AP-HM 2017-35 EPAL	Patient number : _ Centre N°.	Inclusion N°.
N°2017-A01846-47	Patient's initials (First name /famil	y name): -

Cancer patients' opinion on the Claeys-Leonetti law: EPAL study

AP-HM 2017-35 EPAL	Patient number :	
N°2017-A01846-47	Centre N°.	Inclusion N°.
IV MOLIT-INVIOLO-TI	Patient's initials (First name /family	y name): -

Medical form

PERSONAL DATA:		
Gender: ☐ Male ☐ Female		
Date of birth: / /		
Date of interview: / /		
Hospitalized patient: ☐ Yes ☐ No		
If Yes, date of hospitalization: / /	_ _	_
Date of death: / /		
INCLUSION CRITERIA		
Male or female, of legal age	☐ Yes	□ No
A person with locally advanced or metastatic cancer who is therefore eligible for palliative care according to the definition set out by the French Society for Accompaniment and Palliative Care (active multidisciplinary care in a global approach to the person suffering from a serious progressive illness or at the end of life) [Palliative Care Charter, 1996; Law n°99-477 of June 9, 1999 aimed at guaranteeing the right to access palliative care]. This definition is directly derived from that of the World Health Organization [World Health Organization. WHO pain ladder. Available from: http://www.who.int/cancer/palliative/painladder/en/. Accessed December 9, 2011].	□ Yes	□ No
EPAL CAHIER OBSERVATION Final 03092018.doc		

AP-HM 2017-35 EPAL	Patient number :	 re N°.	Inclusion N°.
N°2017-A01846-47	Patient's initials (First na		
Subject hospitalized in a palliative palliative care beds (LISP) or foll palliative care team) or subjects a network or a mobile palliative care	owed by an EMSP (mobile t home followed by a palliat		s 🗆 No
Patient accepts to participate in st	udy	□ Ye	s 🗆 No
CRITERIA FOR NON-INCLUSION			
Subject understands purpose and c	onditions of study.	□ Ye	es 🗆 No
MEDICAL DATA:			
Date of diagnosis: _ /	/ _		
Which type of cancer does the pat ☐ ENT	ient have?		
□ Digestive			
☐ Gynaecological			
☐ Pulmonary			
☐ Cerebral primitive			
☐ Dermatological			
☐ Urological			
☐ Haematological			
□ Sarcoma			
☐ Other, specify:		•••••	
Number of metastatic sites:			
WHO Index:			
Is the patient receiving any tier III	pain medication?		
EPAL CAHIER OBSERVATION Final	03092018.doc		3/18

AP-HM 2017-35 EPAL	Patient number :	Inclusion N°
N°2017-A01846-47	Centre N°. Patient's initials (First name /family	Inclusion N°.
	Fauent's initials (First name /family	
□ Yes		
□ No		
MEDICAL DATA:		
In the curability phase, the patient (Check more than one box, if appropriate)	t received:	
☐ Adjuvant chemotherapy		
☐ Neo-adjuvant chemotherapy		
□ Radiotherapy		
□ Surgery		
☐ Immunotherapy		
☐ Targeted therapy		
☐ No treatment		
Yes	\Box No	
If yes, date of diagnosis of incurab	oility: / /	_
Since the diagnosis of incurability (Check more than one box, if appropriate)	y, has the patient received:	
□ Chemotherapy		
□ Radiotherapy		
□ Surgery		
☐ Immunotherapy		
☐ Targeted therapy		
☐ No treatment		
How many lines of systemic treat incurable phase)? _	ment were administered (total including	geurable and
Cancer treatment still in progress:	: □Yes □ No	
EPAL CAHIER OBSERVATION Final	03092018.doc	

A D TIM 2017 25 EDAT	Detient man L. L. L.	
AP-HM 2017-35 EPAL	Patient number :	<u></u>
N°2017-A01846-47	Centre N°.	Inclusion N°.
1 2017-1010-0-47	Patient's initials (First name /famil	v name) · -
	Tatient 5 miliais (1 m5t name / amin	<i>y</i> name).
		_
MEDICAL DATA:		
To date, does the patient have	any symptoms (grade according to the Ca	TCAE)
	Symptoms	NCI
		Grade
		Grade
		_
		, ,

