



<i>Title:</i>	Patient Innovation (PI) activities in China: a combination of semi-quantitative and multi-case study approach
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<i>Author:</i>	Shuyue Zhang 154017037
<i>Thesis Supervisor:</i>	Prof. Pedro Oliveira and Prof. Helena Canhão
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Patient Innovation (PI) activities in China: a combination of semi-quantitative and multi-case study approach

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Abstract

User innovation has been extensively and increasingly involved in the health sector in recent years. As a typical performance, patients and caregivers develop innovative solutions beyond professional medical treatment, aiming to better respond to the diseases. In addition, some of those innovations are shared with other patients in need, through non-commercial and commercial approaches. In practice, PI (www.patient-innovation.com) platform was established in 2014 in Portugal, on which 850 innovations from patients, caregivers and collaborators are shared, fulfilling the mission of adding value to other people's lives.

With the huge population base, there has been great diversity and significant regional differences in living, health and medical conditions among Chinese nations. Taken also the limited Reimbursement ratio of medical insurance, as well as the exposure to increasing innovation activities in recent years in China into account, those possibly act as incentives for patients and caregivers to develop innovated, alternative solutions besides medical treatments.

In this research project, we will focus exclusively on the patient innovation (PI) activities in China, thanks to its great potential. We aim to understand the following questions: 1. Do PI activities actively happen in China? 2. What are the findings and typical examples of PI activities in China? 3. What are the characteristics of PI activities and the influencing factors of PI in China? What are the differences of PI China comparing with those in developed countries?

Given the complexity of the research and the limitations of the information sources, in our research work, both a multi-case study (online search for publicly available PI activities) and a quantitative approach (survey among patients with chronic disease and caregivers) are applied. 55 online-available PI cases and 509 survey samples have been collected from China, which we've then screened and identified PI activities for further evaluation and statistical analysis.


Our results have indicated a relatively activeness of PI activities in China with many practical examples. 1/3 patients or caregivers have reported innovation initiatives, and according to medical professionals, 13,5% have got a solution considered as reasonable, and 13,3% holds a meaningful idea, with many constraints possibly hinder implementation. Those PI activities has significantly improved the health and life quality, and some are shared with other people in need. Certain factors such as educational level and geographical region are likely to influence PI activities in China. In addition, PI activities in China shares some characteristics and influencing factors of those in Portugal, despite relatively simple and lower in technical contents.

Keywords: User innovation, Healthcare, Patients, Caregivers, Chronic disease, China



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1 Introduction

1.1 Context and Research Theme

User innovation has over the years been extensively involved in the health sector (Oliveira and Canhão, 2014; Trigo, 2016; Gabriel et al., 2017) A stream of research studies (Czernin, 2013; Engström, 2014; Oliveira et al., 2015; Souliotis, 2016; Canhão, Zejinilovic and Oliveira, 2017) have indicated that, very often, patients, especially those with chronic disease and their caregivers have developed innovative solutions other than professional medical treatment. Those solutions helped to improve the patients' treatment efficacy, physical conditions and life quality at varying degrees. In addition, quite a number of innovators are continually improving their solutions and sharing them with other patients and caregivers in need, either for free, at marginal cost or through commercial approach - by themselves and/ or with external collaborators.

In practice, PI (www.patient-innovation.com, founded by Oliveira and Canhão, 2014) - an open, multi-lingual, multi-national and not-for-profit platform has been established in Portugal, which enable the patients, caregivers and collaborators to share their solutions and actively communicate with other innovators, in the objective of improving the lives of other patients struggling with similar diseases. By far, the platform has over 500.000 visits, 850 medically screened innovations from over 60 countries, 1600 submissions and 60000 users 5 continents.

Owing the greatest population base and the diversified health condition among nations (Deloitte, 2014), in China, there 350 million people suffered from various chronic diseases and have physical disabilities at different levels. Although medical insurance has reached 95% coverage in China (Yu, 2015), public health insurance still covers less than 50% for serious and chronic illnesses on average (Various information sources, 2010-2017), and economic pressure would likely be an incentive for patients and caregivers to develop alternative low-cost solutions. On the other hand, China's innovation capacity is also evolving among the years (McKinsey, 2015; McKern, 2016). With intensive and extensive exposure to innovation, patients, caregivers and others who have noticed a problem or need of patient are likely to be inspired to develop creative solutions.

The above facts, and also taken the limited efficacy of medical treatment for certain type of diseases into account and also the scarcity of study in patient-centralized innovations in China has motivated us to implement this research project, through which we aim to understand better the patient innovation activities in China, especially those from patients and caregivers, what are the characteristics, specific examples and the difference between the PI activities in developed countries. We are also pleased to enrich the PI platform with innovations from China and adapting partially Chinese content. Together with the study of user innovation in healthcare from developing countries (Silva, 2017), we believe our research will add up crucial elements to the user innovations in the healthcare sector globally, as well as improve sharing on Patient Innovation platform between innovators from China and other countries.

1.2 Objective of Research

In this research project, we will focus exclusively on the patient innovation activities from China. A combination of multi-case study and quantitative approach has been applied. Literature research, search and screen of online resources (search engines, forums, social medias and multiple databases), survey design and sample collection, evaluation following the advices from medical professions, statistical analysis, sharing solutions on the PI platform and translation of PI Awards page and respective solutions into Chinese will be carried out during this research project.

The project will main focusing on the following research questions:

1. Do PI activities actively and extensively exist in China? What are the best approaches to identify them?
2. What are the findings for online-available patient innovations? What are the typical examples? What are the percentage and extent that patients and caregivers in China hold an innovative idea or solution?
3. What are the main characteristics of PI activities in China? What are the barriers, positive effect and diffusion of PI in China? What are the influencing factors with PI activities in China? What are the differences between the PI activities in China compared with those in developed countries?

The following sections include an extensive Literature Review in Chapter 2, a detailed description on the methodology for data collection and analysis in Chapter 3, and followed by result and in-depth discussion of online-available PI activities in China and survey among patients and caregivers in China in Chapter 4. Lastly, we will summarize the findings of this project and highlight the limitations and future research directions of our study in Chapter 5.

2 Literature Review

2.1 User Innovation in healthcare

2.1.1 User innovation in the healthcare sector

First proposed in 1976 by Von Hippel, the user innovation concept and phenomena has attracted interests from scholars for decades. User innovators are individual firms and consumers that expect to gain benefits from using their innovation as service or product; while on the other side, the producer and the service provider expect to gain benefits from selling the service or product (Blaya, Fraser & Holt, 2010). The user innovation has an important feature of matching the exact needs of users, other than adapting to the existing services or products. The huge potential of user innovation has been aware of by mainstream companies (Hippel, 2011). In additional, many individual consumers are able to make innovation for themselves as the technology development (Van der Boor, Oliveira & Veloso, 2014). As a result, user innovation has been beneficial to all the stakeholders including users, policy makers and manufacturers, and evidently indicates a paradigm shift from producer to user.

User innovation has also playing been an increasingly important role in the healthcare industry. Shields & Rangarjan (2013) has differentiated the professional users such as nurses and physicians from the non-professional users such as relatives and families of patients and patients themselves based on the study of the user innovation in the healthcare industry. The special needs faced by users and can be considered as a driving force for the development and generation of new solutions, a practical example is patients with some type of rare diseases tend to find possible solutions to the problem and serve themselves (Baker & Nelson, 2005). Snowdon, Bassi, Scarffe & Smith (2015) investigated that about 4-6 % of UK, Finland, Japan citizens has created or modified services and products for personal use, and 7 % of these innovations can be classified into healthcare products. Déglise, Suggs & Odermatt (2012) also reported that there is a positive relation between the influence of a solution on the overall quality of life of respondents and the possibility of the sharing of solution. Trigo (2016) provides an extensive review on the changing role of users in healthcare innovation, and have demonstrated the positive outcomes of treatments upon patient-involvement or patient-centred innovation. Gabriel et al. (2017) explores examples of open innovation in the field of health worldwide: companies, governments, researchers and citizens are collaborating to improve the innovation process, through which problems are identified, products and services are created and then adopted by the healthcare providers.

