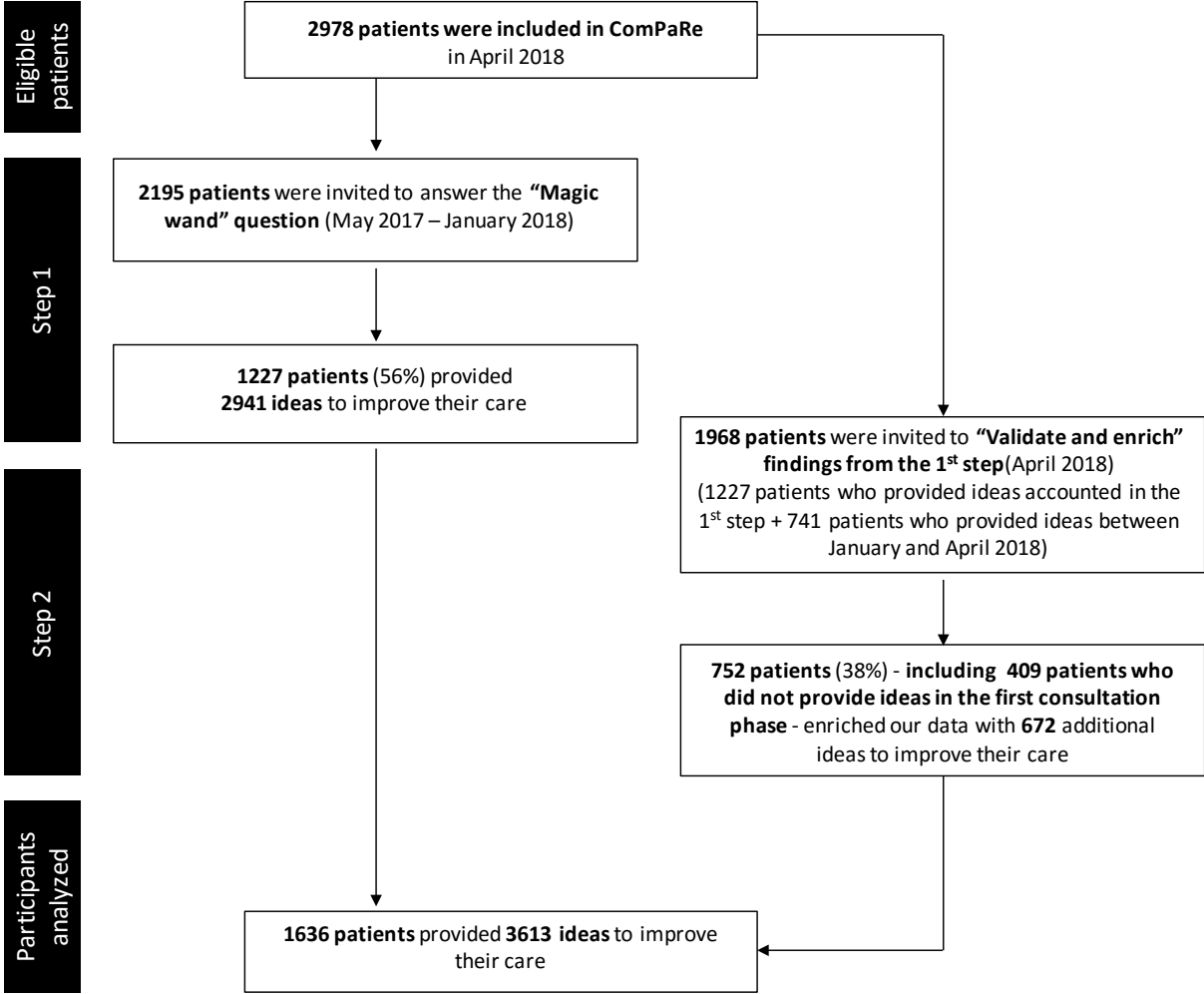


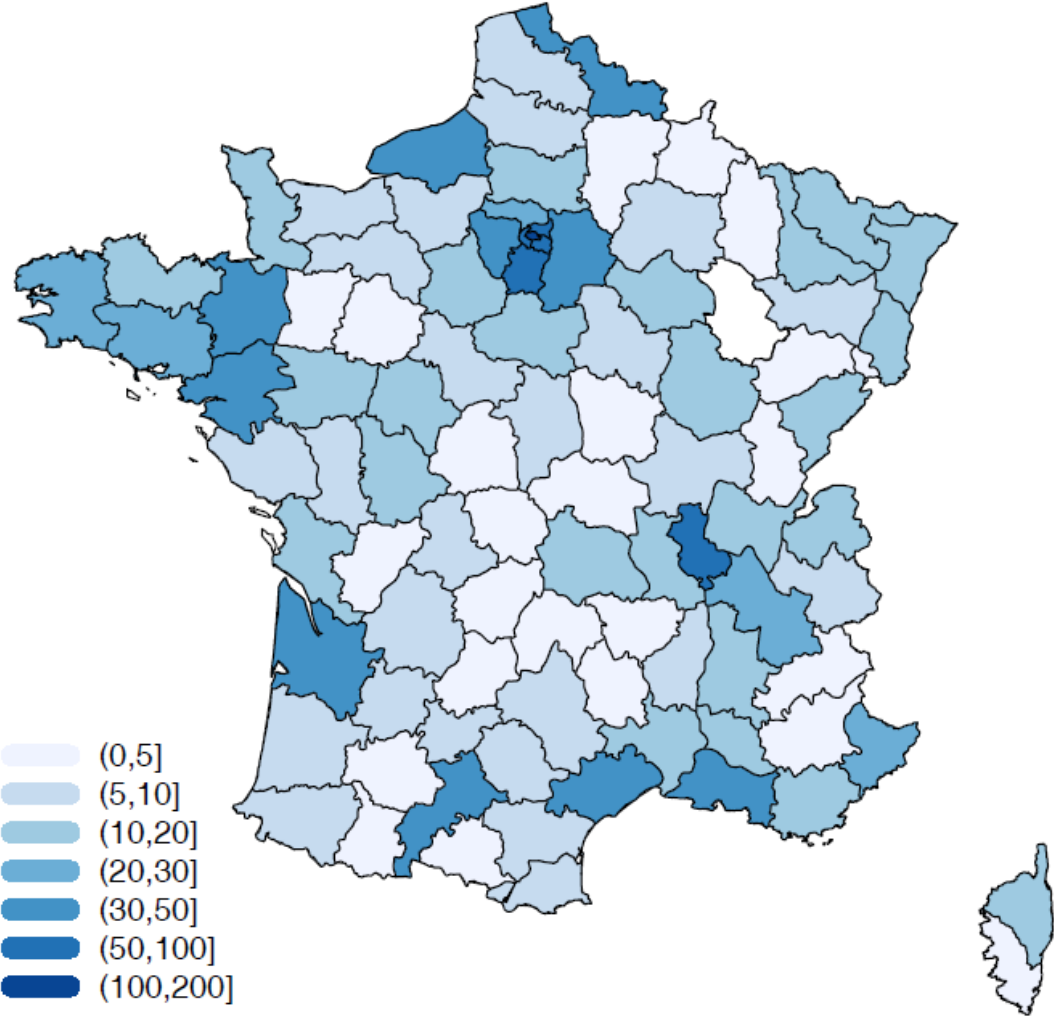
## List of Appendices

Appendix 1: Study flow chart .....	2
Appendix 2: Participants' place of residence .....	3
Appendix 3: Areas for improvement to change consultations. *Areas for improvement identified during step 2 (enrichment)	4
Appendix 4: Areas for improvement to change hospitals/clinics. *Areas for improvement identified during step 2 (enrichment) .....	7
Appendix 5: Areas for improvement change the health system. *Areas for improvement identified during step 2 (enrichment) .....	9
Appendix 6: Cumulative theme accumulative curve. ....	11

# Appendix 1: Study flow chart



**Appendix 2: Participants' place of residence**



### Appendix 3: Areas for improvement to change consultations.

\*Areas for improvement identified during step 2 (enrichment)