Cancer patients' opinion on the Claeys-Leonetti law: EPAL study

AP-HM 2017-35 EPAL	Patient number :	
N°2017-A01846-47	Centre N°.	Inclusion N°.
IV MOLIT-INVIOLO-TI	Patient's initials (First name /family	y name): -

Patient Observation Report

Personal data
What is your current marital status?
☐ Single / Separated / Divorced / Widowed
☐ Married / In couple / Cohabiting
Do you have any children?
□ No
\square Yes, please specify: Number of children: $ \underline{\hspace{0.2cm}} $ Number of dependent children: $ \underline{\hspace{0.2cm}} $
What is the highest educational grade you achieved?
□ No diploma - Primary school certificate
☐ BEPC, BEP, CAP, Secondary school diploma below Baccalaureate
□ Baccalaureate / Diploma equivalent to Baccalaureate
□ Diploma equivalent to Baccalaureate + 2 years
□ Diploma superior to Baccalaureate + 2 years
EDAL CALIFED ODGEDVATION E. 102002010 1
EPAL CAHIER OBSERVATION Final 03092018.doc 6/1:

AP-HM 2017-35 EPAL	Patient number :	
N°2017-A01846-47	Patient's initials (First name /family name): -	
If you have ever worked, what is	s/was your last occupation?	
□ Farmers□ Craftsmen, sales staff and bus□ Executives and freelance prof		
■ Since your hospitalization in this □ Not at all □ Less than once a week □ More than once a week □ Every day	s establishment, have you been visited by your family and friend	ıs?
• Are you religious (All faiths)	□Yes □ No	
If yes, do you practise your religion?	? □Yes □ No	
	Your information	
 2 of the Public Health Code, ab proposed, their possible risks a therefore like to know if you feel Considering the information you you feel you were well informed Considering the information you 	nt must be properly informed, according to article L. 1111 bout his/her state of health, the medical acts and treatment and the foreseeable consequences of a refusal. We would that, up to now, your right to information has been respected by were given about your illness and the associated diagnosis, 1? Please rate this feeling from 0 (no, not at all) to 10 (yes, definite a were given about your treatments and their possible side-efferormed? Please rate this feeling from 0 (no, not at all) to 10 (yes)	ts ld d. , do ely):
EPAL CAHIER OBSERVATION Fina		7/10

AP-HM 2017-35 EPAL	Patient number : _	 ntre N°.		Inclusio	I I
N°2017-A01846-47	Patient's initials (First n		nily naı		
	Your pain				
	- vw. pw				
During the past week, how would no pain and 10 = unbearable pain		ımerical sc	ale: bet	ween 0 a	and 10 (0 =
During the past week, how would $(0 = \text{no pain and } 10 = \text{unbearable})$	-	a numerio	cal scale	: betwee	en 0 and 10
	Your suffering				
The Claeys-Leonetti law replace 5, L. 1110-5-3 and R. 4127-37 the term 'suffering' should be we would like to know how you	of the Public Health Code). A understood to mean all phys	According sical and	to parl moral	iament	ary debate
Regarding your current suffering, suffering imaginable)? _	could you quantify it on a scale f	rom 0 (no	sufferin	g) to 10	(maximum
	Your quality of life				
EORTC QLQ-C15-PAL (version 1)				
We are interested in you and number that best applies to you is strictly confidential.					
	N	ot at all / So	mewhat /	Quite a l	oit / A lot
1. Do you have difficulty tak	ing a little walk outside?	1	2	3	4
2. Do you have to stay in bed	or in a chair during the day?	1	2	3	4
3. Do you need help with eat going to the toilet/bathroom		1	2	3	4
EPAL CAHIER OBSERVATION Fi	nal 03092018.doc				8/18