2.1.2 Patients and caregivers as innovators

Patients and caregivers are frequently found to be the driving force of innovation. Bodenheimer (2005) found that the active participation of patients can promote and drive institutional research. Bogers, Afuah & Bastian (2010) used to showed that this aspect is not sufficiently investigated. However, a serious of follow-up studies have investigated the roles of patients and caregivers as consumers of health with the motivation and capacity to innovate. As explained by Shcherbatiuk & Oliveira (2012), “Caregivers and patients innovators are people who make innovation to overcome barriers and difficulties that are imposed by their disease and consequently to improve their life quality”, and further study has indicated that the patient innovators have proposed new medical or non-medical treatment, strategies, and equipment to help them better deal with their disease (Oliveira, 2014). Agarwal & Shah (2014) has drawn a medium conclusion that the caregivers and patients have developed and invented many valuable solutions to their own diseases to improve their personal health situations. Such conclusion are verified by a stream of studies before and afterwards (Czernin, 2013; Engström, 2014; Oliveira et al., 2015; Souliotis, 2016; Von Hippel et al., 2016; Canhão, Zejniliovic and Oliveira, 2017), as a typical example, the study of von Hippel (2016) has investigated 500 respondents with rare diseases, of which 36% of these respondents claimed that they have created an innovative solution and 8% of them are considered to have introduced some new things into the world, according to the medical professionals. Some evidences of innovation made by patients show a strong influence on practices related to diseases and some demonstrate the state of art technology.

Moreover, with the aging population and decreasing birth rate especially in developed countries, the cost and expenditure of healthcare services are also increasing. As a result, user innovation can be a possible solution to such problem (Oliveira & von Hippel, 2011). Innovation made by patients and caregivers can help to generate a reform on the sector. There are three situations when the patient innovations are common. They are the dead-end situations, strong constraints on daily life and rare conditions (Ranck, 2011). The patients' innovation is more likely to happen in the situation when the disease is considered as severe. In addition, people who are suffering from chronic diseases tend to have higher needs of health and they are usually living in constraint reminders of their restrictions and they suffer from a decrease of life quality (Oliveira et al., 2015 & 2017). This explains the reasons that improving the quality of life is a large challenge and it is important to deal with this problem timely.

In general, the innovations by patients and caregivers are generating huge influences on their life and providing supports to other patients and their caregivers in the process as well. The patients and caregivers can embrace a powerful role and a game changer in the healthcare industry.

2.1.3 Diffusion and barriers of innovation from patients and caregivers

Just as other user innovators, patients and caregivers also face certain diffusion decisions and challenges. When patients restrict their novel solutions and methods to personal usage without sharing, it prevents and prohibits other people from experimenting and improving them (Taylor, 2015). Moreover, diffusion is quite important and relevant since these innovations can help to improve the quality of life of these patients in the healthcare paradigm and decrease the costs related to the healthcare. In some situations, it can even generate a huge difference between dead and life situations. For example, the British Engineer Tal Golesworthy is a patient innovator who fixed his heart problem through generating a mechanism to sustain his aorta; Louis Plante who developed the frequencer to tackle his cystic fibrosis (Zurovac, Talisuna & Snow, 2012) is another example. These two patients were able to develop things not only to satisfy their own demands, and since they shared these solutions and resources to other patients, they are able to save the life or significantly improve the life quality of other people. The invention of Golesworthy have saved the life of 41 people so far, and many people in Canada, US and other countries are using the innovation of Louis Plante.

On the other hand, since the user innovations are developed mainly for personal use, diffusion may not happen or even fail many situations. A number of caregivers and patients have developed innovations while they do not diffuse (Oliveira & Canhão, 2014). Under such condition, their innovation dies there. Those potentially useful solutions are not shared and others have to independently develop new innovation when they have similar needs. Another possible reason of low diffusion rate is the decrease of social welfare, according to the study of Dul & Hak (2007), which indicates that only 28% of people have ever made efforts to inform other people and share their innovation with other patients.

Despite the strong need of innovation, there are still several barriers hindering caregivers and patients to implement their ideas. The level of education, experience, availability, expertise may help to explain the reasons that innovation by caregivers and patients is lower than innovation in the general population in commercial and industrial products, professional communities or services (Lüthje, 2005). Although caregivers and patients are likely to make more innovations in more severe or pressing situations, they may not be able to create or develop something new. Baldwin, Hienerth & von Hippel (2006) suggested the differences in the user involvement in healthcare sector in comparison with other sectors and the shortage of user innovation culture in the health sector are the major barriers for the user innovation.

DePasse et al. (2016) identified the existence of six forces influencing innovation in healthcare sector. Those are the accountability, customers, technology, public policy, funding and industry players, in which certain system barriers would possibly affect the diffusion of innovation. Innovators may perceive that, industrial players are sometimes in shortage of incentives to promote or help to commercialize their innovations as those low-cost solutions would be a competitive product and lower the profits; at the same time, those non-professional solutions may be considered as authoritative as a threat to the powers and authoritative of the medical professionals. The position and mindset of certain players are likely to become barriers for the innovation and sharing process of patients and caregivers.

The potential negative influences and legal aspects of some innovations are also relevant in some cases, which may act as hindering forces for the innovation activities of patients (De Jong et al, 2015).

Another barrier is the complicated financial mechanism and approval as well as the dynamics between the regulators, insurances, doctors and hospitals (DePasse & Lee, 2013). There are also barriers related to the accountability and the needs to comply with strict regulations that usually requires long time and create effort to make the innovation from the patients or caregivers available to the market.

2.2 PI (Patient Innovation) Platform

Started as an academic research project with the objective to study user innovation (von Hippel, 1988) by patients and their non-professional caregivers (Oliveira et al., 2015) and funded by The Portuguese Science and Technology Foundation (FCT), Carnegie-Mellon Portugal Program and Pieter Pribila Foundation, Patient Innovation project was founded and led by Prof. Pedro Oliveira (Copenhagen Business School & Católica SBE Lisbon) and Prof. Helena Canhão from the FCM - NOVA Medical School. As one of the project's outcomes, the online Patient Innovation platform (PI, www.patient-innovation.com) was launched on February 7, 2014 in Lisbon, Portugal. The project is supported by a number of distinguished individuals, including Nobel Laureate Sir Richard J. Roberts, Eric von Hippel, Nobel Laureate Aaron Ciechanover, Katherine Strandburg, Robert Langer, Lee Fleming and Keld Laursen – has been served on the Advisory Board. The PI platform shares online contributors' ideas to help managing personal health issues and improve life quality.

In brief, Patient Innovation (PI) is an open, multinational and not-for-profit platform, which enable the patients, caregivers and collaborators to share their solutions (strategies, treatments, devices and knowledges) and interact with other innovators. PI is also a multilingual platform currently adapting English, Portuguese, German and part of Chinese contents. In 36 months, PI platform has reached over 500.000 visits, 60000 users from 5 continents, and over 1600 solutions are submitted, of which 850 medically screened innovations from over 60 countries are available online, curated and shared to improve the lives of others struggling with different health conditions. PI Awards was also launched with the objective of honouring all patients, caregivers and collaborators who have developed innovative solutions to cope with the challenges of their health condition and help others, and 17 solutions in patient, caregiver and collaborator category became the winner of 1st, 2nd and 3rd PI Awards in 2015-2017.

Since its inception, PI has been extensively involved in the media (<https://patient-innovation.com/in-the-media>) and has received numerous honours. In December 2016 Patient Innovation has won the Healthcare Startup Awards and was named "Non-Profit Startup of The Year" by the HealthCare Startup Society. The London Science Museum has selected Patient Innovation project as one of seven case studies to be featured in the exhibition 'Beyond the Lab: The DIY Science Revolution' which opened July 7, 2016 and will visit 29 European countries until the end of 2018.

2.3 Health conditions and Healthcare system in China

2.3.1 Healthcare in Developing vs. Developed Countries

In general, huge differences exist in the healthcare between the developing and developed countries. (Surbhi S, 2015). The healthcare system is assumed to take the responsibility of maintaining and improving the health through the treatment, diagnosis and prevention of injury, illness, disease and other physical and mental impairment while actually, the healthcare sector in developing countries sometimes failed to take these roles (Chen, Chen & Zhao, 2012). Another significant difference is healthcare industry consumed different proportion of the economy in developing and developed countries. The healthcare accounted for a much larger proportion of the total GDP for developed countries: The proportion is as much as 17.7% in US, 11.8% for Netherlands, 11.5% in France and 11.3% in Germany. However, the proportion is usually smaller than 5% for developing countries (Gu & Zhang, 2006). The healthcare sector in developed countries have usually experienced a long period of development and optimization, though which a mature system is established to provide sufficient healthcare service to patients in need. On the other side, in developing countries, the healthcare sector is still exploring and improving, and usually faces challenges such as underdeveloped technologies, insufficient financial supports and the immature facilities and incomplete equipment in the development (Giuliano & Droms, 2012). In addition, different from developed countries, cultural issues may be involved in healing and become an obstacle for the improvement of healthcare in developing countries (Ibeneme, 2017).

2.3.2 Current status of population' health in China

Since 1949, the population' health in China has significantly improved (gapminder.org). The life expectancy has reached 79,9 for female and 73,4 for male in 2016 (Healthdata, 2018), and morality rate for infants and kid below 5 has been consistently reduced. From year 1990 to 2016, the Healthcare Access and Quality (HAQ) Index has an average increase of 2,4% annually (IHME, 2016).

