COLLECTION

The quantitative survey had two challenges to overcome for the sake of territorial continuity in statistical data gathering operations. Our data gathering arrangements had to be suited to the real situation in these departments, but the methodology and questionnaire had to be sufficiently close to the one used in metropolitan France to make comparisons feasible. A presentation of the protocol for the metropolitan France survey can be found in Legleye et al. [30]. Starting from a sample of death certificates, the survey was conducted among the physicians who had issued the certificates. It was a retrospective survey: a self-administered questionnaire asked the physicians about the end-of-life circumstances of the person concerned by each certificate. So the survey concerned two populations: the decedents and the physicians who certified their deaths. This procedure gave us data about the causes and individual characteristics of deaths wherever they occurred – at home, in hospital, in a nursing home or even in the street.

The survey on end-of-life circumstances in the overseas departments (*Fin de vie – DOM*) used the same broad topics as the metropolitan France survey. It addressed end-of-life care and the application of the current end-of-life legislation (laws of 2005 and 2016). Some questions were altered to ensure respondents' anonymity in such a small territory (for example, the physicians' specialities were grouped into only two categories rather than the ten in the metropolitan France survey). Other questions were added, notably about religion and sedation. Lastly, the survey enabled us to analyse in greater detail the family environment and the family's role in patient care at this stage of life. It also improved the information gathering, notably as regards residential transitions and the medical reasons for such moves (usually from home to hospital).

The data was gathered in two phases:

- First, data about the death was taken from the death certificates (characteristics of the deceased, name and address of the certifying physician);
- Then the physicians were asked to complete a questionnaire about the end of life of patients whose certificate they had signed. They were given enough information (including the name of the deceased) for them to identify the patient. A paper questionnaire was used, as this was the form most physicians had preferred in the metropolitan France survey (72% of replies on paper vs. 28% online). To ensure the physicians' anonymity, the questionnaire was self-administered, and their replies were collected by a 'postal voting' protocol involving a trusted third party.

PHASE ONE: DATA COLLECTION FROM DEATH CERTIFICATES

SAMPLE OF DEATHS

In order to have enough responses for a detailed analysis of each overseas department and given the 40% response rate in the metropolitan France survey [30], all the deaths in one year were included². Only persons aged 18 and over were included. The number of child deaths would have been too small to allow quantitative analysis, and the survey protocol and questionnaire would have needed adjusting to address the particularities of care for dying children and the legal aspects involved.

Taking the mortality figures for 2018 [31], the survey covered about 927 deaths in French Guiana, 3280 in Martinique, 3195 in Guadeloupe and 5044 in La Réunion, making a total of 12,446 deaths.

The survey covered deaths from March 2020 to February 2021.

To avoid too long a time between the death and the physician's receipt of the questionnaire, and to spread our requests among physicians who often sign death certificates, we divided the data collection into three waves of four months of deaths.

- Wave 1: deaths from March to June 2020
- Wave 2: deaths from July to October 2020
- Wave 3: deaths from November 2020 to February 2021.

BUILDING UP THE “PHYSICIANS/DECEDENTS” FILE

Before we could contact the physicians who had certified deaths and invite them to fill in the questionnaire for the decedents concerned, we had to take information from the death certificate: the date of birth, date of death, sex, place of death, and the name and address of the certifying physician (from their stamp on the certificate).

The death certificates were processed by the regional health agencies or CépiDc-Inserm, depending on the type of certificate (paper or online) and where they were collected.

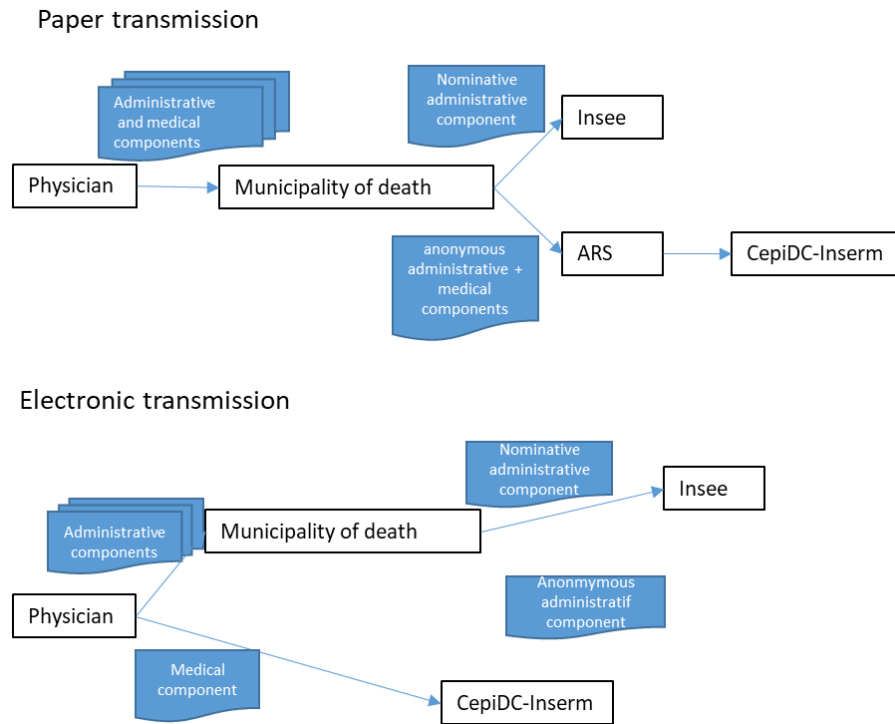
Electronic certificates are sent directly to CépiDc-Inserm. We could therefore obtain electronic death certificates from CépiDc-Inserm very soon after the death and did not have to manually input the data on them.

Paper certificates are signed by the physician and delivered to the municipality, which sends them to INSEE and the local ARS. These make a number of checks and procedures, add a supervision sheet and send the certificates to CépiDc-Inserm in monthly batches.

For the paper certificates, we had to manually input the data needed for the survey, e.g. the contact details of the certifying physician. It was preferable to gather information directly from the ARSs for paper certificates because it minimised the time lag between the death and the dispatch of a questionnaire to the physician. However, this option was only possible for La Réunion thanks to a partnership with the Réunion ARS, which had their staff input the death certificate data.

² For the metropolitan France survey, we had a sample of 14,999 deaths occurring in December 2009. Questionnaires were sent out for 14,080 of them (sometimes the certifying physician could not be found; we limited the number of questionnaires per physician; etc.). We received 5217 responses.

Figure1: Transmission of deaths certificates



Source: Simplified version of the process described in [33]

For Martinique, Guadeloupe and French Guiana, death certificates were input by INED on CépIDC-Inserm’s premises. This significantly increased the time between the death and the dispatch of the questionnaire to the certifying physician, given the unavoidable time lag between the death and the information reaching CépIDC-Inserm.

The fact that the local ARS was inputting the La Réunion data gave a three-month advance on the data for Martinique, Guadeloupe and French Guiana, which was input by CépIDC. We could thus contact the certifying physicians in La Réunion three months earlier than in the other overseas departments.

Because the death certificate data was acquired in two different ways, we adjusted the initial protocol and divided the data collection into four periods (see calendar below).

We built a database associating death with their certifying physicians. For this, information from all the death certificates were entered in an application that INED’s surveys department had developed especially for this survey. This data input operation was overseen by the medical inspector at the La Réunion ARS and the CépIDC director. The data entered were the patient’s dates of birth and death, their sex, place of death, commune of residence and of death, and an indicator of ‘violent death’ and transfer to a forensic medicine unit. For the physicians, the necessary information for contacting them was entered: full name and professional address when they certified the death.

When the certifying physician could not be identified (rubber stamp absent or illegible), the municipality of the place of death was contacted to try to obtain the missing information. Sometimes it can be more legible on the burial/cremation authorization form.

The data entered (indirectly nominative for the patient, nominative for the physician) were sent to INED's surveys and polls department, either by entering it via a secure internet link or by uploading files to a secure server.

From the second data collection period, this file was matched with the public death records (available from a government website, data.gouv.fr) so as to add the first and last names of the patients so that their physicians could identify them. This information is often useful for finding a patient's hospital file.

The resulting file was then processed to match each death certificate with the physician concerned. These matched death/physician pairs constituted our sample. We removed from the sample all deaths certified by forensic pathologists, ARS-funded certification networks that we had identified, and physicians for whom we could find no contact details. These seemed often to have been medical interns or temporary physicians.

Given the large number of physicians who had signed multiple death certificates within the same period, we decided to send no more than four questionnaires to any one physician, to avoid overburdening them. We made an exception for hospital unit heads and supervising physicians at care homes and retirement homes. These physicians had not only certified some deaths in person but were also named if we could not identify the actual certifying physician in their establishment (name absent or illegible). They could then pass the questionnaires on to the physicians concerned.

The file of death/physician pairs was entered into the tracking tool developed and managed by INED's surveys department to manage and monitor the data collection. Data extracts (containing only the necessary information) were sent via secure server to the survey service providers tasked with dispatching the questionnaires and reminders (postal and phone).

PHASE TWO: COLLECTING DATA FROM PHYSICIANS

THE PHYSICIAN CONTACT LETTER

The data collection followed a similar protocol to that used in metropolitan France but was split between the four survey periods.

Each physician asked to take part in the survey was sent the following, by post:

- a presentation brochure (appendix 2.1)
- a letter describing the aim of the survey (Appendix 2.2), giving practical information for participating and explaining the data processing procedures
- a presentation of the care taken to ensure respondent anonymity, and legal information such as the physician's right of access to their information under the Law of 6 January 1978 as amended in August 2004 (appendix 2.5).
- for each death,
 - o a patient identification sheet (Appendix 2.4)
 - o an A5-format paper questionnaire (Appendix 2.6)
 - o a blank envelope
 - o a prepaid return envelope.

If the physician had made out the death certificate for a person who was not in their care, they could send INED's package on to the colleague who had cared for the patient at the end of their life. Or they could send us the regular physician's contact details or any other information (regular physician not known, deceased unknown, etc.), using the prepaid envelope and the transfer coupon at the bottom of the patient identification sheet. The

information on the transfer coupons was entered in the tracking tool so that the data collection material could be sent to the regular physician and the physician initially contacted would be troubled no further for this death.

From the second wave, emails were sent to physicians who had certified deaths during that wave, to let them know that they would soon be receiving a letter by post for the new survey wave. Email addresses were obtained during the first telephone reminder.

THE REMINDERS

At intervals of about six weeks, one or two reminder letters were sent to physicians who had not yet responded, enclosing the same documents as the first time (Appendix 2.6). The design and content of the letter was changed, to make it less likely that the recipient would hastily discard it.