A	P-HM 2017-35 EPAL	Patie	nt num	ber:	 : N°.		Inclusion	 N°.
N°.	2017-A01846-47	Patient's in	nitials	(First na	me /far	nily naı	me):	-
In	the past week:			Not at all /	Somewh	at / Quite	a bit / A lo	t
4.	Did you experience shortness of b	reath?		1	2	3	4	
5.	Did you feel any pain?			1	2	3	4	
6.	Did you have trouble sleeping?			1	2	3	4	
7.	Did you feel weak?			1	2	3	4	
8.	Did you lose your appetite?			1	2	3	4	
9.	Did you experience nausea or feel	sick?		1	2	3	4	
10.	Were you constipated?			1	2	3	4	
11.	Did you feel tired?			1	2	3	4	
12.	Did any pain interfere with your d	aily activitie	s?	1	2	3	4	
13.	Did you feel tense?			1	2	3	4	
14.	Did you feel depressed?			1	2	3	4	
	or the following question, pleas our situation	e circle the	numb	er betwee	en 1 an	d 7 tha	t best ap	plies to
15	. How would you rate your overall	quality of life	e over tl	ne past wee	ek?			
1	2 3		4	5		6		7
V	ery poor						Excel	lent

Your opinion on the Claeys-Leonetti law and on euthanasia (1/9)

According to the Claeys-Leonetti report, which was submitted on December 12, 2014, to the President of the French Republic, the new law on the rights of ill people was to address two issues: on the one hand, better **respecting their autonomy**, in particular the autonomy of their will; on the other hand, better **preserving their dignity**. Provisions have been made in this sense, and we would like to get your opinion on each one.

AP-HM 2017-35 EPAL	Patient number :	
N°2017-A01846-47	Centre N°.	Inclusion N°.
IV 2017-A010-00-47	Patient's initials (First name /family	v name): -
	•	/ I——I I——I

Respecting the autonomy of patients

1. by respecting their verbally expressed wishes regarding the continuation, limitation, refusal or cessation of treatment and medical procedures.

You will first be asked about the **question of refusing a treatment or requesting its discontinuation**. This is a patient's right set out in article L. 1111-4 of the Public Health Code. The word 'treatment' is to be understood as **anything that helps to cure, relieve symptoms or prevent the onset of a disease**. Treatments therefore include *chemotherapy, radiotherapy and immunotherapy*. Since the Claeys-Leonetti law of February 2, 2016, artificial feeding and hydration are considered treatments.

When a patient decides to refuse or discontinue a treatment, do you think that the physician should, in all circumstances and including when it puts the patient's life in danger, respect the patient's expressed will, after having informed the patient of the consequences and the seriousness of his or her decision, and after having given the patient reasonable time to repeat it?

☐ Yes

□ No

☐ Don't know

AP-HM 2017-35 EPAL	Patient number : _ Centre N°.	Inclusion N°.
N°2017-A01846-47		
	Patient's initials (First name /fam	my name): -
X 7 • • 41		• (2/0)
Your opinion on th	e Claeys-Leonetti law and on eutha	nasia (2/9)
(articles L. 1110-5-1 and R. 4127 undertake medical acts or tre mean a preventive act (a medica MRI). As stated above, treatment onset of a disease. From a legal be continued as much as possible example, baths, massages, aesth pain relief. On the contrary, to constitute obstinacy, i.e. when the Claeys-Leonetti law stipulates the	the issue of unreasonable obstinacy. 7-37) stipulates that the physician's du atments with unreasonable obstinated consultation) or an investigative act at it is anything that helps to cure, relieve point of view, treatment is the oppose because it provides comfort to the present treatments, in other words, body reatments must be stopped when the present more drawbacks than benual artificial nutrition and hydration which are now considered as treatments be obstinacy.	ty is not to pursue or to acy . By medical act, we (an X-ray, a scanner, an symptoms or prevent the site of care . Care should patient. This includes, for y care and any means of their continuation would refits for the patient. The (administered by gastric
expressed will of the patient, it is	Tusal of unreasonable obstinacy, do you necessary to impose on the physician not ed to be useless, disproportionate, or having	to continue or to undertake
☐ Yes☐ No☐ Don't know		
As far as artificial feeding and l other?	nydration are concerned, do you think the	ey are treatments like any
☐ Yes ☐ No ☐ Don't know		