However, great challenges still exist: In China, there are more than 260 million people with various chronic diseases (Bloomberg, 2012), and 83 million people have physical disabilities at different levels (UN Enable, 2014). There are more than 100 million cigarette smokers and HIV-AIDS epidemics is estimated to more than 2 million in China (Yip & Mahal, 2008). In addition, the hepatitis B infection is also widely spread in China, with 10% of population contracted this disease. Moreover, there is an increasing obesity rate in the population. The obesity rate in China has reached 10.8% (Yip & Hsiao, 2018), which is correlated with the risk of suffering from hypertension, hyperglycaemia, hyperlipidaemia and CVD (Cardiovascular disease). Public health problem also rises concern, such as environmental health degradation (air and water pollution), greater prevalence of non-communicable diseases and food safety issues (Huang, 2016). Furthermore, a few avian flu outbreaks among Chinese cities successively in recent years, which generate some panics among the residents (WHO, 2018).

2.3.3 Healthcare system in China

The healthcare system in China includes both the private and public medical institutions and insurance programs. Fundamental health insurance has covered 95% of population in China (Yu, 2015). However, the public health insurance normally only covers half of the medical expense and an even lower proportion of costs related to chronic diseases and serious diseases are covered (Wang et al, 2016).

Currently, all major cities in China have hospitals specialized in comprehensive or specific areas and equipped with advanced, modern equipment and facilities (Tang, 2013). The best Medicare in China is still provided by a joint venture of international or oversea-trained experts and the best domestic medical care resources (mainly advanced, imported facilities) available in Beijing, Shanghai, Guangzhou and other first tier cities (internationalcitizens.com). They are usually expensive and may cost up to ten times in comparison with public hospitals and could not be reimbursed by public health insurance. Public hospitals and clinics with different qualities are available throughout the urban areas in China (Cheng, 2008). Hospitals in China are organized according to a 3-tier, 10 level system that recognizes a hospital's ability to provide medical care, medical education, and conduct medical research, and the high-quality treatment can be expected in 3rd-tier, city-level hospitals (Li et al., 2008).

Trend has indicated that China's medical system and quality are moving towards industrialized countries. In the past decade, Chinese government has implemented national health care reform to improve access

to essential services and reduce high out-of-pocket medical spending focusing on public hospitals (Barber, 2013). According to the Global Hospital Management Survey (2014), the overall average management score across large public hospitals in China was 2,86 on the 1-5 WMS management, slightly below the standard average score of 3 in US, but has exceeded UK (2,82), Sweden (2,68) and Germany (2,64). Chinese hospitals demonstrated particular strength in standardization and operations management but acute weakness in talent management.

In rural areas of China, healthcare services are provided by doctors with less medical experience, and limited medication and medical equipment are available. It is estimated that 80% of health and medical services are concentrated in cities, which means that timely medical care is not available to more than 100 million people in rural areas (Chelala, 2013). Nevertheless, the rural health services in China have developed rapid in recent years with a significant improvement in quality (Liu, 2014). China's New Cooperative Medical Scheme (NCMS) was brought to life to reduce the inequity in access to health care in rural China (Yang et al., 2013). Chinese Health Ministry and Bayer HealthCare has launched "Go West" program aiming to provide 10,000 doctors for rural areas (mainly in undeveloped west part of China) with post-graduate medical training, Bayer is increasing its sponsorship and have invested the equivalent of a further US\$ 3.09 million by 2017.

In addition to the modern medical care and facilities, the traditional Chinese medicine (TCM) is also widely applied in China. Many Chinese medicine treatment facilities and hospitals are located in China, in addition, general hospitals are increasingly utilizing TCM strategies for chronic disease care and prevention (Fan et al., 2018).

In recent years, problem such as unaffordable medication, insufficient medical resources in top-tier hospitals as well as health risks brought by urbanization such as air pollution and traffic hazards are rising concerns in China (Huang, 2016), but as well provide opportunities to improve. Since the late 2000s, the Chinese government has pursuing a new round of healthcare reformation including essential drug policies, universal basic medical insurance, and detailed measures for public hospitals and community healthcare centres (Liu et. al, 2017). Based on an investigation, public healthcare services, but not private clinics are the priority choices among Chinese residents (Tang, Xu & Zhang, 2016).

Under the "Healthy China 2020" initiative, China has been undertaking efforts to reduce healthcare costs, and the government requires that insurance will cover 70% of costs by the end of 2018 (NYTimes, 2011). The main goal of Chinese government is to provide affordable basic healthcare to all residents by 2020 (China Business Review, 2011).

The list of references we've reviewed and applied in our study are presented in Appendix A.

3 Methodology

3.1 General methodology

Given our initial research has indicated complexity and limited transparency of patient innovation (PI) activities in China, we've applied a combination of two approaches in our study:

1) Multiple-case study, in which we've searched online for PI activities that are publicly available in China and combined the results from various information resources; results were screened and analysed, and specific cases were further studied and shared (partially in Chinese) on the PI platform.

2) Semi-quantitative study, in which we've designed a survey targeting the patient and caregivers in China, to evaluate whether they have an innovative idea or developed innovative solutions to improve their health conditions. Samples were collected, translated, organized and classified according to the advices from medical professionals. Data were further screened and statistical analysis (general, Chi-Square and ANOVA) are conducted using SPSS. Results are organize analysed in detail to identify the main characteristics and influencing factors of PI activities in China.

3.2 Data collection method

3.2.1 Online search for Chinese PI activities

After initially screened a variety of online resources, including multiple search engines, patient communities (comprehensive and typical disease type such as lymphoma and spinal cord injury), social media and video websites, patent and academic databases etc., and also by discussing with other researchers in the PI platform, we've applied search engine as the main approach for online search and supplemented with other channels. The main process and method are as follows:

1) We've used Baidu (the most commonly used search engine in China) and Google, and searched for a combination of Chinese keywords related to patient innovation: patient + innovated, patient + innovation, patient + invented, patient + invention, suffered from disease + innovated/ invented/ innovation/ invention, disabled [or other chronic disease type] + innovated/ invented/ innovation/ invention, etc.;

2) We've clicked further the links related to PI activities and checked carefully. If it's likely to be related to PI, we would summarize the key information in an excel file, including topic, category (patient, caregiver, collaborator etc.), disease type, gender, region, solution, representative figures, etc. We also used specific keywords to search for other available resource of the same innovation, and recorded other useful information sources in the file;

3) Database with potential PI solutions were further analysed, in which a number of representative solutions are shared on the PI platform and/ or selected for case study. In addition, all the related links are recorded, and unqualified / uncertain results were also discussed with medical professionals.

An example of the database structure of online-searched potential solution are presented in Appendix B.

3.2.2 Survey among patients and caregivers in China

For semi-quantitative analysis, a bilingual (English-Chinese) online survey targeting patients and caregivers in China was designed referring to the existed PI surveys (Czernin, 2013; Oliveira et al., 2015) All questions were grounded in user innovation literature and verified by medical professionals.

The survey was partitioned into 4 sections with 36 questions (part contains supplementary questions and sub-questions): **1) General questions:** to identify respondent as patient or caregiver, type of disease and the related influences, as well as a screening question to identify whether the respondents has got an innovative idea and the stage (have idea only, developing an innovation, developed an innovation or have reached important milestone); **2) Innovation-related questions:** this part is classified as **2a** (for respondents with ideas only), to understand why the respondents didn't go further with the idea, and **2b** (for respondents developing or have developed a solution), to learn more about the motivations, influences and implications of innovation; **3) Demographic questions:** this part includes gender and age of patients (innovators), location, employment status, educational level and marital status of all the respondents, as well as whether they've joined a patient community/ group and stay active; **4) ICT-related questions:** this part aim to measure the respondents' exposure to Internet and Social media, as well as their willingness to join the PI community.

In particular, we've taken the habitual and cultural differences into consideration and modified or redesigned a few questions to make it more adaptable to the Chinese background. E.g. For the effectiveness of treatment (Q5, Part 1), we include TCM as it's still commonly used as main or auxiliary approach for the treatment of chronic diseases in China; Consider the huge regional differences, in Q29 (Part 3) we include the location and administrative division of residence (~50 key and big cities, other prefecture level cities, counties/ towns and countryside).

The complete questionnaire in this study with all the questions are presented in detail in Appendix C.

3.2.3 Data collection

Samples are collected in collaboration with GRT Market Research Co. (a listed company in China) after initial screening and inquiry of 15 companies. The company has a sample bank of 2.3 Mio active users with 19 diversified demographic attributes. The 1st question of the survey is used as a screening question, which only patients with chronic disease and their caregivers are eligible to answer the complete survey. 798 collected samples were manually screened to remove those with repeat submission, same IP-address with highly similar contents, or obviously unreasonable and irrelevant answers. As a result, a total of 509 sample from patients and caregivers in China were collected in 2 weeks.