For each collection period, after two months of field work, telephone reminders were made by a call centre provider. The purpose of these was to present the survey to physicians who had neither responded nor explicitly refused to take part and encourage them to participate. No questionnaires were filled in by telephone during these calls.

In the fourth and last data collection period, reminder calls were made both to physicians who had certified deaths in this period and physicians who had never responded or only partially responded at any previous period.

Phase Three: detailed recording and anonymisation of questionnaire responses

To ensure anonymity, we used a two-envelope system such as is used in postal voting: a plain envelope containing the questionnaire inside a (prepaid) envelope identifying the death/physician pair. The prepaid envelope was sent to an institution independent of the survey promoter. This ‘trusted third party’ was the medical data department of Besançon university hospital (see appendix 6.3: *Procedure to ensure anonymity*). The trusted third party opened the prepaid envelope with the identification number on it and removed the blank envelope containing the questionnaire. They listed the identification numbers received each day and sent the list to INED by FTP server. INED updated its tracking interface with this data. The blank envelopes were collected in a ‘voting box’

Phase Four: inputting the questionnaires

The questionnaire responses were entered by the trusted third party to whom the prepaid envelopes had been addressed, via an internet interface developed in Limesurvey and run by INED’s surveys department). Once there were enough questionnaires in the voting box to ensure complete anonymity, the blank envelopes containing the questionnaires were opened. The third party had been supplied with sheets of labels with which to number the questionnaires and so avoid duplication. No link exists between death identification numbers on the prepaid envelopes and the questionnaire number, as described on the “survey procedure, medical confidentiality and anonymity” sheet (appendix 2.6)

CALENDAR

To shorten the time between the physician filling in the death certificate and being asked to take part in the survey, and to smooth requests across the year for physicians certifying more than one death, we divided the fieldwork into three waves of four months of deaths. As the La Réunion data, input by ARS, reached us faster than the data entered manually at CépiDc, collection was divided between four periods, as follows:

Period of data collection	Wave of deaths
Period 1	Wave 1 for La Réunion
Period 2	Wave 2 for La Réunion Wave 1 for Guadeloupe, Martinique and French Guiana
Period 3	Wave 3 for La Réunion Wave 2 for Guadeloupe, Martinique and French Guiana
Period 4	Wave 3 for Guadeloupe, Martinique and French Guiana

QUALITATIVE DATA COLLECTION

In La Réunion, in addition to the project's quantitative strand, semi-directive interviews were held with recently-bereaved relatives and two focus groups of healthcare professionals (carer networks, voluntary carers and palliative care teams or networks). The aim was to shed fresh light and provide new information on end-of-life care, especially for those who die at home. The qualitative approach was based on existing studies by Southampton University [34] and INTEGRATE project by the End-of-Life group at Vrije Universiteit Brussel. [www.endoflifegroup.be].

For the sake of anonymity, we did not link these interviews with the quantitative questionnaires filled in by physicians.

INTERVIEWS WITH DECEDENTS' RELATIVES

FINDING PEOPLE TO INTERVIEW

The search for those who had cared for a dying relative at home was mainly conducted by the sociology professor at the La Réunion IRTS (the regional social workers' institute). She asked the various services and professionals involved with patients and their families – i.e. Hospital at Home (HAD) services, mobile palliative care teams, independent nurses, etc. The IRTS students helped with the recruiting, meeting some services, support groups, etc. and using the snowball approach to find people who had cared for a loved one.

TRAINING THE STUDENT INTERVIEWERS

The eight students who joined the project were in their third (and final) year of various courses at the IRTS, e.g. social work, special education or social engineering diploma courses. They were tasked with interviewing people who had cared for a dying relative at home, transcribing these interviews and translating them from Creole to French where necessary. Their involvement was voluntary, but participation went towards their training (and in some cases was assessed), and they were paid for post-data-collecting tasks. Although all were training for social work occupations, they were in different training programmes and varied somewhat in their previous experience of qualitative surveys (with a research angle).

All had attended the seminars about the project as a whole and the findings of the 2010 quantitative survey in metropolitan France. For the La Réunion qualitative strand, their training included several presentation stages which progressively gave them a grasp of the project. It started in December, when the project was discussed and formalised with an initial session about the recruitment process of future interviewees; a one-day session in January focused on how to conduct an interview (a combination of guiding and actively listening; the interviewer's posture; taking ownership of goals and topic-based secondary goals; the question of triggering; taking and using notes; reminder techniques and examples; ending an interview). There were practical exercises including a half-day collective assessment around the first contacts made, using recordings of the first interviews (two at this stage). The training also included some instruction on the students' other tasks (transcription and anonymisation of the interviews) and information on the legal, practical and logistical aspects of the survey (interviewees' rights, commitment to confidentiality, equipment, secure entry and processing of the data, etc.).

SAMPLE:

About 40 semi-directive interviews with bereaved relatives were envisaged. The interviews took place between March and June 2019. The interviewers (social workers in training) were particularly alerted to the ethical aspects of this kind of survey. For this reason, interview of the relative had to take place at least 6 months after the death of person (ideally between 6 and 18 months). They were asked not to interview anyone they knew personally or with whom they were liable to have some relationship in the future. Interviewees were given an information leaflet about the survey, featuring the phone number of a bereavement helpline (Appendix 3.1 and interviewer's contact sheet, appendix 3.2)).

The topics raised in the interviews with relatives were:

- The person's role in the last stage of life of the person they cared for, how long it lasted, coordination with others involved (formal and informal carers), their role in decisions about where the patient spent the last phase of their life and where they died, and their role in end-of-life medical decisions;
- Perceptions and representations of their caregiving, their expectations, and proposals for improving end-of-life care;
- Knowledge of the law on the end of life: trusted third party, refusing treatment, palliative care, continuous sedation until death in some cases;
- Etc.

The interview guide is appended (Appendix 3.3).

FOCUS GROUPS

Two focus groups were formed in La Réunion, bringing together medical personnel, relatives and other carers. The topics addressed include the links between professional and non-professional carers; between carers and the family in caregiving, the need of psychological support for carers. The difficulties encountered and the possible ways to improve matters locally or in public policy are among the topics discussed.

Some of the topics addressed came from information gathered in the first interviews with relatives.

ANALYSIS OF DATA

The quantitative dataset is weighted and standardised by sex, age, place of death, period of data collection and FOD to account for territorial disparity in response rate and to maximise representativeness of deaths [29].

To conduct the studies, descriptive analysis methods will be applied to the quantitative data: percentages, bivariate analysis with Pearson chi-square tests, multivariate analysis, etc. Logistic regression models gave the adjusted effects of socio-medical profiles on the variables of interest. Optimal matching will be used to analyse patients' residential transitions in the last month of life. SAS and R statistical software will be used for the analysis.

The semi-directive interviews and focus groups will be analysed by traditional methods: transcription, analysis by category/theme. The triangulation with other sources will serve to enrich the analyses by crossing the different data and insights provided by doctors (quantitative survey), relatives (individual qualitative interviews), and professionals of home end of life support (focus groups). These methods will be coupled, when appropriate, with text analysis (Iramuteq software).

APPENDIX

APPENDIX 1— REFERENCES

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APPENDIX 2 – DOCUMENTS CONNECTED WITH THE QUANTITATIVE SURVEY

APPENDIX 2.1 – SURVEY PRESENTATION BROCHURE

The brochure is a vertical document with a blue background and white text. At the top, it features logos for INED, CHRU, IReSP, CNSA, and Fondation de France. Below these is the 'ENQUÊTE FDY' logo, which consists of a stylized sun and waves inside a circle. The main title 'ENQUÊTE LA FIN DE VIE EN OUTRE-MER' is prominently displayed in large, bold, white letters, with the years '2020-2021' underneath. The INED logo is also present at the bottom right. The text is organized into several sections, each with a heading in bold. The left side contains contact information and a section titled 'UN BESOIN D'INFORMATION SUPPLÉMENTAIRE ?'. The middle section is titled 'QU'EST-CE QUE L'INED ?' and describes the institute's mission and research areas. The right side contains a section titled 'POUR QUEL(S) DÉCÈS ÊTES-VOUS INTERROGÉ ?' and another titled 'COMMENT RÉPONDRE À CETTE ENQUÊTE ?'. The bottom of the brochure features three columns of text, each with a heading: 'QUEL EST L'OBJECTIF DE CETTE ENQUÊTE ?', 'QUELS SONT LES PARTENAIRES DE CETTE ÉTUDE ?', and 'COMMENT SE DÉROULE L'ENQUÊTE ?'. The overall design is clean and professional, with a clear focus on providing information about the survey.

UN BESOIN D'INFORMATION SUPPLÉMENTAIRE ?

Nous sommes à votre disposition pour répondre à vos questions ou recueillir vos commentaires par téléphone ou par courrier électronique.

Enquête
La fin de vie en Outre-mer
INED, 9 Cours des Humanités
CS 50 004, 93322 Aubervilliers Cedex

Tél. : 01.56.06.22.22
E-mail : fdv@ined.fr
Site internet : fdv.site.ined.fr

QU'EST-CE QUE L'INED ?

L'Institut national d'études démographiques est un organisme de recherche public qui étudie les questions de population, en France et à l'étranger. Il s'intéresse aux grands phénomènes démographiques – fécondité, mortalité, migrations – ainsi qu'à leurs déterminants. Les travaux menés sur la santé et la mortalité, en particulier, concernent de multiples aspects : causes de décès, inégalités sociales en santé, handicap, vieillissement et dépendance, lieu du décès...

L'ined a aussi une mission d'information du grand public sur les questions de démographie. Au niveau national et international, il diffuse les résultats de ces recherches en publiant une revue scientifique *Population* et un bulletin mensuel de vulgarisation *Population et Sociétés* et en éditant des ouvrages.

L'équipe de recherche est pluri-disciplinaire et regroupe des chercheurs de l'ined, du CHRU de Besançon, de l'APHP-Robert Debré et de l'université de Strasbourg. La conception du protocole et la collecte des données bénéficient de la collaboration du service des enquêtes et des sondages (SES) de l'ined.

Un site Internet présente les travaux de l'ined : www.ined.fr

**ENQUÊTE
LA FIN DE VIE
EN OUTRE-MER**

2020-2021

ined
INSTITUT
NATIONAL
D'ÉTUDES
DÉMOGRAPHIQUES

QUEL EST L'OBJECTIF DE CETTE ENQUÊTE ?

