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Patients' perspective on how to improve the care of people with chronic conditions in France: a citizen science study within the ComPaRe e-cohort

Viet-Thi Tran,^{1,2} Carolina Riveros,² Clarisse Péan,³ Arnaud Czarnobroda,⁴ Philippe Ravaud^{1,2}

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¹METHODS Team, Centre de Recherche Epidémiologie et Statistique Sorbonne Paris Cité (CRESS UMR 1153), INSERM, Paris, France

²Centre d'Epidémiologie Clinique - Hôpital Hôtel-Dieu, Assistance Publique-Hôpitaux de Paris, Paris, France

³Montpellier, France

⁴Paris, France

Correspondence to

Dr Viet-Thi Tran, METHODS Team, Centre de Recherche Epidémiologie et Statistique Sorbonne Paris Cité (CRESS UMR 1153), INSERM, Paris 06100, France; thi.tran-viet@aphp.fr

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ABSTRACT

Background This study aimed to involve patients with chronic conditions in generating ideas for improving their care.

Methods We performed a citizen science study. Participants were adult patients with chronic conditions recruited in Community of Patients for Research 'ComPaRe,' a French e-cohort of patients with chronic conditions. Participants generated ideas to improve their care in answer to the open-ended question, 'If you had a magic wand, what would you change in your healthcare?' Three researchers and two patients independently extracted ideas from open-ended answers by using thematic analysis. Ideas were grouped into areas for improvement at the consultation, hospital/clinic and health system levels. Findings were validated and enriched by a second sample of participants recruited in ComPaRe.

Results Between May 2017 and April 2018, a total of 1636 patients provided 3613 ideas to improve consultations (1701 ideas related to 58 areas for improvement), hospitals/clinics (928 ideas related to 41 areas for improvement) and the health system (984 ideas related to 48 areas for improvement). At the consultation level, most ideas were related to improving physician-patient discussions, informing patients about their own care, and adapting treatment to patient preferences and context. At the hospital/clinic level, most ideas aimed at improving the coordination and collaboration in care. At the health system level, most ideas were related to decreasing the administrative burden imposed on patients, improving access to care and reducing the costs of care.

Conclusion Patients have many ideas to improve their care, from the content of consultations to the organisation of hospitals. Our study provides the proof of concept for a method to leverage patients' practical knowledge of the care system to improve it.

BACKGROUND

Chronic disease is a global epidemic.¹ In western countries, 40%–60% of adults have a chronic condition; 50%

of these adults have multiple conditions and are considered multimorbid.^{2 3} This epidemic of chronic conditions challenges disease-centric care models in both European and American settings.⁴ Despite recent improvements, the care for patients with chronic conditions, in France and in other western countries, remains fragmented and uncoordinated, with a risk of polypharmacy and harmful interactions.^{5 6} This situation generates an important burden of treatment for patients that can affect their lives as much—or more—than the diseases themselves.^{7 8} In addition, in France, the care for patients with chronic conditions is affected by the decreasing medical coverage of large parts of the French territory because of a cost containment-driven policy to limit the number of professionals trained in medical schools and the progressive closure of local care structures for the benefit of larger urban medical centres.⁹ As a result, health professionals are asked to do more in less time and patients are hurried along in their consultations.^{10–12} Worse, initiatives to improve healthcare may have paradoxically contributed to the emergence of myriad norms, standardised protocols and pay-for-performance regulations, which hinder the importance of human relationships in care and contribute to a feeling of cumulative bureaucracy.^{13–15}

Transforming healthcare is difficult because all parts of the system are intricate and influenced by political, economic and cultural factors and are constrained by value conflicts and resistance to change.^{16 17} In 2013, an international

movement called the ‘Patient Revolution’ was formed to enlist patients, who live and experience the health-care system every day, to help in designing care services better suited to them.¹⁸ The Patient Revolution mirrors initiatives launched in other fields that rely on citizen science methods and the collective intelligence of large groups of people to tackle complex problems. For example, the project Collective Intelligence for Public Transport in European Cities gathered ideas provided by 500 citizens to invent cleaner and better transport in cities¹⁹ and the Climate CoLab gathered propositions to tackle climate change from more than 90 000 people all over the world, over 7 years.²⁰

In care improvement, despite multiple studies on patient-reported experiences, expectations and satisfaction in care,^{21–27} only a few studies have involved patients in identifying which components of the care system needed to be improved and how, and these studies often addressed specific issues, in given conditions or contexts.^{28 29} In the present study, we aimed to engage patients with chronic conditions, on a large scale, to identify which components of their care require improvement and to generate ideas to do so.

METHODS

We performed a citizen science study with two steps. In the first step, patients with chronic conditions provided ideas on aspects of their care they wanted changed by using an online questionnaire with a broad open-ended question. Then, in a second step, another sample of participants reflected on and enriched the ideas identified.