Collected samples were manually screened and typos as well as nonsense words and symbols are corrected. In addition, due to the imperfections during survey design and data collection, data were fixed to pave the way for further analysis, the process for fixation of data are listed in Appendix D. The whole survey data were then translated into English using google translator and proofread manually.

3.3 Data Analysis Method

3.3.1 Primary evaluation for PI activities

Primary evaluation of potential PI-relevant solutions was conducted based on the following criteria (s):

1) Identification of Effective PI Solutions: All the 55 potential solutions are first justified by:

a. Effectiveness: The solution has worked well and improved the health/ life of patients (caregivers).

b. PI and sub-category: Whether a solution is considered as a PI activity and specific category (patient, caregiver, collaborator) with the help of medical experts and specialists, since some of the solutions are initiated or extensively involved by people with professional medical knowledge.

Only those in line with the above 2 features are considered as **Effective PI Solutions**, and are evaluated further to justify whether they are qualified solutions;

2) Evaluation of Quality: All the effective PI solutions are rated based on the following features:

a. Innovative and/ or Uniqueness (based on the innovator's knowledge); **b. Likely to share among and/ or inspire other patients;** **c. Enough information and resources are available.**

Consider the enormous complexity of PI activities in China, for each feature we used 1 (clearly), 0,5 (to some extent) and 0 (almost no) for rating, and then we added up the scores for each solution. A solution that scored 2,5-3 is rated as "Good Example", that scored 1,5-2 is rated as "Ordinary Example", and that scored 0,5-1 is rated as "Limited Example";

Then a brief statistic of the solutions based on the above criteria plus gender and region information were conducted, and the main characteristics as well as specific examples are further discussed.

For the unqualified and uncertain results, we've discussed all of them and explored some in detail, but finally chose not to include them in this study. Nevertheless, the main tendency and patterns of findings are used as supporting evidences in this study.

3.3.2 Statistical Analysis for PI Survey

Translated survey results were imported or inputted into SPSS Software (IBM, V23.0). A total of 502 samples were imported, and the following adjustment, calculation or evaluation were proceeded:

1) Further Classification: For Q1 and Q2, we've classified the relationship of caregivers (7 categories) and type of diseases (16 categories), each as an independent variable;

2) Multiple Choices: For Multiple choice questions (Q12, Q16, Q17, Q20, Q21, Q35), we've set each choice as an independent variable;

3) Secondary Data: To enable further analysis, we've generated some new variables, including Average disease Burden (Q4), Average treatment efficiency (Q5), Number of disease(s) suffered (Q2), Number of social medias used (Q35), Joined patient association + group/ forums (Q32 and Q33);

4) Rating of Ideas and Solutions: As some of the idea/ solutions are obvious nonsense or thoughts that are very unlikely to improve health or help others, we've screened and rated the 174 ideas and solutions following the guidance of medical professionals. Solutions are rated as: 1 – “Nonsense”; 2 – “Thoughts, but not qualified for PI”; 3 – “PI – Ordinary Example” and 4 – “PI – Good Example”.

5) Screening of Ideas and Solutions: based on the rating, we've then selected all the ideas and solutions that are scored at 3 or 4, which we've considered to be valid PI ideas (N=67) and PI solutions (N=68), and the rest samples are considered to be “non-innovators” (N=367) in our further analysis.

New variables (None | Idea), (None | Innovation), (None | Idea | Innovation) and (None | Idea + Innovation) are created to identify and classify different groups for statistical analysis in our next steps.

Descriptive statistics (4.2.1-4.2.3) for variables were achieved using “Descriptive Analysis” tool in SPSS, values were recorded and organized in tables. For respondents with innovative ideas (4.2.2) or innovative solutions (4.2.3), sub-dataset was created to facilitate analysis.

To analyse influencing factors of PI (4.2.4), Chi-Square and ANOVA analysis were conducted in SPSS, of which ANOVA (plus post-hoc) were used for ordinal and scaled factors such as Disease duration (Q3) and Number of social medias used (Q35), Chi-Square were used for nominal factors (mainly demographics) such as Marital status (Q31) and Educational level (Q29). p-values (Sig.) of all the factors in respective of different groups (Idea, Innovation, Idea + Innovation) were organized in table for further analysis and discussion, to justify whether a factor would affect PI activities in China.

4 Results and Discussion

4.1 Results for online-searched Chinese PI activities

4.1.1 Extents and quality of online available Chinese PI activities

Our initial screening has resulted in more than 100 results, however, the solution developed by medical experts (nurses, doctors, scientists), profit-oriented commercial products, and the solution with little information about the innovator and the innovations process are excluded. In brief, a total of 55 potential

PI-relevant solutions were recorded for further evaluation, of which ~95% are considered as effective and 45 (81,8%) are justified as **Effective PI Solutions**.

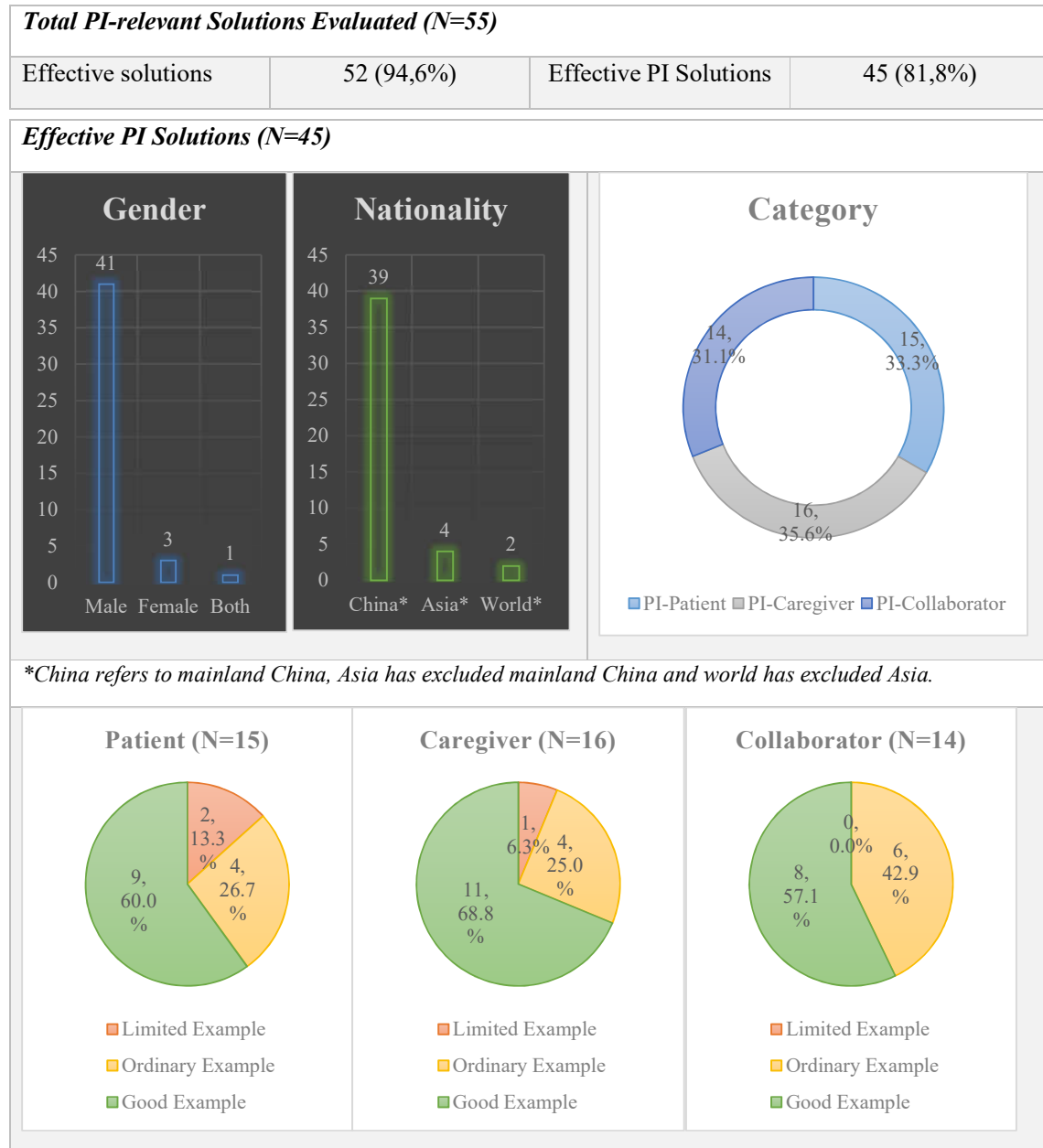


Figure 1. Extents and Quality of online-available PI solutions in China

The majority (41 out of 45) of solutions are developed by male innovators; PI solutions are mainly from mainland China (39 out of 45), and also from Chinese people living in other countries.