Your opinion on the Claeys-Leonetti law and on euthanasia (3/9)

When the patient is no longer able to express his or her wishes orally, either because he or she is in a coma or because he or she is unable to express a clear and coherent wish, the physician is legally obliged to seek the wishes that the patient may have previously expressed: either in advance directives; or from the trusted person he or she has designated;

AP-HM 2017-35 EPAL	Patient number : _	
N°2017-A01846-47		
	Patient's initials (First nam	<u>ne /family name): - </u>
and, in the absence of a trusted per L. 1111-12 of the Public Health C	· ·	ls. This is provided for in article
a) Advance directives		
• If you heard someone talk about a	ndvance directives, would you kn	now what they are?
□ Yes		
□ No		
A dyram as dimentity as among de arrows	at duorrin rin hay a manaan riiha l	has march ad the age of marianity
Advance directives are a documer expressing his or her wishes con	1 7 1	
refusing medical treatment or pro-	•	
concerned is no longer able to exp		
- XX 1 6: 1 1 1		
 Have you drafted any advance dir 	ectives?	
□ Yes		
□ No		
Before the adoption of the Claey	s-Leonetti law, advance direc	ctives were valid for three
years.	T 44* 1 1 1	1' .' 1 1
Since the adoption of the Classification stipulated duration of validity.	•	
supulated duration of various.	They are valid until modified (or revoked.
• Regarding the validity of advance	directives, do you think that the	ere should be a time limit?
□ Yes		
□ No		
☐ Don't know		
If yes, for how long (in years): _	.1	
Your opinion on the	e Claeys-Leonetti law and on	euthanasia (4/9)
Before the adoption of the Claey		•
physician was obliged to consult t	them but was not obliged to re	espect them.

AP-HM 2017-35 EPAL	Patient number : _ Centre N°.	Inclusion N°.
N°2017-A01846-47		
	Patient's initials (First name /family	y name): -
must not only consult them but	rs-Leonetti law, advance directives are to must also respect them (except for mediation or their manifest inappropriateness	ical emergencies, non-
These provisions are to be found	in Article L. 1111-11 of the Public Hea	lth Code.
Regarding the value of advance dire	ectives, do you agree that they should be bir	nding?
☐ Yes ☐ No ☐ Don't know		

AP-HM 2017-35 EPAL	Patient number : _ Centre N°.	Inclusion N°.
N°2017-A01846-47	Patient's initials (First name /far	
	·	
Your opinion on the Claeys-Le	eonetti law and on euthanasia (5/9)	b) The trusted support
	person	· • • • • • • • • • • • • • • • • • • •
• If you hear the term 'a trusted pe	erson', do you know what that means?	
□ Yes		
□ No		
The trusted person is a close re	lative, a parent or a doctor who is	designated by an adult. He
	hat the latter is unable to express his	
medical meetings in order to help	person can accompany him or her in him or her make decisions	his or her steps and attend
	d in article L. 1111-6 of the Public	Health Code. In addition,
	de stipulates that the testimony of th	e trusted person prevails
over any other testimony.		
	as the "trusted support person", do you that's previously expressed wishes?	hink that he or she is capable
□ Yes		
□ No		
☐ Don't know		
Regarding the value of the testing any other testimony?	mony of the trusted person, do you agre	e that it should prevail over
□ Yes		
\square No		
☐ Don't know		
•	of the testimony of the trusted person, wang on the physician the course of action	•
□ Yes		
□ No		
☐ Don't know		
Your opinion on the Claeys-Leonetti law and on euthanasia (6/9) Respecting the dignity of ill people		
	X _ X	
1. By creating a right to dec	_	1.0
1	animent and Palliative Care (SFAP) or a decrease in vigilance that ca	