Setting and participants

This study was nested within the Community of Patients for Research (ComPaRe), an ongoing citizen science project based on an e-cohort of patients with chronic conditions (www.compare.php.fr). Participants are adults (>18 years old) who report having at least one chronic condition (defined as a condition requiring healthcare for at least 6 months). ComPaRe involves mostly patients in France, although some participants may be from French-speaking countries (Belgium, Switzerland, and so on). Patients join the project to donate time to accelerate research on their conditions. They can do this by answering regular patient-reported outcomes and patient-reported experience instruments, suggesting ideas for new research or participating in the set-up or analysis of research projects. The recruitment started in January 2017 and is still ongoing, with about 18 000 patients included in November 2018. All participants provide electronic consent before participating in the e-cohort.

First step: the ‘magic wand’ question

In a first step, we analysed, in January 2018, data from a specific online questionnaire inviting patients to suggest ideas to improve their healthcare. The

questionnaire was sent to all participants enrolled in ComPaRe (ie, adults with at least one chronic condition) starting from 9 May 2017. A single open-ended question was used to capture patients’ ideas to improve their care: ‘If you had a magic wand, what would you change in your healthcare?’ This open-ended question was inspired by (1) the ‘Miracle’ question used in solution-focused therapy to encourage participants to focus on possibilities rather than problems,²⁹ and (2) a previous work aimed at identifying the propositions of patients with HIV to reduce their burden of treatment in sub-Saharan Africa.³⁰ The magic wand question was pilot-tested by six patients from ComPaRe to ensure its clarity. Because testing took place before the development of the questionnaire, answers during the pilot phase were not merged with research data.

Open-ended answers were analysed by using thematic analysis with multiple rounds of analysis. In a first step, two investigators (VTT and CR) read the first 180 responses and independently identified ‘ideas’: literal sentences used by participants to describe their ideas to improve healthcare. Coding was limited to explicit statements of potential modifications in healthcare. For example, changes related to patients’ conditions or symptoms (eg, ‘If I had a magic wand, I would like to cough less’) or wishes for more research (eg, ‘I would like more research on my condition so that new effective treatments could be developed’) were dropped from the analysis. Patients’ statements of barriers and burdens in healthcare were extrapolated into wishes for improved care (‘There are too many visits’ was coded as ‘I wish there were fewer visits’). During regular meetings, the two investigators reached consensus on the ideas identified and grouped them into ‘areas for improvement’ according to the context, people and processes involved to implement these ideas. In a second step, this initial set of areas for improvement was used to classify the remaining responses. Each participant’s response was read by the two investigators, who independently assigned data segments to each area for improvement. During frequent meetings, the investigators compared their analyses and reached consensus on coding. This second phase involved more than simply sorting data segments: whenever new ideas emerged, researchers discussed these ideas and refined and enriched the list of areas for improvement.

Second step: enrichment of findings by patients

In April 2018, in a second step, we asked all patients who had answered the ‘magic wand’ question to reflect on and enrich the list of areas for improvement identified in the first step. We invited both people who had participated in the first step (n=1227) and people who had not because they enrolled in ComPaRe after January 2018 (n=741). We invited these participants to answer a second web questionnaire presenting all areas for improvement identified so that they could (1)

Table 1 Characteristics of participants (n=1636)

Characteristic	Value
Age, mean (SD)	49 (14.4)
Female sex, n (%)	1210 (74)
Education level, n (%)	
Low	190 (11.6)
High school	245 (15.0)
Associate's degree	351 (21.4)
Higher education	756 (46.2)
Undisclosed	94 (5.7)
Chronic conditions, n (%)	
1	802 (49.0)
2	334 (20.4)
3	195 (11.9)
>4	305 (18.6)
Time since first chronic condition diagnosis (years), mean (SD)	17.1 (14.3)
Conditions*	
Asthma	105 (6.4)
Chronic obstructive pulmonary disease	33 (2.0)
Other respiratory diseases and Ear Nose Throat (ENT) diseases	138 (8.4)
Diabetes	146 (8.9)
Thyroid disorders	176 (10.8)
High blood pressure	180 (11.0)
Dyslipidaemia	76 (4.6)
Other cardiac or vascular diseases	134 (8.2)
Chronic kidney diseases	92 (5.6)
Rheumatological conditions	488 (29.8)
Systemic conditions	145 (8.9)
Digestive conditions	214 (13.1)
Neurological conditions	331 (20.2)
Cancer (including blood cancer)	133 (8.1)
Endometriosis	108 (6.6)
Dermatological conditions	385 (23.5)
Depression	110 (6.7)

*Total exceeds 100% because patients have multiple chronic conditions.

assess whether they agreed with the list and (2) suggest new ideas that could have come up when reviewing the list. Indeed, reflecting on others' inputs may enhance creativity and improve the quality of answers.^{31 32} To ensure that all three levels (consultation, hospital/clinic and health system) would receive similar attention by participants, these levels were presented in a random order to participants.