In China, PI Solutions are distributed across different categories: patient, caregiver and collaborator. The percentage are quite similar, with each account for ~1/3 of the total PI solutions.

In terms of quality, PI solution under different categories are relatively similar, with about 3/5 of the solution rated as “Good Example”. “Limited Example” also exists (3 out of 45), but was found only in the patient and caregiver category, but not the collaborator category.

4.1.2 3 Examples of PI activities in China

Innovation example from Patient

Yunlu Gao, a primary school student, was born in 2005 in Shenzhen, China. He was diagnosed of serious hyperopia and congenital phoria, which gradually developed into strabismus with age. The doctor said a surgery was required for his eyes and if he had not recovered at a certain age, non-surgical early treatment would be the solution to improve his condition.

During his treatment, Yunlu Gao and his father learned as much as they could on strabismus through the internet and international ophthalmic books, through which they understood the key factors. After four years of hard work, Gao's binocular vision has been effectively controlled, together with his binocular fusion function and strabismus.

After recovery, he improved the detector further to help the patients with similar situation. The device can guide the rotation of the eye and analyse the muscle condition, and justify the results through comparison and data analysis. Besides, it can conveniently send the eye-related data through the Internet to the relevant professional medical institutions, and provide treatment plan for the patients.

Gao's eye muscle detection device has won the silver award in the 69th IENA invention exhibition in Nürnberg, Germany. His explanation on the principle of the invention, combining with his own experiences, has received high praise among the professional judges. Gao hopes he could share his treatment process and methods to help more people suffering from strabismus.

Innovation example from Caregiver

Xu Yin, born in 1995, currently studying at Nanjing Medical School in China, has developed an epilepsy alarm device for his grandmother together with his classmates. The device can send alarm when "clenching teeth", a normal symptom of epilepsy occurs.

Since childhood, Yin remembered that her grandmother suffered from epilepsy, which occurred every few months and usually during the night. "Normally, the whole family was asleep when my grandmother had seizures", Yin recalled. In the early spring of 2017, his grandmother had seizures and Yin was extremely worried. At midnight, Yin came to an idea of developing a device to alarm the caregivers when the seizure occurs, and wrote down his initial plan at 2 am.

Yin shared his idea with his classmates, and soon a group of five people started designing the device. Through consistent learning and improving, the device was finally developed in 2017. Once the patients' epilepsy symptom last by more than 8 seconds, the device will send alarm sound to inform the caregivers. Yin's group also designed a mobile app to record and manage the patients' history of occurrence and conditions and enable the caregivers to keep track and share data with doctors.

The cost of the device is about 70 EUR. In addition to helping his grandmother, Xu and his group members have been busy pitching the epilepsy alarming device to medical device producers, and they hope they could soon bring the innovation into the market.

Innovation example from Collaborator

Nana Wang, born in 1994, and Shuang Huang, born in 1995, in China, are postgraduate students from top universities in China. To help Wang's friend who suffers from hearing loss and other deaf people, they developed a translation armband, which can convert sign language into speech.

Inspired by a deaf friend, Nana Wang and her friend Shuang Huang started developing a solution for people with hearing disorders in 2015. The armband collects the signals of sign languages, analyse through AI deep learning and finally convert them into speech. "It is extremely difficult to accurately recognize a gesture. Usually it requires to collect the signal for a thousand, even several thousand times." explained the inventors.

After two years of hard work and thousands of experimentations, they successfully developed a gesture recognition armband which recognize the most common 400 gestures from sign language.

"In China, there are 70 million people with language dysfunction, for a variety of reasons", said Shuang Huang, Nana Wang's friend and roommate in the university, a student from Tsinghua University.

Although currently the armband can only translate common gestures one by one, the students believe that they will be able to improve it with the fast development of AI. The sign language recognition armband has also won the championship in an innovative competition held by the United Nations and an Internet company. The girls said they are not thinking of making money out of their invention yet, but would be pleased to help more deaf people communicate normally.

4.2 Results for survey among patients and caregivers in China

4.2.1 General and demographic information of respondents

Patients

General and disease related information of 502 patients are summarized in Table 1-4. As indicated, the patient has an average age of 50,2 and 260 (51,8%) of which are women. The patients are suffering from 1-4 chronic diseases (the majority only have 1 or 2 diseases), and the main type of diseases suffered are hypertension, asthma, diabetes, heart diseases/ CVD. The diseases have created strong negative impact on 43,3% of patients and 35,7% of caregivers, and the current medical treatments are quite ineffective for more than ¼ of patients. 373 and 90 out of 502 patients have a disease duration of 1-10 years and

more than 10 years, respectively. The diseases also increase monthly expense of more than 250 EUR for 87 patients and 100-249 EUR for 208 patients (converted from local currency).

	<i>Gender of patient</i>		<i>Birth year of patient</i>			
	<u>Female</u>	<u>Male</u>	<u>Max</u>	<u>Min</u>	<u>SD</u>	<u>Avg.</u>
<i>Value</i>	260 (51,8%)	242 (48,2%)	2000	1920	14,6	1967,8
					Avg. Age	~50,2

Table 1. Gender and Birth year of Patients (N=502)

	<i>No. of diseases suffered</i>		<i>Type of diseases suffered (Top 5)</i>		
	<u>No. of patients</u>	<u>(%)</u>		<u>No. of patients</u>	<u>(%)</u>
<u>1 disease</u>	363	72,3%	<u>Hypertension</u>	191	38,0%
<u>2 diseases</u>	108	21,5%	<u>Asthma</u>	117	23,3%
<u>3 diseases</u>	27	5,4%	<u>Diabetes</u>	107	21,3%
<u>4 diseases</u>	4	0,8%	<u>Heart diseases/ CVD</u>	98	19,5%
<u>Total</u>	502	100.0%	<u>Osteoporosis</u>	41	8,2%

Table 2. Number and Type of Diseases Patients suffered (N=502)

	<i>Negative Impact</i>		<i>Effectiveness</i>		
	<u>For the patient</u>	<u>For the caregiver</u>	<u>Western Medicine?</u>	<u>Chinese Medicine?</u>	<u>Portable devices?</u>
<u>Average</u>	3.28	3.10	2.95	2.94	3.00
<u>Strongly Negative impact</u>	222 (43,3%)	179 (35,7%)	-	-	-
<u>Serious Flaws</u>	-	-	130 (25,9%)	157 (31,3%)	160 (31,9%)

Table 3. Disease Burden and Treatment Efficiency (N=502)

<i>Disease duration</i>		<i>Increase in monthly Expense</i>	
< 12 Months	18	Yes, but less than 100 EUR per month	197
1 year (included) - 3 years 11 months	192	Yes, 100 (incl.) -250 EUR per month	208
4 years (included) - 9 years 11 months	191	Yes, 250 (incl.) -499 EUR per month	63
> 10 years (included)	90	Yes, 500 (incl.) -1199 EUR per month	16
Not sure	11	Yes, > 1200 (incl.) EUR per month	8
		No increase	10
<u>Total</u>	502	<u>Total</u>	502

Table 4. Disease duration and Increase in Expense (N=502)

Respondents (Patients or Caregivers)

Socio-demographic information of 502 respondents are summarized in Table 5. As indicated, among which we have 215 patients and 287 caregivers with similar demographic properties. 370 (73,7%) of the respondents are employed, 86,7% are married, 71,7% have a university or higher degree, 92% have access to internet on a daily basis, 81,5% use 2 or more social media and 13,1% are a member of disease association (groups) and/ or visit/ post on disease forums.

	<i>Total (N=502)</i>		<i>Patient (N=215)</i>		<i>Caregivers (N=287)</i>	
<u>Employed</u>	370	73,7%	169	78,6%	201	70,0%
<u>Married</u>	435	86,7%	191	88,8%	244	85,0%
<u>University degree or above</u>	360	71,7%	157	73,0%	203	70,8%
<u>Access to internet daily</u>	462	92,0%	194	90,2%	268	93,4%
<u>Use 2 or more Social Media</u>	409	81,5%	182	80,0%	237	82,6%
<u>Member of Disease Forum/ Association</u>	66	13,1%	26	12,1%	40	13,9%

Table 5. Socio-demographic information of Respondents (N=502)

As shown in Table 6, among the 502 respondents, 290 (57,8%) have never thought nor heard about an idea or innovation, 38 (7,6%) haven't thought by have heard of innovative idea or solutions, and 174 consider they've got an innovative idea or solution: of which, 104 (34,6%) respondents only have ideas but didn't implement it (or tried but stopped), 61 are developing a solution and 9 have developed a solution or reached important milestone.