Group	Areas for improvement	Number of ideas proposed by patients
<b>Adapt patients' treatment and home care</b>	Enable some drug holidays, if possible	4
	Propose drug/treatments that are easier to store	1
	Find treatment strategies that minimize adverse effects	61
	Allow flexibility in drug intakes	1
	Propose drug/treatments that are easier to use/take	27
	Propose drug/treatments that are easier to transport	12
	Reduce the number of drug intakes per day	5
	Reduce the number of medications per intake	59
	Change in the treatment shape, taste, size	33
	Emphasize the use of alternative medicines, if possible	67
	Emphasize the use of non pharmacological treatments, if possible	54
	Soften dietary hygiene rules	8
<b>Avoid unnecessary procedures/tasks</b>	Avoid low-value exams and tests	16
	Avoid low-value treatments*	10
	Enrich existing health records with more information	8
	Do not re-ask an already available information or test	1
	Simplify self-monitoring at home	20
<b>Create the context for real discussions with patients</b>	Improve how some conditions are acknowledged by health professionals	45
	Be more proactive in meeting patients needs	26
	Avoid stereotyping people	16
	Avoid giving patients false hopes	9
	Avoid a defeatist and fatalistic attitude	8
	Avoid judgemental or paternalistic attitudes	54

	Be careful of words used with patients	50
	Learn humility	16
	Listening, openness and sharing from care professionals	191
	Benevolence and empathy from care professionals	66
	Trust patients' expertise in their diseases	27
	Do not look down on patients	86
	Use validated patient-reported outcomes to support patients' words	4
	Encourage dialogue between care professionals and patient associations	3
<b>Improve patients' autonomy</b>	Teach patients methods to avoid forgetting medications	5
	Improve patients' capacity for self-management	8
<b>Improve patients' care pathway</b>	Know when to “pass the baton” (refer to another physician)	26
	Improve continuity of care (moving away, changing hospitals)	8
	Improve diagnostic processes	62
	Improve patients' follow-up after acute events or disease remission	13
	Regular check-ups for patients with complex conditions	5
<b>Improve the support of chronic patients</b>	Involve family and entourage in care	9
	Facilitate access to psychological care/support for patients with chronic conditions	60
	Train care providers to act like coaches for patients	15
	Introduce patients to patient associations	10
<b>Personalize care and care goals</b>	Identify common goals with patients	41
	Involve patients in care decisions	32
	Provide personalized care rather than standardized “one size fits all” care	33
	Take into account patients' contexts	15
<b>Develop prevention</b>	Improve primary prevention for chronic conditions	11
	Prevent exacerbations rather than wait for them (secondary prevention)	5
<b>Provide a holistic care</b>	Avoid “siloed” care (care focused on single organs)	42
	Care for the person in addition to the organs	52
	Avoid neglecting some medical problems or symptoms	25

	Improve pain management	67
	Account for the interactions between different conditions and treatments*	1
<b>Provide patients with the best information adapted to them</b>	Provide patients with written information on their conditions	7
	Provide patients with adequate information on their conditions at adequate times	121
	Help patients understand/learn the medical language	8
	Provide patients with information on research advances	11
	Spend more time to explain things to patients	21

#### Appendix 4: Areas for improvement to change hospitals/clinics.

\*Areas for improvement identified during step 2 (enrichment)

Group	Areas for improvement	Number of ideas proposed by patients
<b>Improve coordination and collaboration in care</b>	Care should not rely on poorly supervised residents	7
	Implement tele-expertise	9
	Account for all care providers' opinion independently from their disciplines or hierarchy	5
	Collective intelligence from the care team	40
	Enable multidisciplinary care	48
	Improve the coordination between care professionals	99
	Avoid contradictions in the care team	17
	Improve the sharing of health records and information between care professionals	39
	Identify a care conductor to lead the care team"	36
<b>Improve structures and equipment</b>	Improve the architecture and design of care facilities	3
	Improve the technical equipment of care facilities	18
	Improve privacy in care structures	5
<b>Improve the interaction between patients and the care team</b>	Create a listener line for patients"	8
	Develop systems for patient–physician communication outside of consultations	41
	Identify a point of contact person for exchanges between patients and the care team	17
<b>Improve the number and attitude of non-medical personnel</b>	Increase the number of non-medical personals in hospitals/clinics	5
	Change the attitude of reception staff and non-care professionals	29
<b>Increase patients' knowledge of their own health</b>	Facilitate the understanding of test results (graphs, data visualization, etc.)	2
	Systematically provide patients with copies of medical reports and results	16
	Develop online training programs for patients*	3
	Create medically certified online information centers	6
	Meet expert patients	22
	Organize patient groups and activities	33