Open-ended data collected during this second step were analysed by two investigators (VTT and CR) using the same methodology as during the first step. Investigators extracted all novel patients' ideas to improve their care and during meetings decided how these ideas could be classified under existing areas for improvement or could define new areas for improvement.

Then, another investigator (PR) and two patients (AC and CP) triangulated all findings from both the first and second steps of the study. During recorded

meetings with the main investigator (VTT), they went back to the raw data and independently recoded participants' answers (the whole corpus was recoded by PR and 10% of the corpus was recoded by the two patients) to challenge both the list of areas for improvement and how ideas had been classified. Finally, all investigators reached consensus on the classification of all patients' ideas in areas of improvement.

Assessment of the point of data saturation

The objective of our study was to identify and list ideas for improvement in the care of patients with chronic conditions, from patients' perspective. To ascertain that we achieved an exhaustive description of these ideas, we assessed whether data saturation had been reached. Data saturation represents the point in data collection and analysis when new information produces little or no change to the codebook, the codebook representing the collection of codes that link expressions found in text to all abstract constructs identified by the researchers.³³ To determine the point of data saturation, we used a mathematical model to predict the potential number of new ideas that could be identified by adding new participants in the study.³⁴

This model involved (1) drawing the 'observed' theme accumulation curve (eg, number of different areas for improvement identified during the course of the study); (2) predicting the theoretical number of areas for improvement that could be found with the inclusion of more patients; and (3) estimating the local slope of the expected theme accumulation curve (ie, the number of patients to be included to identify a new theme). Thus, the model did not inform on the nature ('quality') of themes identified but rather on the probability to find new themes by recruiting new participants. We examined the number of additional areas of improvement that could have been found by including more participants globally and in different subgroups defined by sex, age (≤ 50 and > 50 years old), multimorbidity and educational level (college vs lower education). Analyses involved use of R V.3.3 (<http://www.R-project.org>, the R Foundation for Statistical Computing, Vienna, Austria).

Patient and public involvement

Two patients (CP, AC) who expressed interest in contributing 'more' than just answering questionnaires independently recoded 10% of all answers and contributed to the elaboration of the list of areas for improvement resulting from participants' answers. They were also invited to be authors of the manuscript and critically revised it before submission.

RESULTS

In the first step of the study, 1227 participants provided ideas to improve their care (2195 patients had been invited to answer the 'magic wand' question; response rate: 56%). In the second step, 752

participants, of whom 409 (54%) had not previously proposed ideas, reflected on the findings from the first step and suggested at least one new idea to improve their care (1968 patients were invited in the second step; response rate: 38%). As a result, 1636 patients (1210 (74%) female) proposed ideas to improve their care (online supplementary appendix 1). The mean age was 49 years (SD=14.4). Participants living in France (n=1600, 98%) were geographically dispersed among large cities, smaller cities and rural areas (online supplementary appendix 2). About 50% of our participants had multimorbidity (mean number of conditions 2.4 (SD=2.3)). Patients' conditions included diabetes (n=146), asthma (n=105), rheumatological conditions (n=488), neurological disorders (n=331) and

cancer (n=133). Patients' characteristics are detailed in table 1.

During the first step of the study, we gathered 2941 patients' ideas (51 140 words), grouped into 138 areas for improvement. In the second step, patients' feedback on ideas previously discovered resulted in the identification of 672 new ideas (27 729 words) and nine additional areas for improvement. Therefore, patients proposed a total of 3613 ideas during the study. These ideas covered 147 areas for improvement: 58 (39.5 %), 41 (27.8 %) and 48 (32.6 %) at consultation, hospital/clinic and health system levels, respectively (online supplementary appendices 3, 4 and 5).