	<i>No.</i>	<i>(%)</i>	<i>Patient</i>	<i>Caregiver</i>
<u>Never and haven't thought of it</u>	290	57,8%	126	164
<u>Never, but know others did</u>	38	7,6%	10	28
<u>Have idea but no action</u>	104	20,7%	46	58
<u>Developing a solution</u>	61	12,2%	28	33
<u>Developed a solution</u>	9	1,8%	5	4
<u>Total</u>	502	100%		

Table 6. Potential PI activities of Respondents (N=502)

The type and quality of self-reported innovations are shown in Table 7. From which we could see that half (50,6%) of the idea and solution are behaviour/ habit/ strategy, the other types are treatment/ therapy (18,4%), food/ drink/ natural product (17,2%) and medical equipment (9,2%). According to medical professionals, the quality of idea or solution varies, with a higher % of low-quality examples in treatment/ therapy category. However, 79 and 56 are considered as "Ordinary Example" or "Good Example", respectively, which in total account for 77,6% of self-reported data.

	<i>No.</i>	<i>%</i>	<i>Nonsense</i>	<i>Thoughts</i>	<i>Ordinary Example</i>	<i>Good Example</i>
<u>A medical equipment</u>	16	9,2%	1	2	3	10
<u>A Treatment/ Therapy</u>	32	18,4%	4	11	10	7
<u>A Behaviour/ Habit/ Strategy</u>	88	50,6%	2	5	51	30
<u>A food/ drink/ natural product</u>	30	17,2%	1	6	15	8
<u>Others</u>	8	4,6%	5	2	0	1
<u>Total</u>	174	100%	13	26	79	56

Table 7. Type and Quality of Potential PI activities (N=174)

Due to limitations, specific example of innovative ideas or solutions would be included in our future study, and the full list of innovation description including rating is shown in Appendix E.

4.2.2 Patients and caregivers with innovative ideas

67 out of 104 ideas were rated as “Ordinary Example” or “Good Example” and included in our analysis of innovative ideas from respondents. As indicated in Table 8, only 17 of them have moved a few steps forward (10 have specified in a draft/ description and 7 once started working but stopped), but the majority haven’t taken any actions so far. Communication of ideas seems more likely to happen, nearly half (32) chose to share with family members and 1/6 (11) choose to share with other patients with similar disease. 3 have shared their ideas with doctors. However, 20 among them have never talked with anyone about their innovative ideas.

<i>Stage of innovative ideas</i>		<i>Communication of innovative ideas</i>	
<u>Just thought about but no action</u>	50	<u>No</u>	20
<u>Specified in a drawing/ written description</u>	10	<u>Yes, other patients with similar disease</u>	11
<u>Started working on my idea but stopped</u>	7	<u>Yes, my family and relatives</u>	32
		<u>Yes, other friends (non- patients)</u>	1
		<u>Yes, my doctor(s)</u>	3
<u>Total</u>	67	<u>Total</u>	67

Table 8. Stage and Communication of Innovative Ideas (N=67)

What factors would prevent patient and caregivers from implementing their ideas? Table 9 has shown that “Perceive it’s difficult to execute” is the most common reason (50,7%), other important reasons are time constraints (41,8%), economic constraints (37,3%), physical constraints (32,8%) and others think it’s not interesting (23,9%).

<i>Respondents with innovative idea (N=67)</i>	<i>No.</i>	<i>(%)/ Specific Reason</i>
<u>Physical constraints (Disease related)</u>	22	32,8%
<u>Time constraints</u>	28	41,8%
<u>Economic constraints (cost)</u>	25	37,3%
<u>Perceive it's difficult to execute</u>	34	50,7%
<u>Others think it's not interesting</u>	16	23,9%
<u>Other reasons</u>	2	2,94%

Table 9. Reasons for stop implementing Innovative Ideas (N=67)

4.2.3 Patients and caregivers with innovative solutions

68 out of 70 solutions were rated as “Ordinary Example” or “Good Example” and included in our analysis of innovative solutions from respondents. As indicated in Table 10, most of the innovations (50) takes 6 months to 5 years and the cost varies significantly, with 31 solutions cost no more than 1000 EUR, 12 solutions cost 1001-3000 EUR and 11 solutions cost more than 3001 EUR.

<i>Duration of innovation</i>		<i>Cost related to innovation</i>	
<u>Less than 6 months</u>	11	<u>Not specified or not significant</u>	14
<u>6 months (included) – 1 years 11 months</u>	31	<u>0-200 EUR</u>	9
<u>2 years (included) – 4 years 11 months</u>	19	<u>201-1000 EUR</u>	22
<u>More than 5 years (included)</u>	5	<u>1001-3000 EUR</u>	12
<u>Not sure</u>	2	<u>3001-10000 EUR</u>	7
		<u>>10000 EUR</u>	4

Table 10. Duration and Cost (real or expected) of Innovative Solutions (N=68)

As shown in Table 11, those solutions have significantly improved the life quality of patients. 49 (72,0%) have reported improved in life quality after the innovation versus medical treatment, the average score of life quality (based on 1-7 scale) has increased by 1,18 after the innovation.

	<i>Value/ No.</i>
<u>Minimum</u>	-2
<u>Maximum</u>	5
<u>No. of innovations (>1)</u>	49 (72,0%)
<u>Mean</u>	1,18
<u>Medium</u>	1

Table 11. Effectiveness of Innovative Solutions VS. Medical Treatments (N=68)

Score (PI vs. Medical treatments?)	Count
-2	3
-1	10
0	6
1	18
2	21
3	5
4	4
5	1

Table 12 indicates the collaboration and active learning during innovation. Very often, the innovators are working with their family members (69,1%) and friends (32,4%), other collaborators include students (17,6%), company (5,9%) and other kind-hearted people (5,9%). Active learning during innovation is also significant, 65 have learned new knowledge and 31 suppose they've learned a lot during the process.

<i>Help from others during innovation</i>			<i>Active learning to develop the solution</i>	
<u>No</u>	3	4,4%	<u>No</u>	3
<u>Family</u>	47	69,1%	<u>Yes, I've learned a little but not much</u>	32
<u>Friends</u>	22	32,4%	<u>Yes, I've learned a lot</u>	24
<u>Students</u>	12	17,6%	<u>Yes, I've learned a huge amount and intensively/ consistently</u>	9
<u>Company</u>	4	5,9%		
<u>Others</u>	4	5,9%	<u>Total</u>	68
Table 12. Collaboration & Active learning of Innovative Solutions (N=68)				

As seen in Table 13, 64 out of 68 innovators have discussed with other people about the innovation, including other patients with similar disease (16), family members and relatives (44) and other non-patient friends (3). Only 1 innovator has ever discussed with the doctor. Some innovations are also known by public, 6 has participated in competition/ exhibitions and 8 were reported by media.

<i>Communication of innovation</i>		<i>Innovation known by public</i>	
<u>No</u>	4	<u>No</u>	55
<u>Yes, other patients with similar disease</u>	16	<u>Participated in Intl Competition</u>	4
<u>Yes, my family and relatives</u>	44	<u>Participated in national/ regional competition</u>	2
<u>Yes, other friends (non- patients)</u>	3	<u>Reported by media</u>	8
<u>Yes, my doctor (s)</u>	1	<u>Others</u>	1
<u>Total</u>	68		
Table 13. Communication & Public Awareness of Innovative Solutions (N=68)			

As seen in Table 14, besides 1 innovator, the rest 69 innovators are willing to share their innovations with other patients in need, of which 19 has already shared and worked on others and 28 are about to share with others. A certain % of innovators have positive attitude towards innovation, with 24 feel proud and improved confidence, 42 are planning to improve it further and 29 would like to share for free or with marginal cost. Moreover, 5 innovators would like to start business out of their innovation.

Interestingly, 45 out of 68 innovators intend to apply for patents and 8 have already submitted application (none are yet granted). Of the 5 innovators as potential entrepreneurs, 3 are looking for manufacturers, 1 planning to start business soon and 1 is collaborating with manufacturers (Table 15).

<i>Willingness to share innovations</i>		<i>Personal Attitude to innovation</i>	
<u>I've already shared and it worked on others</u>	19	<u>Proud of myself, improved confidence</u>	24
<u>I've talked and about to share with others</u>	28	<u>Planning to improve it further</u>	42
<u>I'm happy to share with others, but haven't yet due to constraints</u>	20	<u>Would like to share for free/ marginal cost</u>	29
<u>Currently haven't considered sharing</u>	1	<u>Would like to start a business</u>	5
<u>Total</u>	68		

Table 14. Sharing and personal attitude to Innovative Solutions (N=68)

<i>Start a business out of innovation</i>		<i>Plan and action on patents</i>	
<u>Planning to start/ cofound soon</u>	1	<u>No, and I'm not planning to apply</u>	23
<u>Collaborating with manufacturer</u>	1	<u>No, but I'm planning to apply</u>	37
<u>Looking for manufacturer</u>	3	<u>Have applied patent but not yet granted</u>	8
<u>Total</u>	5	<u>Total</u>	68

Table 15. Plan of Business (N=5) and Patents (N=68) for Innovative Solutions

4.2.4 Factors that influences innovative ideas and solutions

In this section we aim to explore the influencing factors of PI activities in China. Although both innovative idea and innovative solution are considered as PI activities, however, since they belong to different stages of innovation and the respondents' initiative and the time/ effort involved are likely to be different in those two categories. Therefore, we've analysed "Innovative Idea", "Innovative Solution" and "Innovative Idea+ Solution", respectively, versus the "Non-innovation" group to identify the possible influencing factors of PI activities in China. Results for the significance of nominal and ordinal factors corresponding to each aforementioned group are shown in Appendix F.