L'objectif de cette enquête est de dresser un panorama des conditions de la fin de vie en Outre-mer. Elle fait suite à une première enquête réalisée en France métropolitaine en 2010.

QUELS SONT LES SUJETS ABORDÉS PAR LE QUESTIONNAIRE ?

Le questionnaire aborde notamment :

- les conditions générales du déroulement de la fin de vie ;
- la diffusion des soins palliatifs ;
- la nature des décisions médicales en fin de vie : abstention de traitement, poursuite, arrêt ou limitation de soins actifs, traitement de la douleur, sédation ;
- les conditions dans lesquelles sont prises ces décisions ;
- la mise en œuvre des dispositions relatives aux directives anticipées ou à la désignation d'une personne de confiance.

À QUOI SERVIRA L'ENQUÊTE ?

Il ne s'agit en aucune manière d'une évaluation des pratiques professionnelles. Les résultats de l'enquête permettront de connaître de façon objective les modalités de la prise en charge des malades en fin de vie dans les Dom. Ils contribueront aussi à mieux apprécier les conditions de mise en œuvre de la loi du 22 avril 2005 sur les droits des malades et la fin de vie, dite « loi Leonetti », et en particulier sa diffusion et son application ; ainsi que de la loi du 14 février 2016, dite « loi Claeys-Leonetti » sur les nouveaux droits pour les personnes malades en fin de vie. L'enquête permettra aussi de comparer les conditions de la fin de vie entre les départements d'Outre-mer et avec la métropole.

QUELS SONT LES PARTENAIRES DE CETTE ÉTUDE ?

L'Institut national d'études démographiques (Ined) réalise cette enquête avec le concours du CepiDc de l'Institut national de la santé et de la recherche médicale (Inserm) et certaines agences régionales de santé (ARS). Elle est soutenue par le Conseil national de l'ordre des médecins (Cnom). Elle bénéficie de l'aide financière de la Caisse nationale de solidarité pour l'autonomie (CNSA), dans le cadre de l'appel à projet lancé par l'IReSP ; de la Fondation de France ; ainsi que de l'ined.

COMMENT SE DÉROULE L'ENQUÊTE ?

De manière à avoir un échantillon suffisamment important pour permettre des analyses statistiques robustes, l'enquête portera sur l'ensemble des décès de personnes de 18 ans et plus survenus de mars 2020 à février 2021. Elle se déroulera en 3 vagues successives afin de réduire la durée entre la survenue des décès et le remplissage des questionnaires.

Vague 1 : décès de mars à juin 2020

Vague 2 : décès de juillet à octobre 2020

Vague 3 : décès de novembre 2020 à février 2021.

COMMENT AVEZ-VOUS ÉTÉ SÉLECTIONNÉ(E) POUR RÉPONDRE À CETTE ENQUÊTE ?

Pour chacun de ces décès survenus entre mars 2020 et février 2021, nous relevons le nom et l'adresse du médecin figurant sur le certificat de décès, sans avoir accès aux informations relatives à la cause du décès, qui relèvent du secret médical. Vous recevez ce(s) questionnaire(s) car vous avez certifié au moins l'un des décès survenus au cours de cette période ou parce que le médecin certificateur vous a désigné comme le médecin ayant suivi la fin de vie de cette personne. Lorsque seul le service est identifiable sur le certificat de décès, le courrier est adressé au chef de service, en lui demandant de bien le faire suivre à son confrère réellement concerné.

POUR QUEL(S) DÉCÈS ÊTES-VOUS INTERROGÉ ?

Nous vous communiquons les caractéristiques d'une personne décédée dont vous avez certifié le décès ou suivi la fin de vie : sa date de naissance, sa date de décès, son âge, son sexe, le lieu et la commune de son décès ainsi que sa commune de domicile. Elles vous permettront d'identifier le patient concerné par notre enquête. Le nom de la personne décédée n'est pas indiqué car le certificat de décès auquel nous avons eu accès est anonyme. Si vous avez certifié plusieurs décès durant la période concernée, il se peut que vous soyez interrogé sur plusieurs d'entre eux. De même, vous pourrez être sollicité à une ou plusieurs des vagues de l'enquête.

COMMENT RÉPONDRE À CETTE ENQUÊTE ?

Il s'agit d'un questionnaire auto-administré par voie postale avec une méthode similaire au vote par correspondance : une fois le questionnaire rempli, mettez-le dans l'enveloppe ne comportant aucune indication et glissez celle-ci dans l'enveloppe T.

MES RÉPONSES SONT-ELLES ANONYMES ?

La méthodologie d'enquête retenue garantit strictement l'anonymat du médecin et de la personne décédée ainsi que le secret médical.

Elle a fait l'objet d'un avis favorable du Comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé (Ceres – mars 2018) et d'une autorisation de la Commission nationale de l'informatique et des libertés (Cnil – DR-2018-102 de mai 2018).

Survey on the last stage of life in the overseas departments 2020-2021

What is the purpose of the survey?

The purpose of the survey is to provide an overview of end-of-life circumstances in the overseas departments. It follows on from a survey conducted in metropolitan France in 2010.

What issues does the questionnaire address?

The questionnaire addresses

- How the last phase of life unfolds in general terms;
- The availability of palliative care;
- End-of-life medical decisions: withholding of treatment, continuation or withdrawal of active care, pain treatment, sedation;
- The conditions in which these decisions are taken;
- Implementation of provisions in advance directives, consultation with trusted third party.

What will the survey be used for?

This survey is in no way intended to assess professional practice. The survey results will provide information about patterns of end-of-life care in the overseas departments. They will also provide a better understanding of the application of the Leonetti Law of 22 April 2005 on the rights of the dying, notably how widely it is known and applied, and the Claeys-Leonetti Law of 14 February 2016, which granted new rights to the dying. The survey will also enable comparison between end-of-life circumstances in the overseas departments and those in metropolitan France.

Who are the survey partners?

The *Institut national d'études démographiques* (INED, the French institute for demographic studies) is conducting this survey with CépiDc (a branch of Inserm, *Institut national de la santé et de la recherche médicale* the French institute of health and medical research) and some regional health agencies (ARSs). It is supported by the *Conseil national de l'ordre des Médecins* (French medical council). It has been funded by subsidies obtained by tender from the *Caisse nationale de solidarité pour l'autonomie* (CNSA, national solidarity fund for autonomy), the Fondation de France and INED.

How will the survey unfold?

In order to have a large enough sample for reliable statistical analysis, the survey will cover all deaths of persons aged 18 and over occurring between March 2020 and February 2021. It will take place in three waves to reduce the time lag between the deaths and the completion of the questionnaires.

Wave 1: deaths from March to June 2020

Wave 2: deaths from July to October 2020

Wave 3: deaths from November 2020 to February 2021.

How were you selected to take part in the survey?

For every death occurring between March 2020 and February 2021, we recorded the name and address of the physician who certified the death (but without having access to the cause of death, as that is a medical secret). You are receiving one or more questionnaires because you have certified at least one death in the period concerned, or because the certifying physician has named you as the physician who cared for the patient at the

end of their life. When only the unit is identifiable from the death certificate, the questionnaire is sent to the unit head, asking them to pass it on to the colleague concerned.

What death are you being asked about?

We are giving you the characteristics of a person whose death you certified or whom you cared for at the end of their life: dates of birth and death, age, sex, place and commune of death and home commune. You should be able to identify the patient from this information. The name of the deceased is not given because we only have access to anonymised death certificates. If you certified several deaths in the period concerned, you may be asked about more than one. You may also be asked to participate in more than one wave of the survey.

How to respond to the survey

A self-administered questionnaire is sent out by post, using a similar method to postal voting: once you have filled in the questionnaire, please put it in the blank envelope and put the blank envelope in the prepaid envelope.

Will my responses be anonymous?

The survey methodology ensures medical secrecy and strict anonymity for both the physician and the deceased person.

It was approved by the *Comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé* (CEREES, expert committee for health-related research, surveys and evaluations) in March 2018 and by the *Commission nationale de l'informatique et des libertés* (CNIL, the French data protection authority) (Cnil – DR-2018-102, May 2018).

What is INED?

The *Institut national d'études démographiques* is a public research body that studies population issues in France and elsewhere. It looks at major demographic trends in fertility, mortality and migration and their determinants. Its research on health and mortality addresses a number of aspects including causes of death, social inequality in health, disability, ageing and dependence, place of death and experience of death.

INED is also tasked with informing the public on population issues. It disseminates the results of its research throughout France and internationally, publishing books, a journal (*Population*) and a monthly news sheet (*Population & Societies*).

The research team for this study is multi-disciplinary and includes researchers from INED, the Besançon university hospital, the Robert Debré hospital (Paris) and the University of Strasbourg. The research protocol was designed, and the data collected, with the help on INED's surveys and polls department.

Information about INED and its research can be found online at:

<http://www.ined.fr>

If you need more information

We will be happy to answer your questions or receive your comments, by phone or email:

Tel: 33 (0)1 56 06 21 27

Email: fdv@ined.fr

<http://fdv.site.ined.fr>

APPENDIX 2.2 – FIRST LETTER OF EACH WAVE



ENQUÊTE

SUR LES CONDITIONS ET LES PRATIQUES
MÉDICALES RELATIVES À LA **FIN DE VIE** EN OUTRE-MER

Réf: ident

Dr

VAGUE 1

Le 11 Février 2021

Madame, Monsieur,

L'Institut national d'études démographiques (Ined) vous sollicite pour participer à une enquête sur la fin de vie en Outre-mer (La Réunion, Guadeloupe, Guyane, Martinique). Cette enquête a pour but de connaître quelles sont les conditions de la fin de vie, en particulier la diffusion des soins palliatifs et la nature des décisions médicales.

La recherche a été conçue par une équipe pluridisciplinaire de chercheurs de l'Ined, du CHRU de Besançon, de l'université de Strasbourg et de l'AP-HP, en collaboration avec le CépiDc de l'Inserm et certaines agences régionales de santé.

De manière à avoir un échantillon suffisamment important pour permettre des analyses statistiques robustes, l'enquête porte sur l'ensemble des décès de personnes de 18 ans et plus survenus de mars 2020 à février 2021.

Afin de réduire la durée entre la survenue de chaque décès et le remplissage du questionnaire qui lui est associé, la collecte va se dérouler en 3 vagues successives. Nous entamons actuellement la première vague, portant sur les décès survenus principalement de mars à juin 2020.

Vous recevez cette lettre car vous ou l'un de vos collaborateurs avez certifié un ou plusieurs décès ou parce que vous avez suivi la fin de vie de certaines personnes décédées au cours de ces 4 mois.