According to the mathematical model to predict data saturation, more than 99% of the potential

Table 2 Examples of patients' ideas to change consultations (1701 ideas)*

Area for improvement	Example of ideas
Create the context for real discussions with patients (n=601)	Kind and humanistic care <i>'Learn to announce a diagnosis. Learn to listen. Learn how to enter in a hospital room (...) Learn how to introduce yourself when you're an intern and leave your ego aside. Stop telling patients 'the doctor (or intern) will come to see you this morning' (...) In short, I would like not to have the impression to be at the orders of very busy people who hardly spend more than 30 s in my room without explaining anything...'</i> (Female with multiple sclerosis)
Provide a holistic care (n=187)	Care for the person in addition to his/her organs <i>'[I would like] That obstetrician gynecologists (...) finally listen to their patients... [I would like] care that is no longer only chemical, surgical or medical, but also human, psychological and dietary (endocrine disrupters)...'</i> (Female with endometriosis)
Personalise care and care goals (n=121)	Provide personalised care rather than standardised 'one size fits all' care <i>'Practitioners should behave like researchers, instead of simply following recipes they know about specific situations.'</i> (Male with COPD)
Improve patients' care pathway (n=114)	Know when to pass the baton <i>'... [My physician] should learn not to hesitate, for one second, before consulting a colleague's opinion.'</i> (Male, 66 years old with osteoarthritis) Improve patients' follow-up after acute events or disease remission <i>'Do not neglect the support (explanations on treatments, potential events or who to contact...) for patients who leave the hospital so that they do not suddenly find themselves alone whilst being very surrounded and cared for in the hospital.'</i> (Female with thyroid cancer)
Adapt patients' treatment and home care (n=332)	Emphasise the use of non-pharmacological treatments, if possible <i>'I would have preferred to be followed-up by a physiotherapist from the beginning and benefit from physical therapy rather than to be force-fed with drugs which only had a brief effect (...) and to which I became dependent.'</i> (Female patient with diabetes and ankylosing spondylitis) Allow flexibility in drug intakes <i>'I would like to take my medicines at the time of my choice.'</i> (Male with HIV infection)
Avoid unnecessary procedures/tasks (n=55)	Avoid low-value exams and tests <i>'Actually use all results from ordered tests. We sometimes have the impression that tests are performed because 'it's the protocol,' but that decisions are taken without knowing test results.'</i> (Female with Hashimoto's thyroiditis)
Develop prevention (n=16)	Improve prevention for chronic conditions <i>'If I had a magic wand my first wish would be that health professionals do not wait flares to act.'</i> (Male with high blood pressure and a myeloma)
Improve patients' autonomy (n=13)	Improve patients' capacity for self-management <i>'Give me the possibility to carry a more appropriate treatment in the event of an acute adrenal insufficiency where vomiting prevents me from taking my hydrocortisone. This treatment would be available at any time as a pen filled with an injectable product, ready to use, similar to the treatment for diabetic patients.'</i> (Female with adrenal insufficiency)
Improve the support of patients with chronic condition (n=94)	Involve family and entourage in care <i>'Patients' entourage should also be more involved. Thus, all changes generated by the pathology and/or the treatment that goes with it are better understood. This would avoid unnecessary conflicting reactions.'</i> (Female with high blood pressure and asthma)
Provide patients with the best information adapted to them (n=168)	Provide patients written information on their conditions <i>'I would have liked to know immediately everything about vitiligo. How it works, what elements of the body are defective, how to explain it. I would also have liked that someone told me about all existing solutions right away. In fact a notebook or a leaflet explaining all this (...) would have allowed me to have all this information without having to look for them on the unreliable websites.'</i> (Female with vitiligo)

*All texts were translated from French to English.
COPD, chronic obstructive pulmonary disease.