As indicated in Table S2, "negative impact of disease" and "number of social medias" used for [Idea + Solutions VS. None], as well as "negative impact of disease" for [Idea VS. None] have p value < 0,05. Those two factors for all groups have p-value < 0,1. Other p-values are greater than 0,1.

As indicated in Table S3, "Field of study", "Location of Residence", "Educational Level" and "Member of patient association or group" have a p-value of <0,05 for [Idea + Solutions VS. None] and [Solution vs. None] groups. Also, for those 2 groups, "Access to internet daily" and "Would like to join PI" have p value <0,1. "Location of residence" for [Idea vs. None] and [Solution vs. None] group have p-value of 0,03 and 0,009, respectively. Other p-values are greater than 0,1.

Following our initial results, factors resulted in a p-value < 0,05 in either "idea", "innovation" and "idea + innovation" groups are further analysed, and mean values (scale and ordinal factors) and percentages

(nominal factors and sub-factors) are presented in Table 16. As indicated, the negative impact of disease is higher (3,33-3,44) for “Idea” (p=0,007), “Solution” (p=0,070) and “Idea+ Solution” (p=0,003) groups compared with “Non-innovator” group (3,12); the number of social media used is also higher (2,56-2,58) for all 3 innovative groups compared with “Non-innovation” group (2,34), and has stronger effect on “Idea+ Solution” group (p=0,016); a significantly higher % of the respondents study natural science for the “Solution” group (30,88%) and “Idea+ Solution” group (15,56%) compared with “Non-innovator” group (9,26%, p=0,000). For geographical location, a significantly higher % of respondents in all 3 innovative groups (44,78%-47,06%) live in key cities compared with “Non-innovator” group (30,79%), and on the opposite, a obviously lower % of respondents in all 3 innovative groups (2,94-5,97%) compared with “Non-innovator” group (15,53%), with p-values of 0,003 (“Idea”), 0,009 (“Solution”) and 0,000 (“Idea+ Solution”), respectively; a greater % of the respondents in “Solution” group (26,47%) and “Idea + Solution” group (17,78%) hold a master degree and above, which highly exceed the “Non-innovator” group (4,36%, p=0,000), and in those 2 innovative groups, a much higher % of respondents (33,82% for “Solution” group and 22,22% for “Idea+ Solution” group) are a member of patient association group, compared with less than 10% (9,81%) in the “Non-innovator” group (p = 0,000).

In contrast, studying technology and holding a bachelor’s degree don’t exhibit an effect on PI (p>0,1).

<i>Factors</i>	<i>Parameters</i>	<i>Ideas</i>	<i>Solutions</i>	<i>Ideas + Solutions</i>	<i>None</i>
<u>Negative Impact of Disease</u>	p	0,007*	0,070***	0,003*	-
	Mean	3,44	3,33	3,39	3,12
<u>No. of social media used</u>	p	0,054***	0,080***	0,016**	-
	Mean	2,58	2,56	2,57	2,34
<u>Field of Study</u>	p	0,378	0,000*	0,000*	-
	Science (%)	8,96%	30,88%	15,56%	9,26%
	Technology (%)	34,33%	22,06%	31,06%	28,14%
<u>Location of Residence</u>	p	0,030**	0,009*	0,000*	-
	Key cities (%)	44,78%	47,06%	45,93%	30,79%
	Countryside (%)	5,97%	2,94%	4,44%	15,53%
<u>Educational Level</u>	p	0,180	0,000*	0,000*	-
	Bachelor (%)	68,66%	61,76%	65,19%	63,22%
	Master + (%)	8,96%	26,47%	17,78%	4,36%
<u>Member of patient association group</u>	p	0,872	0,000*	0,000*	-
	Member (%)	10,45%	33,82%	22,22%	9,81%

Table 16. Influencing factors and sub-factors for PI activities

(Calculated using 1-way ANOVA (with post-hoc) and Chi-square analysis in SPSS;

*p<0,01, **p<0,05, ***p<0,1; Green: with higher value/ %, Yellow: with lower value/ %)

We've also analysed the effect of 15 types of disease between different groups, of which heart disease/CVD have a p-value < 0,01 for "idea" group and malnutrition have p-value < 0,5 for "innovation" group.

4.3 Discussion

4.3.1 Online-searched Chinese PI activities

Our research results have clearly indicated that, similar to the finding from developed countries and other developing countries, PI activities of different categories (patient, caregiver and collaborator) are actively happening in China. Upon initial screening, a total of 45 efficient PI solutions were identified, with almost an equal number of solutions (~15) in each category.

It is worth mentioning that, during our research process, we've frequently encounter examples that Chinese nurses, doctors and scientists have developed solutions (very often in their free time) to improve the patients' treatment and comfort. In addition, we've found some innovative and effective solutions nevertheless, in which the patient didn't take an active role in the innovation process. Those solution are not the focus of our research but may as well provide valuable information and help other patients.

An interesting finding is that almost 95% of the effective PIs are developed by male innovators, indicating that male tend to be far more likely to bring an innovative idea into practice in China. In terms of geographical location, PI occur both among local residents and Chinese people living in overseas.

The quality of online-searched PI activities varies. According to the rating results, 3/5 among them are considered to be good examples and ~90% of the solutions are acceptable (Good + Ordinary examples). In the collaborator category there is no limited examples, which possibly owing to the higher competence and/ or availability of collaborator relative to patients and caregivers. Some of the sectors such as automatic turning bed are overcrowded, with 10 out of 45 solutions belong to this category.

In general, the 45 PI solutions we've found so far are quite similar to the existed ones on the PI platform, many of them are commented as "interesting" and "meaningful" according to the professionals working at Patient Innovation, and 20 are already shared on the PI platform.

Most of those PI solutions took great effort and a certain amount of time, the innovator strives to improve it consistently, the majority of them have won awards and reported by media, and more importantly, the innovator is willing to share with other patient in need, either personally or commercially.

4.3.2 Survey among Chinese patients and caregivers

In general, our survey results have indicated a great diversity and a relatively active level of PI activities (innovative ideas and solutions from patient and caregivers) in China. Of the 502 respondents, 174 (34,7%, 79 patients and 95 caregivers) have reported having an innovative idea or solution. The most

common type of idea or solution is “behaviour/ habit/ strategy” (50,2%), and more than 1/6 are “treatment/ therapy” or “food/ drink/ natural product”, and medical equipment accounts for 9,2%. A number of self-reported ideas and solutions are completely nonsense or thoughts that are hardly valuable, nevertheless, 136 (77,6%) of the ideas and solutions are considered as valid PI examples and 59 (33,9%) are considered as good PI examples according to medical specialists. Our further analysis is based on those screened, valid examples (67 ideas and 68 solutions).

For the 67 respondents who have innovative ideas, 3/4 respondents have only thought about the idea and 1/4 have specified it in a drawing/ text or have ever tried. Communication of the idea are more likely to happen, 3/4 have ever talked to other people, mostly with family members, other patients and friends. Interestingly, 3 (4,7%) have talked with the doctors. The respondents also reported several reasons that prevent them from implementing the idea, more than half perceived their idea “difficult to execute”, and more than 1/3 have time/ physical/ economical constraints. Sometimes respondents were also demotivated by others who think the idea is “not interesting”.

For the 68 respondents who have innovative solutions (innovators), the majority have invested considerable time and money on developing the solution, with 35,3% took more than 2 years and 33,8% cost over 1000 EUR (converted from local currency). The innovators have also reported significant improvement of life quality (1,18 based on a 1-7 scale) after the innovation versus original medical treatments. 95,6% of innovators have received help from other people, in most situations are family and friends, and some are also helped by students and companies. Similarly, 95,6% of the innovators have been actively learning new knowledge during the innovations.

Diffusion of innovations is also significant for innovators, 94,1% have discussed or showed their innovation to others, although unfortunately only 1 have talked to the doctor. Those innovations also generate public awareness, 19,1% have participated in competition/ exhibition or reported by media but the rest 55 have not yet known to the public. Moreover, 98,5% of the innovators are willing to share with other patients and 27.9% of innovations have already worked on others.

Most innovators hold a positive attitude towards their innovation, such as planning to improve further (61,8%), would like to share for free or marginal cost (42,6%), which is in line with the findings in user innovation area (von Hippel, 2011). Many innovators also felt proud and improved confidence (35,3%).