Dans cette enveloppe, vous trouverez des informations pour identifier la ou les personnes décédées et les modalités pour répondre à cette enquête. La méthodologie de l'enquête garantit strictement votre anonymat, celui de la personne décédée et le secret médical.

Répondre à ce questionnaire ne vous prendra qu'une vingtaine de minutes et quelques minutes seulement si le décès a été soudain. Dans tous les cas de figure, votre réponse est importante pour la qualité des résultats et leur représentativité statistique.

En vous remerciant pour votre contribution, nous vous prions de croire, Madame, Monsieur, à notre parfaite considération.



Magda Tomasini
Directrice de l'ined



Dr Régis Aubry
Chef du pôle Autonomie –
Handicap.
Chef du Service de Gériatrie
- CHRU de Besançon
Membre du Comité Consultatif
National d'Ethique



Sophie Pennec
Responsable de l'enquête



POUR INFORMATION ET QUESTIONS :
Enquête Fin de vie en Outre-mer
INED, 9 Cours des Humanités
CS 50 004
93322 Aubervilliers Cedex
Tél : 01.56.06.22.22
E-mail : fdv@ined.fr
Site internet : fdv.site.ined.fr

Cette enquête a reçu l'avis favorable du
Cercès et l'autorisation de la Cnd
(DR-2018-102).
Droits d'accès, rectification,
suppression : vous pouvez exercer votre
droit d'accès aux informations
nominatives vous concernant, en
l'occurrence vos coordonnées
professionnelles, en vous adressant au
Service des enquêtes et sondages de
l'ined (adresse postale ci-dessus).

Dear Sir/Madam,

The French Institute for Demographic Studies (INED) would like to invite you to participate in a survey on the end of life in the French Overseas departments (La Réunion, Guadeloupe, French Guiana, and Martinique). This survey aims to describe the end-of-life conditions, in particular access to palliative care and types of medical decisions.

The research was designed by a multidisciplinary team of researchers from INED, CHRU of Besançon, the University of Strasbourg and AP-HP, in collaboration with the CépiDc of Inserm and some regional health agencies.

To have a sufficiently large sample for robust statistical analysis, the survey covers all deaths of 18-year-olds from March 2020 to February 2021.

To reduce the time between the occurrence of each death and the completion of the questionnaire associated with it, the collection will take place in 3 successive waves. We are beginning the first wave, dealing with deaths occurring mainly from March to June 2020.

You have received this letter because you or one of your staff has certified one or more deaths or because you monitored the end of life of certain people who died during these 4 months.

In this envelope, you will find information to identify the deceased persons and how to respond to this survey. The survey methodology strictly guarantees both your anonymity and that of the deceased, and medical confidentiality.

It will take about twenty minutes to answer this questionnaire, and only a few minutes if the death was sudden. Your answer is important for the quality of the results and their statistical representativeness.

Thanking you for your contribution.

Yours sincerely,

APPENDIX 2.3 – REMINDER LETTER



ENQUÊTE SUR LES CONDITIONS ET LES PRATIQUES
MÉDICALES RELATIVES À LA FIN DE VIE EN OUTRE-MER

RAPPEL

VAGUE 3

Réf:

Dr

Le

Madame, Monsieur,

L'Institut national d'études démographiques (Ined) s'adresse de nouveau à vous pour vous demander de participer à l'enquête que nous menons sur la fin de vie en Outre-mer. Il s'agit d'une enquête importante, la première dans les DOM, qui complètera celle réalisée en métropole en 2010. La recherche a été conçue par une équipe pluridisciplinaire de chercheurs de l'Ined, du CHRU de Besançon, de l'université de Strasbourg et de l'AP-Hôpitaux de Parus. Elle bénéficie du soutien du Conseil national de l'ordre des médecins, du CépiDc de l'Inserm et certaines agences régionales de santé.

Si vous avez déjà répondu au(x) questionnaire(s) concernant les décès survenus entre **novembre 2020 et février 2021** (3^{ème} et dernière vague de l'enquête) mentionnés dans les feuillets ci-après, nous vous en remercions et veuillez ne pas tenir compte de ce courrier.

Sinon nous nous permettons de vous demander de bien vouloir consacrer un peu de votre temps pour répondre à cette enquête. Votre expérience est en effet précieuse pour améliorer les connaissances sur la fin de vie et votre réponse contribuera à la représentativité des résultats de l'enquête.

Si vous rencontrez des difficultés pour répondre ou si vous avez des commentaires à nous transmettre, n'hésitez pas à nous contacter par mail à fdv@ined.fr ou par téléphone au 01 56 06 22 22.

Nous vous rappelons que la procédure utilisée pour l'enquête garantit totalement la confidentialité de vos réponses, votre anonymat ainsi que celui de la personne décédée.

Les principaux résultats de cette enquête seront disponibles au fur et à mesure de leurs publications sur le site <https://fdv.site.ined.fr>.

En vous remerciant pour votre contribution, nous vous prions d'agréer Madame, Monsieur, l'assurance de notre considération la meilleure.

Magda Tomasini
Directrice de l'Ined

Dr Régis Aubry
Chef du pôle Autonomie – Handicap.
- CHRU de Besançon
Membre du Comité Consultatif National d'Ethique

Sophie Pennec
Directrice de recherche
Responsable de l'enquête

POUR INFORMATION ET QUESTIONS :
Enquête Fin de vie en Outre-mer
INED, 9, Cours des Humanités
CS 50 004, 93322 Aubervilliers Cedex
Tél. : 01.56.06.22.22
E-mail : fdv@ined.fr
Site internet : fdv.site.ined.fr

Cette enquête a reçu l'avis favorable du Cerees et l'autorisation de la Cnil (DR-2018-102).
Droits d'accès, rectification, suppression : vous pouvez exercer votre droit d'accès aux informations nominatives vous concernant, en l'occurrence vos coordonnées professionnelles, en vous adressant au Service des enquêtes et sondages de l'Ined (adresse postale ci-contre).

ined 
INSTITUT NATIONAL
D'ÉTUDES DÉMOGRAPHIQUES

Dear Sir/Madam,

The French Institute for Demographic Studies (INED) is once again asking you to take part in the survey we are conducting on the end of life in the French Overseas departments (DOMs). This is an important survey, the first in the DOMs, which will complement the one conducted in mainland France in 2010. The research was designed by a multidisciplinary team of researchers from INED, CHRU de Besançon, the University of Strasbourg and AP-Hôpitaux de Paris. It is supported by the National Council of the Order of Physicians, CépiDc of Inserm and certain regional health agencies.

If you have already completed the questionnaire(s) concerning deaths between November 2020 and February 2021 (3rd and last wave of the survey) mentioned in the following leaflets, we thank you and please disregard this letter.

If not, we would appreciate it if you could devote some time to responding to this survey. Your experience is important in improving knowledge of end-of-life and your response will contribute to the representativeness of the results.

If you have any difficulties answering, or if you have any comments to provide, please contact us at fdv@ined.fr or by phone at 0156062222.

As a reminder, the procedure used for the investigation fully guarantees the confidentiality of your answers, your anonymity as well as that of the deceased.

The main results of this survey will be available when they are published on <https://fdv.site.ined.fr>.

Thank you for your contribution.

Yours sincerely,

APPENDIX 2.4 – DEATH CHARACTERISTICS AND TRANSFER COUPON



CARACTÉRISTIQUES DE LA PERSONNE DÉCÉDÉE ET MODALITÉ DE RÉPONSE

Si vous avez certifié plusieurs décès, vous recevez dans ce même courrier plusieurs feuillets comprenant les caractéristiques de chacune des personnes décédées.

Les caractéristiques socio-démographiques ci-dessous sont celles figurant sur le certificat médical de décès que vous avez signé.

Les informations nominatives ont été ajoutées par appariement à partir de fichiers disponibles en accès libre sur la plateforme data.gouv.fr. Le nom indiqué est le nom de naissance, le nom d'usage n'étant pas disponible.

Réf:

Date du décès :

Age au décès :

Sexe :

Commune du décès :

Lieu du décès :

Date de naissance :

Commune de domicile :

Prénom :

Nom :

MODALITÉ DE RÉPONSE :

Afin de garantir votre anonymat, nous utilisons le même procédé que pour les votes par correspondance :

- une enveloppe sans signe distinctif dans laquelle vous insérez le questionnaire rempli et qui ne doit porter aucun élément permettant de vous identifier (tampon professionnel...);
- une enveloppe T dans laquelle vous glissez l'enveloppe contenant le questionnaire. Ne pas inclure le coupon avec votre nom.



SI VOUS N'ÊTES PAS LE MÉDECIN AYANT PRIS CE PATIENT EN CHARGE AVANT SON DÉCÈS

Si vous connaissez ce médecin, vous pouvez lui transmettre cette lettre et tous les documents concernant l'enquête et/ou nous indiquer son nom et ses coordonnées pour que nous lui transmettions les documents. Merci de nous renvoyer le coupon de transfert dans l'enveloppe T jointe, les relances éventuelles seront ainsi adressées directement à votre confrère.

COUPON DE TRANSFERT

Réf:

Nom du médecin ayant pris en charge la personne :

Adresse professionnelle du médecin (du cabinet ou du service de l'hôpital) :

.....

Avez-vous transmis le courrier et les documents joints à ce confrère ?

Oui

Non

Commentaires

.....

.....

.....

DECEDENT'S CHARACTERISTICS AND HOW TO RESPOND TO THE SURVEY

If you have certified more than one death, you will find enclosed a data sheet for each of the decedents.

The socio-demographic characteristics below are taken from the death certificate you signed.

The nominative information has been added by matching with files freely available at www.data.gouv.fr. The name shown is the last name at birth name.

Ref:

Date of death:

Age at death:

Sex:

Commune of death:

Place of death:

Date of birth:

Commune of residence:

First name:

Last name:

RESPONSE METHOD:

To ensure anonymity, we use the same procedure as with postal voting:

- a plain envelope in which to put the completed questionnaire. There must be nothing on it to identify you, such as a professional stamp;
- a prepaid envelope in which to put the envelope containing the completed questionnaire. Do not include the coupon with your name on it.

IF YOU ARE NOT THE PHYSICIAN WHO CARED FOR THIS PATIENT BEFORE THEIR DEATH

If you know the physician, you can pass this letter on to them together with all the survey documents, and/or tell us their name and contact details so that we can send them the papers.

Please send us the transfer coupon in the enclosed prepaid envelope; if a reminder is needed, we can send it directly to your colleague.