Table 3 Examples of patients' ideas to change hospitals/clinics (928 ideas)*

Area for improvement	Example of ideas
Smooth patients' journey in the care system (n=368)	<p>Simplify appointment scheduling processes <i>'Physicians' agendas should account that some follow-ups are annual. You shouldn't need to call to make an appointment (6 months before!). It's a bit of a headache because you must not forget it 6 months before.'</i> (Female with diabetes)</p> <p>Group consultations and exams in same places at same times <i>'Group consultations in the same place where all specialists could discuss with each other and compare their views and diagnoses instead of criticizing and belittling those of their colleagues.'</i> (Female with diabetes and obesity)</p>
Improve coordination and collaboration in care (n=300)	<p>Improve the coordination between care professionals <i>'It would be a big step if all actors involved in healthcare could talk to each other! Currently doctors no longer communicate with each other—except in exceptional cases—. Rather, the patient must act as a messenger. As a result, when doctors do not agree with each other, the patient finds himself caught in the middle...'</i> (Female with chronic fatigue syndrome)</p> <p>Avoid contradictions in the care team <i>'I was prescribed some exams to do in ophthalmology by the internal medicine specialist. So I took an appointment with the ophthalmologist and waited for 6 months. All that to have him telling me that the exam in question is useless and to get a prescription for artificial tears... When I get to see my internal medicine specialist 6 months later, I get lectured because I didn't get the right exam!!!'</i> (Female with multiple sclerosis)</p>
Improve the interaction between patients and the care team (n=66)	<p>Identify a point-of-contact person for exchanges between patients and the care team <i>'The 'height of cool' would be to have an identified contact person (a nurse for example) who could be contacted at any time to answer our questions without waiting the 6 months before the next doctor visit! For example, we could contact her by e-mail and either the nurse can answer, or she asks the practitioner who gives an opinion. I'm not talking about remote consultation but more about advices on a drug and its adverse effects for example...'</i> (Female with Gougerot-Sjögren disease)</p> <p>Develop systems for patient–physician communication outside of consultations <i>'To be able to communicate by e-mail with doctors rather than having to go through an overloaded receptionist who transmits the information 1 out of 2 times in each direction.'</i> (Male with depression and peripheral neuropathy)</p>
Increase patients' knowledge of their own health (n=82)	<p>Help patients to benefit from the experience from others <i>'If I had a magic wand, I'd like to see more patients groups with physicians. They could exchange on their chronic diseases, dramatize them and 'tame' them. Older patients could help those who have just discovered their chronic disease. Doctors could present new studies and how patients are managed in other countries. This could help answering the distressing questions of new chronic patients.'</i> (Female with Hashimoto's thyroiditis)</p> <p>Facilitate the understanding of test results <i>'I would like to see (through a graph?) the influence of my treatment on my cholesterol dosage. Thus, I can see what efforts pay and optimize my treatment.'</i> (Female with a history of myocardial infarction)</p>
Increase time and attention devoted to patients (n=52)	<p>Propose longer consultations <i>'Have REAL appointments. That mean at least 20 min—and not 5—to be able to ask questions about the evolution of my disease and the different therapeutic approaches.'</i> (Female with asthma and low back pain)</p>
Improve the number and attitude of non-medical personnel (n=34)	<p>Improve the attitude of non-medical personnel <i>'During tests and exams, operators should not forget that we are sick, anxious and that, although these examinations are essential, it is preferable to have a kind and benevolent attitude. We are not responsible for technical problems with equipment or difficulties between departments. We did not choose to be sick!'</i> (Female with breast cancer)</p>
Improve structures and equipment (n=26)	<p>Improve the architecture and design of care facilities <i>'Improve signs and directions in hospitals. Last week on the way to an effort testing, I found myself in front of the morgue... and then in the Emergency Room... I spent 15 min, lost, and running in circles in the basement!!!!'</i> (Female with lupus and depression)</p>

*All texts were translated from French to English.

common care goals (n=41) and major care decisions (n=32).

It is not acceptable to endure life-changing decisions without having at least a slight control on some aspects. Treating a disease is good, but if it means that patients will have no control over their lives, it's not. Some decisions used to cure a patient can destroy him if he's not the person who made it. Doctors should enlighten the patient but not decide for him. (Female with breast cancer)

Patients' ideas to change hospitals/clinics

A total of 506 participants proposed at least one idea to change hospitals/clinics, for a total of 928 ideas. Examples of patients' ideas to change hospitals/clinics are in table 3, figure 2 and online supplementary appendix 4. Examples of areas for improvement

identified were to develop tools and processes to smooth the journey of patients with chronic conditions within the care system (n=368) and to improve the coordination and collaboration between the different actors involved (n=300). For example, patients suggested simplifying patients' burden for managing appointments (n=135).

Systematically schedule the next appointment at the end of the consultation. Do not wait for the patient to make the appointment himself from his home. (Female with diabetes)

Another idea to improve care coordination was to define, for each patient, an identifiable and accessible member of the care team they could rely on as their entry point in the care system (n=36).