AP-HM 2017-35 EPAL	Patient number : _ Centre N°.	Inclusion N°.
N°2017-A01846-47	Patient's initials (First name /f	
	2 4400110 0 1111011111111111111111111111	
unbearable by the patient, when a and/or implemented without provided Sedation is said to be deep when when it is maintained until death. The Claeys-Leonetti law introd patient's right to deep and con and incurable disease, and his	it completely alters consciousness	ituation have been proposed. It is said to be continuous ne Public Health Code the is suffering from a serious atening in the short term,
thus threatening his or her vital unbearable suffering. If these co- sedation. It will be associated wit including artificial nutrition and l	ment or has decided to discontinued prognosis in the short term, and additions are met, the patient can as the analgesia (pain treatment) and the hydration. A group of medical profest, a consulting doctor and the heatwood by the law are respected.	I with the risk of enduring sk the doctor to receive this e cessation of all treatments, ressionals is set up including
	incurably ill, and provided that his you approve of the possibility of dee?	= -
☐ Yes☐ No☐ Don't know		
threatening in the short term, do	and incurable, and provided that his a you approve of the possibility of deep a nitiative, decided to stop a vital treatment suffering?	and continuous sedation when
□ Yes		
□ No □ Don't know		
-	express his or her wishes and, in the system of the system	
□ Yes		
□ No □ Don't know		
	o Cloover I a442 land	theresis (7/0)
Y our opinion on th	e Claeys-Leonetti law and on eut	inanasia (//y)

√°2017-A01846-47	Centre N°.	
		Inclusion N°.
P	atient's initials (First name /famil	y name): -
When a nation is seriously and incr	rably ill, and provided that his or her v	ital prognosis is life-
	u approve of the possibility of deep and	1 0
the case of mental suffering withou		
☐ Yes		
□ No		
☐ Don't know		

AP-HM 2017-35 EPAL	Patient number :	Inclusion N°.
N°2017-A01846-47	Patient's initials (First name /fami	ily name): -
<u> </u>	eonetti law and on euthanasia (8/9) 2 litated suicide, assisted suicide and e	•
implementation of facilitated su of lethal products without involv patient is free to administer the ledeliberately terminates the life	xamined in parliament in December 2 icide rather than assisted suicide, by a ing the responsibility of a third party. I ethal product or not. Euthanasia is the of a person in order to put an end liamentary debate, neither facilitated s	allowing the prescription In facilitated suicide, the e act of a third party who to a situation deemed
Definitions:		
Facilitated suicide: prescripAssisted suicide: active assi	ption of lethal products istance of a third party for the administra ntionally causing the death of another pe	
■ The Claeys-Leonetti law did not the law?	legalize facilitated suicide after all. Do yo	ou agree with this point of
☐ Yes ☐ No ☐ Don't know		
• The Claeys-Leonetti law did not the law?	t legalize assisted suicide after all. Do yo	u agree with this point of
☐ Yes ☐ No ☐ Don't know		
■ The Claeys-Leonetti law did no law?	t legalize euthanasia after all. Do you ag	ree with this point of the
☐ Yes ☐ No ☐ Don't know		

AP-HM 2017-35 EPAL	Patient number : L	Inclusion N°.
N°2017-A01846-47	Centre N°.	
	Patient's initials (First name /family	name): -
If you answered 'no' to any of the s	above, would you be in favour of legalizing.	2
		••••
 □ Facilitated suicide (prescription o □ Assisted suicide (active assistance □ Euthanasia □ All of the above □ Don't know 	f lethal products) e of a third party for the administration of let	thal products)
Your opinion on the	e Claeys-Leonetti law and on euthanas	sia (9/9)
■ If a new law on the end of life all person? □ Yes □ No □ Don't know	llowed for euthanasia, could you be led to re	esort to it on your own
Were there any questions in thisYesNo	interview that bothered you?	
If so, which ones (write in Free C	Comments)?	
Has this questionnaire changed yYesNo	our opinion on anything?	
If so, on which subject?		
• Free comments:		