TRANSFER COUPON

Ref:

Name of physician who cared for the patient:

Physician's professional address (practice or hospital department):

Have you sent the letter and documents to this colleague?

Yes

No

Comments:

APPENDIX 2.5 – PROCEDURE ESTABLISHED TO ENSURE ANONYMITY



ENQUÊTE SUR LES CONDITIONS ET LES PRATIQUES MÉDICALES RELATIVES À LA FIN DE VIE EN OUTRE-MER

PROCÉDURE DE L'ENQUÊTE, SECRET MÉDICAL, CONFIDENTIALITÉ ET ANONYMAT

Le service des Enquêtes et Sondages de l'Ined (SES-Ined) et les chercheurs en charge de cette enquête ont élaboré une procédure extrêmement rigoureuse afin de garantir le secret médical, la confidentialité de vos réponses ainsi que votre anonymat et celui de la personne décédée. Ce protocole a été autorisé par la Cnil (DR-2018-102) après avoir reçu l'avis favorable du Comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé (Cerees) en mars 2018.

1. L'étude porte sur l'ensemble des décès survenus entre le 1er mars 2020 et le 28 février 2021, à La Réunion, en Martinique, en Guadeloupe et en Guyane.

Votre nom et vos coordonnées professionnelles ainsi que les éléments d'identification du patient (âge, sexe, dates de naissance et de décès, commune et lieu de décès, commune de domicile) ont été collectés à partir des bulletins de décès administratifs anonymes remplis par l'officier d'état civil et des certificats de décès que vous avez remplis. Aucune donnée confidentielle relevant du secret médical n'a été relevé sur ce certificat.

2. Le fichier ainsi obtenu est utilisé durant la collecte des données et sera détruit après la fin de la collecte.

3. L'organisation de la collecte, et notamment l'envoi des différents courriers, est effectué sous la responsabilité du SES-Ined. Pour cela, il a été défini, pour chaque association « médecin-personne décédée », un identifiant. Vous allez recevoir autant de questionnaires (accompagnés du matériel de retour) que de certificats de décès que vous aurez signés durant la période concernée par l'enquête.

4. Modalité de réponse

Le retour des questionnaires suit une procédure qui garantit l'anonymat de vos réponses. Nous utilisons le procédé de la double enveloppe, comme pour les votes par correspondance : enveloppe sans signe distinctif contenant le questionnaire, insérée dans une enveloppe T comportant l'identifiant du décès.

Votre envoi est reçu par une institution indépendante (« Tiers de confiance »), ayant une expérience éprouvée dans le traitement de données confidentielles.

- Cette institution sépare les deux enveloppes et stocke les enveloppes sans signe distinctif.

- Elle communique l'identifiant figurant sur l'enveloppe T au SES-Ined, afin que celui-ci ne vous relance pas pour répondre sur ce cas.

- Lorsqu'un nombre suffisant d'enveloppes sans signe distinctif aura été réuni, le Tiers de confiance les ouvrira et saisira chaque questionnaire sur une application sécurisée.

Ainsi, l'institution chargée de la réception de votre questionnaire n'a en aucune façon accès à votre nom et le SES-Ined ne peut en aucune façon relier votre nom et vos réponses au questionnaire.

5. En ce qui concerne l'analyse et la publication des résultats, le questionnement a été conçu pour être à la fois pertinent du point de vue statistique mais aussi suffisamment général pour garantir l'anonymat aussi bien de la personne décédée que des médecins ayant participé à l'enquête.

POUR INFORMATION ET QUESTIONS :
Enquête Fin de vie en Outre-mer
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E-mail : fdv@ined.fr
Site internet : fdv.site.ined.fr



Survey procedure, medical confidentiality and anonymity

INED's surveys and polls department (SES-INED) and the researchers responsible for this survey have worked out an extremely rigorous procedure to ensure medical confidentiality, non-disclosure of your responses and the anonymity of yourself and the deceased person. The protocol was approved by the French data protection authority (CNIL approval DR-2018-102, May 2018) after receiving the approval of CERES (expert committee for health-related research, surveys and evaluations) in March 2018.

1. The study concerns all deaths between 1 March 2020 and 28 February 2021, in La Réunion, Martinique, Guadeloupe and French Guiana.

Your name and professional contact details and the patient's details (age, sex, birth and death dates, commune and place of death and commune of residence) were harvested from anonymous death records compiled by a civil registry official and the death certificates you signed. No data covered by medical confidentiality was harvested from the death certificate.

2. The resulting file was used for data collection and destroyed once collection was finished.

3. organising data collection and the various mailings **was tasked by SES-INED**. They allocated an identifier to each physician-decedent. You will receive a questionnaire (with the necessary for returning it) for each death certificate you signed in the period covered by the survey.

4. How to respond

The procedure for returning questionnaires ensures that your responses will be anonymous. We use the same double envelope method as is used for postal voting. You put a blank envelope containing the questionnaire into a prepaid envelope with the identifier of the death.

Your dispatch is received by a 'trusted third party', an independent institution with proven experience in processing confidential data. This institution separates the two envelopes and stores the blank envelopes.

- It gives SES-INED the identifier on the prepaid envelope so that they will not approach you again for the same case.
- When the trusted third party has received enough blank envelopes, they open them and enter the data from the questionnaires in a secure application.

This way, the body tasked with receiving your questionnaire has no way of accessing your name, and SES-INED has no way of connecting your name with the responses on the questionnaire.

5. As regards the analysis and publication of the results, the questioning was designed to be statistically relevant but sufficiently general to ensure the anonymity of the deceased and the physicians taking part in the survey.

APPENDIX 2.6 – THE SURVEY QUESTIONNAIRE

For reasons of space, the initial French version of the questionnaire is available in a clickable PDF.



Some questions about you

1.1 You are:

- ₁ A man
- ₂ A woman

1.2 How old are you?

- ₁ Under 40
- ₂ 40 to 49
- ₃ 50 to 59
- ₄ 60 or over

1.3 You are:

- ₁ a general practitioner
- ₂ a specialist

1.4 Working in what context?

(Several replies possible)

- ₁ Independent practice
- ₂ Hospital, clinic, medical welfare structure, care home or retirement home
- ₃ Mixed structure
- ₈ Other. *Give details*

1.5 Have you received training in end-of-life care?

- ₁ Yes, initial training
- ₂ Yes, in-practice training
- ₃ No

Questions about the decedent

For the purposes of statistical representativeness, please answer these questions about the decedent whose characteristics were sent to you with this questionnaire.

2.1 Sex of the deceased:

- ₁ Man
₂ Woman

2.2 Their age group:

- ₁ Under 40
₂ 40 to 59
₃ 60 to 69
₄ 70 to 79
₅ 80 to 89
₆ 90 or over

2.3 Period of the death:

- ₁ March to June 2020
₂ July to October 2020
₃ After October 2020

2.4 Place of residence of the deceased:

- ₁ Rural commune
₂ Town
₉ I don't know

2.5 To your knowledge, what family did they have?

(Check a box on each line)

	Yes	No	I don't know
a. Partner	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₉
b. Child or children living in the same overseas department as the deceased	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₉
c. Child of children not living in the same overseas department as the deceased	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₉
d. Brother(s) / sister(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₉
e. Others	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₉

2.6 Who did the deceased live with?

(Several answers possible)

- ₁ No one
- ₂ Partner
- ₃ One or more children
- ₄ Other person/people. *Give details*
- ₈ Other (e.g. in retirement home). Give details
- ₉ I don't know

2.7 Department/Region of death:

- ₁ Guadeloupe
- ₂ French Guiana
- ₃ Martinique
- ₄ La Réunion

2.8 Place of death:

- ₁ At home
- ₂ Hospital or private clinic
- ₃ Retirement/convalescent home, care home, geriatric unit
- ₄ Street or public place
- ₈ Other

3. Main cause of death:

- ₁ Cancer
- ₂ Cardiovascular disease
- ₃ Neurological or cerebrovascular disease
- ₄ Infectious disease
- ₅ Respiratory system disease (*other than cancer*)
- ₆ Digestive system disease (*other than cancer*)
- ₇ Mental or psychiatric disorder
- ₈ Violent death, other causes

4. Was the patient suffering from dementia or a neuro-cognitive disorder at the time of death?

- ₁ No
- ₂ Yes, mild cognitive impairment
- ₃ Yes, severe cognitive impairment
- ₉ I don't know

5. Was the death sudden and entirely unexpected?

- ₁ Yes
- ₂ No
- ₉ I don't know

6. How long had the patient been in your care?

- ₁ They were not my patient (*I only certified the death*)
- ₂ Less than a week
- ₃ Less than a year
- ₄ A year or more

7. Do you think you can provide some information about this patient's end of life?

- ₁ Yes → Go to question 8
- ₂ No



If you answered "No" to 7 → End of questionnaire
Thank you for your cooperation.

Place of death, care and treatment

8. Where was the patient staying at the time of their death and in the preceding weeks?
(Check one box per line)

	At home	Hospital (public or private)	Retirement home, care home, geriatric unit	Other place	I don't know
a. Day of death	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8	<input type="checkbox"/> 9
b. One week before death (J-7)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8	<input type="checkbox"/> 9
c. One month (J-30)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8	<input type="checkbox"/> 9
d. Two months (J-60)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8	<input type="checkbox"/> 9



- 8.1 What was their usual place of residence before they were hospitalised?