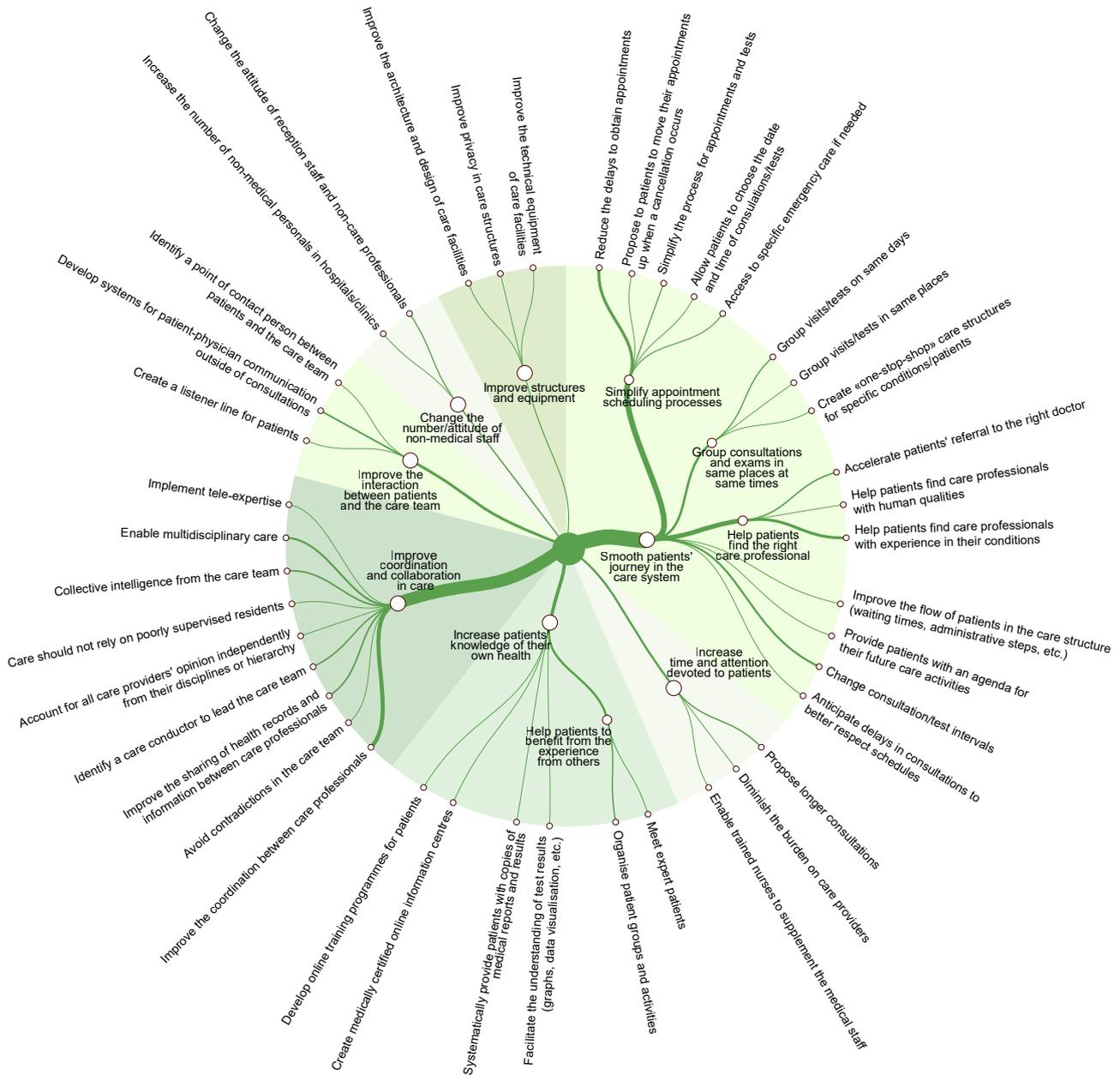


Figure 2 Areas for improvement at the hospital/clinic level. Line thickness represents the number of participants who elicited the idea.

I would create some sort of ‘care conductor’ who would assess the patient’s needs and guide him [in the system] as well as possible. This would alleviate a lot of hardships to a patient already frail due to his disease. (Female with multiple sclerosis)

Patients’ ideas to change the health system

A total of 604 participants proposed at least one idea to change the health system, for a total of 984 ideas. Examples of patients’ ideas to change the health system are shown in table 4, figure 3 and online supplementary appendix 5. According to patients, the main areas of health systems that should be transformed were to decrease the administrative burden imposed on patients with chronic conditions (n=179), improve

access to care (n=155) and reduce the costs of care (n=166).

Create a one-stop-shop for administrative tasks. These places would propose and explain patients how to obtain ALL possible state help for which they would be eligible: CAF [family allowance], help for housing or to adapt the patient’s home (adapt kitchens or bathrooms etc.), recognition of disability etc. It would allow patients to avoid going to multiple places, filling in multiple files and missing help that they ignore. (Female with rheumatoid arthritis)

In line with their demands to change caregivers’ attitudes, patients proposed ideas to transform caregivers’ training (n=128). As an example, a patient suggested