<b>Increase time and attention devoted to patients</b>	Propose longer consultations	33
	Diminish the burden on care providers	18
	Enable trained nurses to supplement more of the medical staff workload	1
<b>Smooth patients' journey in the care system</b>	Help patients find care professionals with human qualities	8
	Help patients find care professionals with experience in their conditions	69
	Reduce the delays to obtain appointments	70
	Propose to patients to move their appointments up when a cancellation occurs	2
	Simplify the process for appointments and tests	28
	Allow patients to choose the date and time of consultations/tests	9
	Access to specific emergency care if needed	26
	Group visits/tests on same days	31
	Group visits/tests in same places	19
	Create “one-stop shop” structures where patients can get all health visits and tests done	7
	Accelerate patients' referral to the right doctor	35
	Improve the flow of patients in the care structure (waiting times, administrative steps, etc.)	10
	Provide patients with an agenda for their future care activities	1
	Change consultation/test intervals	49
	Anticipate delays in consultations to better respect schedules	4



## Appendix 5: Areas for improvement change the health system.

\*Areas for improvement identified during step 2 (enrichment)

Group	Areas for improvement	Number of ideas proposed by patients
<b>Break health rules to smooth patients' journey in the care system</b>	Change sectorization rules for health structures	3
	Soften gate-keeping rules	5
	Simplify refilling processes	24
	Change the legal limit between two refills	33
<b>Transform rules related to medications</b>	Create generic drugs with same shape and color as branded drugs	2
	Homogenize the number of pills per drug box	10
	Re-approve some drugs withdrawn from the market	1
	Limit pharmacists' ability to replace prescription drugs	5
	Accelerate the approval for new treatments already available in other countries	26
	Use filled prescriptions instead of medication boxes*	10
	Develop systems to avoid medication shortages in pharmacies*	2
	Create re-usable medical devices (e.g., inhalers) to avoid waste*	2
<b>Decrease the administrative burden for patients</b>	Limit bureaucracy and soften administrative tasks	74
	Quicken administrative procedures	12
	Create “one-stop shop” structures to get state help	8
	Get human help for administrative tasks	16
	Administrative acknowledgment of some conditions	69
<b>Facilitate the access to adequate care</b>	Create a repertoire of care professionals specialized in specific diseases or treatments	15
	Enable home care	19
	Encourage the geographic dispersion of specialists (not only in major cities)	92
	Improve patients' ability for transportation and parking	20
	Home delivery for medications	4
	Anticipate the retirement of physicians*	4

	Develop online translation services, accessible for all caregivers and patients*	1
<b>Facilitate the access to home support</b>	Facilitate home fitting for patients	9
	Facilitate the access to home care (nurses)	1
	Facilitate home support (housework, grocery shopping, etc.)	31
	Help informal caregivers	7
<b>Improve treatment guidelines</b>	Involve patients in the elaboration of care guidelines	3
	Develop clear care protocols/guidelines for all conditions	8
<b>Transform the training of care professionals</b>	Train care professionals for better interpersonal skills	22
	Train care professionals for improved knowledge in specific conditions/treatments	97
	Ensure that adequate information on every disease is accessible to all care providers	9
	Develop nationwide registries of medical mistakes to avoid repeating errors*	1
<b>Make care more affordable</b>	Prevent doctors from exceeding their fees	7
	Reduce the amount of advances of expenses	9
	Lower the cost of care	13
	Reimburse transportation costs	5
	Increase the number of health interventions covered by the national health insurance	124
	Provide compensation for opportunity costs	8
<b>Promote the professional integration of sick people</b>	Facilitate access to work for sick people	2
	Adapt work conditions for sick people	28
	Adapt work schedules for patients	48
	Adapt work spaces for patients	4
	Help patients get professional retraining	8
<b>Reduce stigma</b>	Improve the general public view on conditions or treatments	60
	Provide patients with official documents to prove to people that they are ill	5
	Avoid discrimination for chronic patients (insurance, loans etc.)	18

**Appendix 6: Cumulative theme accumulative curve.**

Plain lines represent the themes (i.e. areas for improvements) actually identified in the study and dotted lines represent the potential number of themes that could have been identified with more participants.