- 1 Own home
- 2 Retirement/convalescent home, care home, geriatric unit
- 8 Other place
- 9 I don't know

9. Did the patient express a preference for their place of death?

- 1 Yes
- 2 No
- 9 I don't know



9.1 Where did they want to die?

- 1 At home
- 2 In hospital or a clinic
- 3 Retirement/convalescent home, care home, geriatric unit
- 8 Other place. *Give details*

9.2 Did they die where they wanted to die?

- 1 Yes
- 2 No



9.2.1 If the patient did not die in the preferred place, why was this?

(Several answers possible)

- 1 The death happened sooner than expected
 - 2 The family was against it
 - 3 The health care professionals were against it
 - 4 The professional caregivers were against it
 - 5 The patient was living alone
 - 6 Care was too complicated or burdensome to be performed at home
 - 8 Other reason. *Give details*
-
- 9 I don't know

10. Did the patient's partner and/or family express a wish as to where the patient should die?

- 1 Yes
- 2 No
- 3 The patient had no partner or family
- 9 I don't know



10.1 Where did the partner and/or family want the patient to die?

- 1 At home
- 2 In hospital or a clinic
- 3 In a retirement/convalescent home, care home or geriatric unit
- 8 Other. *Give details*

10.2 Were the wishes of the partner and/or family carried out?

- 1 Yes
- 2 No



10.2.1 If the patient did not die in the place chosen by their partner and/or family, why was this?

(Several answers possible)

- 1 The death happened sooner than expected
- 2 The patient was against it
- 3 The health care professionals were against it
- 4 The professional caregivers were against it
- 5 The patient was living alone
- 6 The care was too complex or burdensome
- 8 Other. *Give details*

- 9 I don't know

11. Had the patient appointed a trusted third party?

(The trusted third party within the meaning of the Law of 2 February 2016 is the person named by the patient as their spokesperson if they are no longer able to make decisions for themselves)

- 1 Yes
- 2 No
- 3 Was not able to (*e.g. unconscious*)
- 9 I don't know



11.1 Was the trusted third party

- 1 the patient's partner
- 2 their father or mother
- 3 a brother or sister
- 4 One of their children or descendants
- 5 another member of the family
- 6 a friend
- 7 their regular physician
- 8 Someone else. *Give details*
- 9 I don't know

11.2 Was the trusted third party involved in discussions about medical decisions in the terminal stage?

- 1 Yes
- 2 No
- 9 I don't know



11.2.1 Why?

(Several answers possible)

- 1 Death happened too quickly
- 8 Other reason. *Give details*

- 9 I don't know

12. Were other friends or relatives involved in discussions about decisions in the terminal stage?

- ₁ Yes. *Give details*
- ₂ No
- ₉ I don't know

13. Had the patient drawn up an advance directive?

(An advance directive is a document drawn up by an adult, in which they put down their wishes regarding end-of-life issues, notably concerning the continuation, withdrawal or limitation of treatments)

- ₁ Yes
- ₂ No
- ₉ I don't know

13.1 Was the patient's advance directive complied with in decisions taken in the terminal stage?

- ₁ Yes
- ₂ No
- ₉ I don't know

13.1.1 Why?

(Several answers possible)

- ₁ Death occurred too quickly
- ₂ The wishes expressed in the directives were not appropriate to the situation
- ₈ Other reason. *Give details*

.....

.....

- ₉ I don't know

14. Were the following people involved in care of the patient in the last month of their life?

(Check one box per line)

	Yes	No	I don't know
a. Regular physician	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
b. Pain control or palliative care specialists	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
c. Physician in another speciality (other than psychiatry)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
d. Psychiatrist or psychologist	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
e. Nurse, nursing assistant	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
f. Physiotherapist	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
g. Social worker	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

15. Did the patient receive palliative treatment?

(symptom relief, pain control)?

- 1 Yes
- 2 No
- 9 I don't know

15.1 How long before the death was this treatment begun?

- 1 Several hours
- 2 Several days
- 3 Several weeks
- 4 Several months
- 9 I don't know

15.2 Who administered the palliative care?

(Several answers possible)

- 1 the usual caregivers
- 2 palliative care specialists (palliative care unit, mobile team or network)

16. What was the purpose of treatment given in the last week of life?

- 1 Exclusively curative
- 2 Exclusively palliative
- 3 Curative and palliative
- 4 No treatment

17. At the moment of death, was the patient receiving any treatment that affects vigilance or awareness?

- ₁ Yes
- ₂ No
- ₉ I don't know

17.1 What drugs were used?

(Several answers possible)

- ₁ Morphine or other opiate
- ₂ Midazolam or other benzodiazepine
- ₈ Other class or classes of drug. *Give details*

17.2 How long before the death was this treatment begun?

- ₁ Several hours
- ₂ Several days
- ₃ Several weeks

17.3 The treatment was administered to produce

- ₁ conscious sedation
- ₂ deep sedation

17.4 Was the treatment affecting vigilance or awareness administered

- ₁ continuously
- ₂ intermittently

17.5 Was the treatment affecting vigilance or awareness administered

(Several answers possible)

- ₁ knowing that it would not hasten death
- ₂ knowing that it might hasten death
- ₃ without concern for whether it might hasten death
- ₄ with the explicit intention of hastening death
- ₅ to put an end to what you perceived as a situation the patient found unbearable
- ₆ for another purpose. *Give details*
- ₉ I don't know

18. Did the patient receive artificial hydration?

- 1 Yes, continuously until death
- 2 Yes, but it was stopped a few hours before death
- 3 Yes, but it was stopped a few days before death
- 4 Yes, but it was stopped a few weeks before death
- 5 No
- 9 I don't know

19. Did the patient receive artificial nutrition?

- 1 Yes, continuously until death
- 2 Yes, but it was stopped a few hours before death
- 3 Yes, but it was stopped a few days before death
- 4 Yes, but it was stopped a few weeks before death
- 5 No
- 9 I don't know

20. In your view, to what extent (on a scale of 0 to 10) did the patient display the following symptoms in the last 24 hours before death (despite treatment if any)?

(For each symptom, check the column that matches your assessment)

	0	1	2	3	4	5	6	7	8	9	10	
No pain	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Worst pain imaginable
No nausea or digestive problems	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Severe digestive problems
No fatigue	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Severe fatigue
No respiratory difficulty	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Severe respiratory difficulty
No depression, anxiety or unease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Severe anxiety or depression, or deep unease
No confusion	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Severe confusion
No difficulty moving about	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Confined to bed

End-of-life decisions taken by yourself or another physician

21. As regards this patient, did you primarily decide to do everything possible to prevent death?

- ₁ Yes
₂ No



21.1 What treatment(s) did you administer?

(Several answers possible)

- ₁ Artificial hydration
- ₂ Artificial nutrition
- ₃ Artificial respiration
- ₄ Catecholamines
- ₅ Blood product transfusion
- ₆ Dialysis
- ₇ Oral chemotherapy, hormone therapy
- ₈ Other specific anti-cancer treatment
- ₉ Surgery
- ₈₈ Other treatment. *Give details*

22. As regards this patient, did you decide to withhold a treatment liable to prolong their life?

- ₁ Yes
₂ No



22.1 What treatment or treatments were withheld?

(Several answers possible)

- ₁ Artificial hydration
- ₂ Artificial nutrition
- ₃ Artificial respiration
- ₄ Catecholamines
- ₅ Blood product transfusion
- ₆ Dialysis
- ₇ Oral chemotherapy, hormone therapy
- ₈ Other specific anti-cancer treatment
- ₉ Surgery
- ₈₈ Other treatment. *Give details*

22.2 Did you consider the fact that this decision might hasten death?

- ₁ Yes
₂ No

22.3 Was it your conscious intention to hasten death?

- ₁ Yes
₂ No

22.4 Do you think that this decision did hasten death?

- ₁ Yes
₂ No
₉ I don't know

23. As regards this patient, did you decide to withdraw a treatment liable to prolong life?

- ₁ Yes
 ₂ No

23.1 What treatments were withdrawn?

(Several answers possible)

- ₁ Artificial hydration
- ₂ Artificial nutrition
- ₃ Artificial respiration
- ₄ Catecholamines
- ₅ Blood product transfusion
- ₆ Dialysis
- ₇ Oral chemotherapy, hormone therapy
- ₈ Other specific anti-cancer treatment
- ₉ Surgery
- ₈₈ Other treatment. *Give details*

23.2 Did you consider the fact that this decision might hasten death?

- ₁ Yes
 ₂ No

23.3 Was it your conscious intention to hasten death?

- ₁ Yes
 ₂ No

23.4 Do you think this decision did hasten death?

- ₁ Yes
 ₂ No
 ₉ I don't know

24. As regards this patient, did you decide to intensify treatment of pain and/or symptoms by means of one or more drugs?

- ₁ Yes
- ₂ No

24.1 What drugs were used?

(Several answers possible)

- ₁ Morphine or other opiate
- ₂ Benzodiazepine
- ₈ Other class of drugs. *Give details*

24.2 Did you consider the fact that this decision might hasten death?

- ₁ Yes
- ₂ No

24.3 Was it your conscious intention to hasten death?

- ₁ Yes
- ₂ No

24.4 Do you think this decision did hasten death?

- ₁ Yes
- ₂ No
- ₉ I don't know

25. As regards this patient, did you decide to apply continuous deep sedation until death?

- ₁ Yes
- ₂ No

25.1 How long was it administered for?

- ₁ several hours
- ₂ several days
- ₃ several weeks

25.2 Why was it applied?

- ₁ Because of a stubborn symptom
- ₂ Because it had been decided to withdraw lifesaving treatment
- ₈ Other reason. *Give details*

26. As regards this patient, did you decide to use one or more drugs to deliberately end life?

- 1 Yes
- 2 No
- 9 I don't know

26.1 What drug did you use?

(Several answers possible)

- 1 Barbiturate
- 2 Benzodiazepine
- 3 Pethidine - chlorpromazine - promethazine
- 4 Morphine or other opiate
- 5 Neuroleptic
- 6 Myorelaxant (curare)
- 7 Potassium
- 8 Other drug. Give details

26.2 Who administered the drug(s)?

(Several answers possible)

- 1 You or another physician
- 2 A nurse
- 3 The patient themselves
- 8 Someone else

26.2.1 Were you or another physician present when it was administered?

- 1 Yes
- 2 No

If you answered No to all the questions 21 to 26 → *Go to question 35*

The last medical act mentioned

NB: questions 27 to 34 concern the last act mentioned, i.e. your last “Yes” in response to questions 21 to 26.

27. Did you (or a colleague) discuss with the patient the decision taken for the last act mentioned?

₁ Yes



27.1 During this discussion, did you find the patient able to assess their situation?

- ₁ Yes
- ₂ No
- ₉ I don't know

27.2 During the discussion, did you find the patient capable of making their own decisions?

- ₁ Yes
- ₂ No
- ₉ I express no opinion

₂ No



28. Why was the decision taken for the last act mentioned not discussed with the patient?

(Several answers possible)

- ₁ As a doctor, I do not think I have to raise this question with a patient
- ₂ I did not feel able to raise this question
- ₃ I did not know what would be the best attitude to take
- ₄ The patient was unconscious or barely conscious
- ₅ The patient had dementia
- ₆ The patient exhibited mental deficiency
- ₇ The patient exhibited a psychiatric disorder
- ₈ The last act was clearly the best for the patient
- ₉ A discussion would have done the patient more harm than good
- ₁₀ The patient saw themselves as being in better health than they were
- ₈₈ Other reason. *Give details*
- ₉₉ I don't know

₉ I don't know



29. Was the decision over this last act taken at the patient's explicit request?

- ₁ Yes
- ₂ No
- ₉ I don't know

29.1 Was that request repeated?

- ₁ Yes
- ₂ No
- ₉ I don't know

30. Did you (or a colleague) discuss the decision about the last medical act with anyone else before it was carried out?

(Several answers possible)

- ₁ Yes, with one or more other physicians
- ₂ Yes, with the nursing team
- ₃ Yes, with the patient's partner and/or family
- ₄ Yes, with the trusted third party
- ₅ Yes, with other persons
- ₆ Yes, as part of a collegial process
- ₇ No
- ₉ I don't know

30.1 What was the purpose of the discussion?

(Several answers possible)

- ₁ to inform
- ₂ to get another opinion
- ₃ to make a joint decision

30.2 Were the views expressed in the discussion (with the patient or anyone else) entered in the patient's file?

- ₁ Yes
- ₂ No
- ₉ I don't know

30.3 Were the beliefs or religion of the patient or their family considered in the discussions (with the patient or anyone else) and decision-making?