Table 4 Examples of patients' ideas to change the health system (984 ideas)*

Area for improvement	Example of ideas
Break health rules to smooth patients' journey in the care system (n=65)	Change the legal limit between two refills <i>'Going on vacation for more than a month can sometimes become a challenge. Pharmacies will refuse to fill prescriptions in advance. Storing even a little amount of medicine is perceived in a very pejorative way. However, it's these things that give patients independence. You have tap water in your house; not a delivery guy who brings you exactly 1.5 L per day, regardless if it's hot or cold.'</i> (Male with diabetes)
Transform rules related to medications (n=58)	Homogenise the number of pills per drug box <i>'Why do some medication boxes contain 28 pills when months are 30 or 31 days long? We regularly find ourselves negotiating an additional box with the pharmacist. This puts the patient in an uncomfortable position.'</i> (Female with depression and endometriosis)
Decrease the administrative burden for patients (n=179)	Simplify administrative tasks <i>'I wish I had access to thermal care. I know it's possible. But there are so many procedures... And you have to ask the doctor who sometimes laughs at the request, finds it secondary or refuses it. Because of the fear of rejection and the time and energy it would take, I systematically abandon the idea.'</i> (Female with ankylosing spondylitis)
Facilitate the access to adequate care (n=155)	Create a repertoire of care professionals specialised in specific diseases <i>'Create repertoires of physicians and specialized caregivers who are used to the disease, especially in remote areas far from major care centers.'</i> (Female with Marfan syndrome and endometriosis)
Facilitate the access to home support (n=48)	Facilitate home support (housework, grocery shopping, and so on) <i>'I would not forget to ask the patient his financial and family situation so as to set up home support for those with little income. The illness treated should not be worsened by miserable living conditions.'</i> (Female with psoriatic arthritis and Hashimoto's thyroiditis)
Make care more affordable (n=166)	Increase the number of health interventions covered by the national health insurance <i>'The cost of psychiatric care. I cannot access most of interventions and protocols that would allow me to improve my quality of life because of they are not reimbursed.'</i> (Male with HIV infection, a bipolar disorder and a personality disorder)
Promote the professional integration of sick people (n=90)	Adapt work conditions for sick people <i>'Increased recognition of the impact of the illness on patients' ability to work. Adaptation of workplaces with for example: more isolated offices to facilitate concentration; remote work; reduction of working time; additional salary from social security.'</i> (Female with Hashimoto's thyroiditis)
Transform the training of care professionals (n=129)	Train care professionals for better interpersonal skills <i>'I will provide medical students training in psychology and human relationships. A patient is not just an analysis report!'</i> (Female with chronic fatigue syndrome)
Improve treatment guidelines (n=11)	Involve patients in the elaboration of care guidelines <i>'Clinical practice guidelines elaborated by a group not composed at 90% by surgeons. Guidelines should take into account studies and research that include testimonials by patients who experienced the different treatments.'</i> (Female with endometriosis)
Reduce stigma (n=83)	Improve the general public view on conditions or treatments <i>'Communication about a patient's 'real' daily life instead of American TV shows and movies which depict schizophrenic patients as dangerous psychopaths.'</i> (Male with schizophrenia)

*All texts were translated from French to English.

that all people interacting with patients should be 'put in patients' shoes' to improve their interpersonal skills.

Train professionals to talk correctly to patients and to show empathy. (...) Teach them to listen to patients without systematically questioning their words. Personnel from MDPH [Departmental Structures for people with disability], CAF [Structures for family allowances] and the National Health Insurance system should live one week or more of the life of a sick, diminished or disabled person. This should be a mandatory internship 'Live my Life.' (Female with breast cancer and multiple sclerosis)

DISCUSSION

Statement of principal findings

In this large citizen science study, we engaged 1636 participants in generating and reflecting on ideas to improve their care. This led to the identification of 3613 ideas from patients to improve 147 areas of care

at consultation, hospital/clinic and health system levels. To our knowledge, this is the first study to provide a comprehensive and patient-defined list of areas of improvement in our care system and practical ideas to enact these changes. Patients' 'ideal' care was not very different from the models advocated in the medical literature.³⁵ Care for patients with chronic condition should be effective but minimally disruptive.³⁶ Professionals should work as teams and coordinate their efforts.³⁷ Care should be patient centred and have a holistic approach rather than be disease focused and fragmented.^{4 38-40} Low-value exams and treatments should be avoided.⁴¹ Our collective intelligence study generated practical ideas to get closer to this ideal.

Strengths and weaknesses of the study

This study has several strengths. First, we used an innovative data collection method involving both an initial consultation and an enrichment step. Besides



Figure 3 Areas for improvement at the health system level. Line thickness represents the number of participants who elicited the idea.

significantly augmenting our data, this collective intelligence approach reinforced patients' participation in research: patients were informed about the progress of the analysis and were involved in its finalisation.³¹ Second, the impact of investigators' preconceptions on the analysis was reduced by (1) the independent analysis of data by multiple researchers, each supplementing and/or contesting others' statements, and (2) the triangulation of our findings by patients themselves.⁴² Finally, our study included a large sample of participants with diverse diseases, education level and place of residence. This diverse sample enabled the collection of a comprehensive list of areas for improvement and an abundant number of patients' ideas.

This study has several limitations. First, because we used open-ended questions, the number of times an idea appeared in our data depended on its elicitation. Frequently elicited ideas are not necessarily those most 'desired' by participants but those that were the most evident to them. However, this problem may have been mitigated by our two-step method in that participants were able to react to and reflect on others' ideas. Second, we made the methodological choice to use online surveys with open-ended questions as an alternative to face-to-face data collection methods such as interviews or focus groups in order to gather ideas from a larger and more diverse population. Using an online questionnaire prevented any adaptation to

participants' responses and in-depth probing for more specific information. This choice was a deliberate trade-off between richer answers and more diverse participants, in line with our objective to identify a large amount of different ideas on how to improve the care for patients with chronic conditions. Similarly, the classification of ideas in areas of improvement was driven by their similarity in the contexts, people and processes involved to implement them. Other analysis frameworks could have yielded different results, focused on different aspects of the data. Third, our population is not representative of the general population of patients with chronic conditions. Similar to other online studies, our results reflect a large proportion of younger and more educated women.^{43 44} Regardless, we were able to include a large number of older and less educated patients. In the same way, the use of an online questionnaire may have favoured the participation of patients with striking experiences, with a message to convey, or those who were more invested in their care. Finally, the transferability of our findings is cautioned. Most (98%) of our participants lived in France. Thus, the pitfalls of the system and ideas for improvement were closely tied to the specificities of the French healthcare model (eg, universal health coverage, institutional polycentrism).⁴⁵ As an example, most patients in France benefit from free-of-charge care for their chronic conditions; hence, our participants desired simpler administrative tasks to obtain reimbursement for health expenditures (n=142, 9%) rather than asking for lower health expenses (n=27, 2%).

Comparison with other studies

The literature on satisfaction/experience of care of patients with chronic condition is very rich.^{24 46 47} Our study complements it by asking a conceptually different question: 'What if our care was designed by patients?' Indeed, only a handful of studies involved patients in pointing out precise areas of care that should be transformed and how, and the studies were often limited to specific settings or topics.^{22 48} For example, a recent initiative involved patients, families and professionals in the USA in finding 'health rules' that should be broken for a better experience of patients or staff.²⁷ Obviously, patients' answers were driven by their experience and may overlap with problems already identified. However, our approach also led to the identification of proposals that have, to our knowledge, not been explored before.

In addition, ours is the first study to systematically gather, on a large scale, patients' ideas to improve the healthcare system. Our results are not limited to a single topic, type of change or context; rather, they outline the major care paradigms that should be addressed to improve care, independent of patients' conditions or management place. In that sense, our findings have more in common with patients' feedback on medical

practices that are systematically collected by health organisations or institutions via discharge surveys, patients' feedback on online platforms or complaint procedures.^{49–51} Unfortunately, this routinely collected feedback is often underused by health organisations that collect them and thus only rarely lead to quality improvement.^{49 52}

Implications for clinicians and policymakers

The sharp contrast between the number of patient feedback procedures in health organisations and the reality of care, as experienced by patients, leads us to question the impact of these procedures. Evidence shows, for example, that most physicians mistrust results from patient feedback surveys and question their design, the framing of questions and the fact that they collect numerical data that do not account for the answer's context.⁵³ As stated by Coulter, '*Stories trump data.*'⁵⁴ Stories are more powerful than numerical feedback for capturing the interest of staff and changing minds.^{49 55} Our work aims at embodying a collection of such stories focused on '*informing, infecting, irritating, and igniting a chain reaction that makes the status quo unsustainable (...)* in a push for healthcare that is careful and kind to each patient and community.'⁵⁶ Our work is also an original repertoire of ideas that can be used by researchers, translated into patient-relevant interventions or organisational changes and evaluated in rigorous research.

Beyond our findings, this study is the proof of concept of a method to leverage the untapped resource of patients' knowledge and experience to improve care. This process may be replicated locally, in departments or hospitals, as a new way to generate patients' feedback for identifying bottlenecks in the system and ideas to improve it. It may also be implemented on a larger scale to guide healthcare policies, although new tools to analyse larger and ever-growing amounts of qualitative data will be required. Although our results were at the small scale, they have already been taken into account by the French government in its consultations in preparation for elaborating the national strategy to transform the healthcare system.⁵⁷ Future steps may involve exploring how patients' ideas identified in this study would be prioritised or valued by different groups.

Finally, our results must remind those who work every day with patients—whether at patient reception or in the doctor's office—that top-down strategies (eg, policies, regulations, rules and restructuring) are not the only proponents to improve the quality of care. Professionals should not wait for their institutions or organisations to act. By simply engaging in discussions with patients, they and their patients can already identify key areas of their work that they can

improve and move things by themselves—the first steps to a Patient Revolution.

CONCLUSION

In this study, we engaged patients with chronic conditions, on a large scale, to identify which components of the care system require improvement and to generate ideas to do so. Patients proposed many ideas to improve their care, from the content of consultations to the organisation of hospitals. Our study provides the proof of concept for a method to leverage patients' practical knowledge of the care system to improve it.

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