- ₁ Yes
- ₂ No
- ₉ I don't know

31. What were the reasons for the last act mentioned?

(Several answers possible)

- ₁ The patient's persistent pain despite analgesic treatment
- ₂ The patient's uncontrollable symptoms (*acute asphyxia, cataclysmic haemorrhage*)
- ₃ The patient's mental distress
- ₄ No prospect of improvement
- ₅ Not wanting to pointlessly prolong life
- ₆ The patient's wish or request
- ₇ The wish or request of the patient's partner, family or trusted third party
- ₈ Other reason

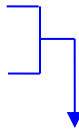
32. What expression do you think best describes the last act mentioned?

(Give only one answer)

- ₁ Treatment of symptoms
- ₂ Decision to withhold or withdraw treatment
- ₃ Continuous deep sedation until death
- ₄ Euthanasia (*"deliberate action by a third party that ends a person's life, with the intention of putting an end to a situation considered unbearable"* – *Comité consultatif national d'éthique* (national consultative ethics committee))
- ₅ Medical aid in dying (when a physician supplies the patient with a substance that they take themselves)
- ₆ Assisted suicide (when a third party deliberately ends the life of someone who cannot kill themselves and asks to be killed)
- ₈ Other. *Give details*

33. Did the patient at any time express the wish to hasten death?

- ₁ Yes, explicitly
- ₂ Yes, but not explicitly
- ₃ No
- ₉ I don't know



33.1 How did you learn of this wish?

- ₁ Orally from the patient
- ₂ From the patient's advance directive (*written or otherwise, e.g. audio recording*)
- ₃ From a relative of the patient
- ₄ From the nursing team
- ₅ Another way

34. Did the patient explicitly request euthanasia?

- ₁ Yes
- ₂ No



34.1 Why?

(Several answers possible)

- ₁ The pain or symptoms were stubborn
- ₂ The patient had a constant fear of death
- ₃ The patient felt a sense of indignity
- ₈ Other

34.2 Was their request complied with?

- ₁ Yes
- ₂ No

34.2.1 Why?

(Several answers possible)

- ₁ The patient was not in the terminal phase
- ₂ There were still medical prospects for lessening the suffering or symptoms
- ₃ The request had not been carefully thought out
- ₄ The request was influenced by a third party
- ₅ The patient retracted their request
- ₆ The partner or family were against it
- ₇ Because of principled objections to euthanasia
- ₈ To comply with the law
- ₈₈ Other reason

Companionship and support

35. For each of the following people, check the box that matches their pattern of care for the patient in the last month before death:

(Check one box per line)

People	Daily	Occasionally	Not involved	Unable to get involved (e.g. reasons of health, distance, no partner)	I don't know
a. Partner	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
b. Children	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
c. Brothers/sisters	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
d. Other family members	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
e. Friends, neighbours	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
f. Volunteer befriender	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9
g. Representative of a religion (e.g. almoner, minister, priest, rabbi, imam)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9

36. Did the patient receive any visits in the last week before death?

- 1 Yes
 2 No
 9 I don't know

36.1 By whom?

(Several answers possible)

- 1 partner
 2 children
 3 brothers, sisters
 4 other family members
 5 friends, neighbours
 6 volunteer befrienders
 7 a representative of a religion (e.g. almoner, minister, priest, rabbi, imam)
 8 someone else

37. Who was present at the patient's death?

(Several answers possible)

- 1 You, another physician, or another health care professional
- 2 Their partner
- 3 Children
- 4 Brothers, sisters
- 5 Other family members
- 6 Friend(s), neighbour(s)
- 7 Someone else (e.g. professional carer, volunteer)
- 8 Nobody was there
- 9 I don't know

38. Was support by a psychologist provided?

(Several answers possible)

- 1 Yes, for the patient
- 2 Yes, for the family
- 3 Yes, for the nursing staff
- 4 No
- 9 I don't know
- 8 N.a.: death came quickly

39. In your opinion, did the conditions of the patient's death meet their expectations?

- 1 Yes
- 2 No
- 9 I express no opinion

40. Today, do you think the conditions in which this death unfolded were

- 1 very decent
- 2 fairly decent
- 3 rather bad
- 4 very bad
- 9 I express no opinion

41. To what extent did you yourself find this death a distressing experience?

0 1 2 3 4 5 6 7 8 9 10
(not at all) (very much)

***That is the end of the questionnaire
Thank you very much for your cooperation***

APPENDIX 3– DOCUMENTS CONNECTED WITH THE QUALITATIVE SURVEY

APPENDIX 3.1 – INFORMATION LEAFLET FOR INTERVIEWEES



Feuille d'informations FDV-DOM-quali « Enquête auprès des proches »

Promoteur :

L'enquête est réalisée sous la direction de Sophie Penneç et Joëlle Gaymu, directrices de recherche de l'institut national d'études démographiques (Ined). L'équipe de recherche pluridisciplinaire comprend aussi des chercheurs de l'université de Strasbourg, du CHU de Besançon, CHU Robert Debré, Paris et de l'Institut régional de travailleurs sociaux de la Réunion (IRTS).

Titre du projet: La fin de vie dans les départements d'outre-mer – enquête qualitative auprès des proches

Objectif du projet de recherche

L'objectif de cette recherche est de dresser un panorama des conditions de la fin de vie dans 4 départements d'Outremer français (Martinique, Guadeloupe, Guyane et Réunion). Son ambition est de comprendre en quoi elles diffèrent de celles de la métropole et quelles adaptations des politiques publiques elles requièrent pour répondre aux besoins spécifiques de ces territoires.

Ce projet repose sur la réalisation de trois collectes de données complémentaires :

- une enquête quantitative auprès des médecins. Elle se situe dans le prolongement de celle effectuée en métropole en 2010 avec pour objectifs de décrire les circonstances de la fin de vie (décisions médicales, trajectoires résidentielles avant le décès, acteurs de l'accompagnement, les souhaits en matière de lieu de décès, etc.).
- des entretiens avec des aidants bénévoles (membres d'associations, communauté religieuse,...) et professionnels (membres de services de soins palliatifs, de soins infirmiers et d'aide à domicile) de la prise en charge en fin de vie.
- **une enquête par entretiens auprès de proches** ayant participé à l'accompagnement d'une personne âgée en fin de vie. C'est celle pour laquelle vous participez. Divers thèmes seront abordés au cours de ces entretiens. Les aspects concrets de l'expérience de l'accompagnement seront évoqués (rôles des divers intervenants, choix du lieu de la prise en charge, décisions médicales, connaissance et conditions d'application des lois relative à la fin de vie ...), mais aussi les perceptions (sources de satisfactions ou de difficultés, attentes et suggestions d'améliorations,...). Grâce à cette enquête sur les forces et les faiblesses de l'accompagnement à domicile des fins de vie, on pourra suggérer d'éventuelles propositions innovantes de modes de soutien (aux soignants et aux familles) afin d'améliorer la qualité de vie à ce stade de l'existence lorsqu'il se déroule à domicile, souhait d'une très large majorité des personnes.

Sur le site internet du projet www.fdv.ined.fr, il sera mis à disposition de tous et surtout des participants à l'enquête, un résumé des principaux résultats de chacune de ces publications issues de l'enquête (et la publication elle-même lorsque cela sera possible).

Pour toutes questions concernant l'enquête, vous pouvez joindre les responsables de l'enquête :

- Par mail : fdv@ined.fr ;
- par téléphone : 01 56 06 20 43

Vos droits

Volontariat et droit de retrait

Votre participation à cette recherche se fait sur la base du volontariat. Vous pouvez refuser d'y prendre part et retirer votre participation à tout moment, sans avoir à fournir d'explication. Vous avez tout à fait le droit de ne pas vouloir discuter de certains sujets et votre souhait sera respecté par l'enquêteur.

Vous pouvez retirer votre participation à l'enquête à tout moment (durant ou après l'entretien). Dans ce cas, les données recueillies seront détruites si vous en faites explicitement la demande.

Soutien aux enquêtés

Si à la suite de l'entretien vous ressentez le besoin d'une écoute ou d'un soutien, vous pouvez contacter la plateforme d'écoute « Accompagner la fin de vie » du centre national soins palliatif et de la fin de vie, au numéro de téléphone 0 811 020 300 de 10-13h et 14-17h (heures de métropole).

Confidentialité:

La confidentialité de vos propos sera totalement préservée. Les enquêteurs se sont engagés à ne pas divulguer les informations que vous leur avez données ; les enregistrements seront anonymisés c'est-à-dire que personne n'aura accès à votre nom ou à toute information personnelle ; les fichiers et transcriptions sont déposés sur un ordinateur sécurisé et effacés de tout autre support.

Aspects éthiques réglementaires

En accord avec la réglementation, la méthodologie de l'enquête a fait l'objet d'un avis favorable du comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé (CEREES) et d'une autorisation de mise en œuvre de traitement de données de la commission nationale informatique et libertés (CNIL – DR-2018-102 de mai 2018).

'FDV-DOM-quali' survey, families' information leaflet

Promoter:

The survey was directed by Sophie Pennec and Joëlle Gaymu, research directors at the *Institut national d'études démographiques* (INED). The multidisciplinary research team also included researchers from the University of Strasbourg, Besançon university hospital, Robert Debré university hospital in Paris and the La Réunion *Institut régional de travailleurs sociaux* (IRTS).

Project title: End of life in the French overseas departments – qualitative survey of family members

Aim of the research project

The purpose of this research was to give an overview of end-of-life conditions in Martinique, Guadeloupe, French Guiana and La Réunion, France's four overseas departments. The aim was to find out in what ways they differ from those in metropolitan France and what changes to public policy would be needed to meet the particular needs of these departments.

The project was based on three complementary data collections:

- A quantitative survey of physicians. This followed on from the one carried out in metropolitan France in 2010. It set out to describe the circumstances of people's last stage of life (medical decisions, residential transitions before the death, caregivers, patients' wishes regarding place of death, etc.).
- Interviews with carers involved in end-of-life care, both voluntary (e.g. from non-profit bodies or religious organisations) and professional (members of palliative care teams, nurses and home care workers).
- **An interview survey of family members or friends** who have cared for an elderly person in the last stage of their life. This is the survey you are responding to.

These interviews address various topics. We will ask about the practical aspects of the caregiving: the roles of different people, the choice of place for the caregiving, medical decisions, knowledge of the law on end-of-life medical decisions and how it was applied, etc. We will also ask about your perceptions (causes of satisfaction, difficulties, expectations, ideas for improvements etc.) This survey on the strengths and weaknesses of end-of-life care in the home will enable us to make innovative proposals for ways of supporting caregivers and families to improve the quality of life for someone dying at home, which is what most people hope for.

A summary of the main results of each of the publications resulting from the survey will be available to everyone on the INED website (www.fdv.ined.fr), as will the full publication where possible.

For further information, contact the survey staff:

- By email: fdv@ined.fr;
- By telephone: 01 56 06 20 43

Your rights

Voluntary participation and right of withdrawal

Your participation in this research is voluntary. You can refuse to take part, or you can withdraw your participation at any moment with no need to give reasons. You have a perfect right to not want to discuss some subjects and the interviewer will respect your wishes.

You can withdraw from the survey at any time during or after the interview.

In this case, the data collected will be destroyed if you explicitly ask for that.

Support for respondents

After the interview, if you feel the need for support or someone to talk to, you can phone the 'Caring for the dying' helpline run by the *Centre national des soins palliatifs et de la fin de vie*, 08 11 020 300 from 10am to 1pm and 2pm to 5pm (metropolitan France time).

Confidentiality

Anything you say will be treated in the strictest confidence. Interviewers pledge not to divulge any information you give them. The recordings are anonymised, meaning that nobody will have access to your name to any personal information: the data files and transcriptions are stored on a safe computer and deleted from all other mediums.

Ethical aspects and regulations

In compliance with regulations, the survey methodology was approved by the *Comité d'expertise pour les recherches, les études et les évaluations dans le domaine de la santé* (CEREES) in March 2018 and by the *Commission nationale de l'informatique et des libertés* (CNIL) (CNIL – DR-2018-102, May 2018).

APPENDIX 3.2 – INTERVIEWERS' CONTACT SHEET

Instructions for FDV-DOM-quali interviewers

Interviewer-respondent contact sheet

Hello,

Presentation

"My name is ... and I am an interviewer for a government-funded research team (from INED...). We are studying end-of-life conditions in the overseas departments. The aim is to produce an overview of the conditions in which people are cared for in their last stage of life and gain a better understanding of how their care is organised between the different people involved – medical staff, family members and friends, etc.

As part of this work we want to talk to people who have cared for a dying relative or friend, to record their testimony and experiences. We are also gathering information from doctors, health care professionals and volunteers who care for the terminally ill. But we think it is very important to also record the experience of the

family, who play an essential part and whose viewpoint complements the others. Your testimony will enable us to pinpoint the strengths and weaknesses of home care and suggest ways for local and national decision-makers to make improvements.

Interview conditions

In practice, the interview will be a conversation, a free discussion, at your home or any other place of your choosing.

Everyone's participation is entirely voluntary and if there are issues you do not want to talk about you can just let me know. Interview length varies from person to person but is about an hour on average. The conversation is usually recorded so as to be faithfully transcribed and analysed afterwards. But you can refuse to have your responses recorded. In any case your anonymity is ensured because names and other identifying information are not kept.

I am personally pledged to respect the confidentiality of anything you tell me. Do you agree to talk to me about the subject and share your experience with me? Do you have any questions?

Additional information for interviewers

The research project's more precise goals

The purpose of this research is to give an overview of end-of-life conditions in Martinique, Guadeloupe, French Guiana and La Réunion, France's overseas departments. The aim is to see in what ways they differ from those pertaining in metropolitan France and what public policy changes would be needed to meet these departments' particular needs.

The project is based on three complementary data collections:

- A quantitative survey of physicians. This followed on from the one carried out in metropolitan France in 2010, to describe the circumstances of people's last stage of life (medical decisions, residential transition before the death, caregivers, patients' wishes regarding place of death, etc.).
- Interviews with carers involved in end-of-life care, both voluntary (e.g. from non-profit bodies or religious organisations) and professional (members of palliative care teams, nurses and home care workers).
- An interview survey of family members or friends who had cared for an older person in the last stage of their life.

Topics addressed in the interview

The practical aspects of caregiving will be addressed, i.e. the roles of the various parties involved, the choice of place for the caregiving, medical decisions, knowledge of the law on end-of-life medical decisions and how it was applied, etc. We will also ask about perceptions (causes of satisfaction, difficulties, expectations, ideas for improvements etc.) This survey on the strengths and weaknesses of home care for the terminally ill may enable us to make innovative suggestions for ways of supporting caregivers and families to improve the quality of life for someone dying at home, which is what most people hope for.

Ethical and regulatory aspects of the project

Confidentiality/Anonymity:

The interview recordings are stored on a safe computer and the interviewers undertake to delete them from their recording devices. The files are anonymised, meaning that nobody will have access to the respondents' names. When the survey results are analysed and published, it will not be possible to identify the respondents.

In compliance with the law, the interviewers pledge not to divulge the information gathered. The service providers that transcribe the interviews will only have access to the anonymised recordings during their mission. They will be under an obligation to destroy all files they may have in their possession.

The recordings and transcriptions will be stored on a safe server at INED, accessible only to the research team. Once the study is finished, they will be archived anonymously.

Compliance with ethical regulations

In line with the regulations (the Jardé act), the survey methodology was approved by the *Comité de protection des personnes* (an ethical review board) on march 2018, by CEREES (expert committee for health-related research, surveys and evaluations) and by the CNIL (the French data protection authority) (CNIL – DR-2018-102, May 2018).

Right of withdrawal

The respondent can exercise their right of withdrawal at any time.

In that case, the data recorded can be destroyed at their explicit request.

Support for respondents

Because of the issues addressed, the interviewer must mention that a partnership has been set up with the Caring for the Dying helpline run by the national palliative care and end of life centre, and that if the respondent feels the need for support or someone to talk to, they can dial 0811020 300 from 10am to 1pm and 2pm to 5pm (metropolitan France time).

Use of participants' information and data

The survey analysis results will be published through the usual channels for science research (journal articles, conference papers etc.).

A summary of the main findings of each publication based on the survey (and the publication itself whenever possible) will be available to the public, and especially the survey participants, on the project website: www.fdv.ined.fr.

Contacts

For further information, contact the survey staff:

- By email: fdv@ined.fr;
- By telephone: 01 56 06 20 43

APPENDIX 3.3 – INTERVIEW GUIDE

Proposed interview guide

Presentation

As I told you on the phone, we at INED are making a study of care for older people at the end of their lives.

Of course, everything said in the interview will remain absolutely confidential. If we ask your permission to record it, it is to facilitate our work and avoid any errors in the note-taking. You are free to refuse that permission. In any case, your anonymity is strictly protected because names and other identifying information are not kept.

Do you have any questions about the interview process?

Starting question:

Could you tell us about the circumstances in which you lost your partner/husband/father/mother/other person?

Elicit the type of illness, how it developed, how long it lasted, the care that was needed, etc.

home care and hospitalisation:

-Did your partner/father/mother/other person stay at home throughout? Was that their wish? Was it your wish? Did you talk about it with them? With your family and friends?

If the person was hospitalised (once or more than once): – Can you tell me how that went? Who decided? (role of physician, patient's participation, family etc.)

Elicit the reasons and duration of hospital stay, why and how the patient came home again.

- During the hospital stay, how did you find the care provided for your partner/father/mother/other person? What were your relations with the medical staff? What did your partner/father/mother/other person think of it?

Relations with others involved in the home care:

- How did it go with other family members and friends?

If some of them helped, who helped whom? In what way? [Explore the type of help: material, logistical, psychological, moral, 'alternative' care?] What did you think of their help?

- What about family members living beyond the department boundaries?

- Did you receive help from other people (nurses, home help, volunteers)? Could you tell me how that went?

Ask about help given to the patient but also help received by the respondent (especially psychological support)

- Did you have help from volunteer carers?

- What did you think of this help?

Ask about complementarity between types of care. Did they provide relief or add to stress (being dispossessed of one's role, one's world), inadequacies.

- Did you get any psychological help from other people or the community? [find out whether some people unexpectedly offered help or support].

The legal provisions

- How was the medical care your loved one received in their last months/week of life?
- Do you know whether it was decided to withhold some treatments, withdraw treatments or treat them with powerful painkillers such as morphine? Did your loved one receive palliative care (meaning treatment to alleviate pain and improve the comfort of a dying patient)?
- Did the physician talk to you about any medical decisions that had to be taken? If so, which?
- Did your loved one take part in that decision process? What part did you play in it? Do you think you were fully informed and listened to?

Ask whether the decedent had made their wishes known as regards their end-of-life care, whether they had named a trusted third party or drawn up a living will, and if so, whether the trusted third party was involved in the decision and whether the living will was taken into account.

- Have you heard of the Leonetti and Claeys-Leonetti laws on patients' rights at the end of life?
- If so, from what information sources? (knowledge in general or knowledge acquired because of the situation with your loved one)? In your opinion, what improvement has it brought? Did you or your loved one make use of any of their provisions (advance directives, appointing a trusted third party, involvement in medical decisions)?

[If not, explain that these laws enable a patient, or their family if they are unable to express themselves, to tell doctors what they want in terms of end-of-life medical treatment]; – These laws don't ring a bell for you? Or: – You had never heard of them?

- Do you think everything possible was done to respect the wishes of your loved one?

General perceptions

- What do you feel about your experience and your role during the last months or weeks of your loved one's life?

If a sense of personal fulfilment is mentioned, inquire further: was it about fulfilling one's role, feeling useful, closeness with the patient, fulfilling their wishes etc.? Or explore: Did you have a sense of personal fulfilment?

Look into the difficulties and the feeling of helplessness (duration of the loved one's illness, how it developed, difficulty of the care required, lack of help from other people, relations with other people involved, etc.) or ask: Were there moments or situations when you felt particularly helpless? If so, what were they?

- **What advice or suggestions would you give to help families in this kind of situation?**
- **Are there any other points you would like to raise?**