Our research also revealed some business potentials out of those innovations. Although only 7,4% are planning to start business or collaborate with manufacturer, 66,2% would like to apply for patents and 11,8% have applied for patents already.

We’ve achieved interesting results upon analysing the factors that possibly affect PI activities in China. In general, respondents with a higher negative disease impact ($p<0,01$) and living in key cities ($p<0,05$) are likely to have an innovative idea, such results are quite understandable as disease might stimulates the desire for innovation and respondents living in key cities have better access to information and

activities including those related to innovation. Respondents studying natural science ($p < 0,001$), holding a master degree or above ($p < 0,001$), living in key cities ($p < 0,01$) and being a member of patient group/ association ($p < 0,001$) are likely to have an innovative solution. Quite reasonably as well, as those are all likely to act as promoting factors for implementing an idea, as respondents with those features are probably have more professional knowledge and expertise to develop a solution, and/ or more motivated or have more resources for putting an idea into practices. Living in the countryside act as a negative factor of both have an idea ($p < 0,05$) and having a solution ($p < 0,01$), probably due to poor access to information and other resources or maybe economical constraints.

If we consider the respondents having either an idea or innovation in the same group (idea + solution), all the factors mentioned above (negative impact of disease, living in key cities, having a master degree or above, study natural science and being a member of patient group/ association, living in countryside) are highly likely to impact PI activities in China ($p < 0,005$). Besides, the number of social medias used indicate a higher likelihood of PI activities in China for “Idea+ Solution” group ($p < 0,05$). Factors with a relatively weak effect ($p < 0,1$) on PI are “have access to internet daily” and “would like to join the PI community”. Besides the aforementioned reasons, the last 3 factors possibly indicate willingness and easiness to exchange information and sharing, which are likely to contribute to innovation activities.

Not completely as expected, factors such as the number of diseases suffered, disease duration, treatment efficiency, increase in monthly expense, marital status and employment status don't seem to be the influential factors of PI activities in China according to our study. Take into consideration of overall survey results, a certain number of patients and caregivers would find it comfortable to follow the advices from doctors and prefer to keep the Status quo than to challenge the professional medical treatment they've received. Getting married and in employment also might affect in two opposite ways for innovation: more support and stronger economical basis, but less personal time for innovation.

Finally, most of the 15 diseases (based on our classification) don't seem to affect PI activities in China, only heart diseases/ CVD has significant effect ($p < 0,01$) on “Idea” group and malnutrition has moderate effect ($p < 0,05$) on “Solution” group. A possible reason could be most of those are common disease types with matured treatment plans, and thus demotivating patients and their caregivers from seeking for alternative, innovative solutions. In the future, it would be meaningful to investigate further on rare diseases and diseases that lack of efficient treatments, which patients and their caregivers possibly have more innovative motivation to improve treatment and life quality.

4.3.3 Comparison of PI activities in China and developed countries

Overall, our research has demonstrated the diversity of innovations in Chinese patients and caregivers. It would also be interesting to compare those innovations with those from developed countries, which were systematically studied and practical examples are shared on the PI platform.

For the online-searched solutions, we've acquired a total of 45 examples that we consider qualified as PI activity, of which 28 are "Good Examples" suitable to share on the PI website. (~20 have already shared) However, this number is relatively small consider the huge population base (1,4 Bio) in China, in comparison to more than 100 solutions from USA, UK or Europe respectively on the PI platform. By comparing with existed solutions on he PI platform, our overall impression is that the Chinese solutions are relatively low-end, low-cost, simple and somehow less innovative than the solutions in developed countries. For instance, the fast-lifting wheel chair developed by a Chinese boy functionate quite well, but indeed appear to be simpler, economic and less advanced than the other type of wheelchairs including 3D-printed wheelchair, eye-controlled wheelchair and stand-up wheelchair from developed countries. However, those simple solutions would also create great value to the patients and others in need, and simple / low-cost solutions would be also advantageous to be followed remotely.

For the survey among Chinese patients and caregivers, although the 502 patients involved in this sample have an average age of ~50 and includes a certain % of elder people, which may be different from the related survey of 496 patients and caregivers in Portugal (Oliveira et al., 2015), where the patient have an average of 33 and the less % of respondents are employed or holding a university degree. However, our studies has indicated some similarities between the PI activities in China and Portugal. For instance, only part of the self-reported solutions is considered to be useful or innovative. Initial screening would remove un-novel examples, and less than half of the novel examples are considered to be relatively useful (For the Chinese survey, if we only account for solutions but not ideas), the solution also spread among different categories (products, services, etc). In additions, innovators are likely to share the solutions with other patients but very few (less than 5%) choose to share with the doctors.

Nevertheless, our research suggested the activity level of PI in China is lower than those in Portugal, as only 70 out of ~500 are actually creating innovations, even considering the respondents with only ideas, a total of 175 (34,9%) are innovators, which is significantly lower than 53% of self-reported innovators in Portugal. Communication of PI solutions to other patients also exhibits huge difference: only 23,5% of Chinese innovators have shown the innovation to other patients (however, 2/3 have shown to their family), compared with ~90% of the Portuguese innovators have shown it to other patients.

For the influencing factors to PI activities, we've also found interesting patterns by comparing the two countries: For both Chinese and Portuguese innovators, disease burden and educational level would have a significant effect on innovators, whereas marital status, employment status and disease duration has no effect. A factor that showed differences between two countries are being a member of patient association or group, which have an effect on Chinese innovators (likely to promote innovations from patients and caregivers) but without effect for Portuguese innovators.

Unfortunately, due to the missing of gender and age information of ~30% of the caregivers, the influence of gender and age would not be studied and compared in our current study, but deserves to explore further and compared with innovators from other countries in our future studies.

Lastly, valuable components would be added to our research by studying the specific innovations and ideas from our survey and compared the results from Portuguese PI survey.

5 Conclusions

5.1 Implication of our Research

<i>Online available PI Activities</i>	
<u>Extent</u>	Actively exist for different categories (patient, caregiver, collaborator). Absolute number is low consider the huge Population Base in China.
<u>Quality</u>	Relatively low-end, simple, low-cost solutions. Quality varies but most are acceptable. Some are innovative and inspiring.
<i>Survey Among Patients and Caregivers</i>	
<u>General</u>	Actively exist with 1/3 self-reported innovators, but only part of them is qualified. 13,3% respondents have an idea and 13,5% have a solution.
<u>Respondents with ideas</u>	Only 1/4 have specified in text/ draft or have ever tried, but 3/4 have talked to others, mainly family and other patients (very few to doctors), many constraints restrictions hinder the implementation of ideas.
<u>Respondents with innovations</u>	Many invested time and money, 72% improved in life quality after the innovation. 94% have shown or talked to others, mainly family and other patients (very few to doctors). Some awareness by public. Positive attitude and willingness to share, 28% shared and worked on others. Certain commercial potential exists.
<u>Influencing factors</u>	Idea: negative disease impact, living in big cities, not living in countryside Solution: study natural science, holding a master degree and above, being a member of patient group/ association, living in big cities but not countryside Idea + Solution: All above factors, maybe no. of social media used etc. <i>*CVD/ Heart disease affects "idea" group; malnutrition maybe affects innovation group.</i>
<i>Survey Among Patients and Caregivers</i>	
<u>Online (VS. US/ UK/ Europe)</u>	Lower active level in China. Relatively simple, economic and less advanced in technology (less innovative), either for general impression or similar solutions.
<u>Survey (VS. Portugal)</u>	Similarities in the diversity, quality and influencing factors (as well as factors without significance). Portugal has a higher level of PI activities and significantly greater % of innovators sharing solutions with other patients.
Table 17. Main findings of PI activities in China	

In general, we are inspired throughout different stages of our research project, from which we have observed the innovative inventions of patients and caregivers from various dimensions. The main findings of our research project are summarized in Table 17. To our best knowledge, this is the first study in the field of patient innovation in China, and we believe our research will add up crucial elements to the user innovations in the healthcare sector, as well as improve sharing on Patient Innovation platform between innovators from China and other countries.

5.2 Limitations of Research

Our research study based on the innovation activities by patients and caregivers in China have several limitations, which include:

1) Our samples could hardly in representative of the overall Chinese population: In the multiple-case study, the samples are all collected online, which means only the solutions that are shared or reported publicly are collected, however those the innovator have not yet shared had been omitted; in the survey among patient and caregivers in China, the samples are collected from a database of more than 2 million Chinese users, however, those people are probably more likely to participate in online surveys and complete it on a timely manner. Those may create a modest conservative bias in our findings regarding innovation activities among Chinese patients and caregivers.

2) Our sample size was still relatively small due to some constraints: Despite the diversity and richness of resources, our research would still have been benefited from a bigger sample size. We were expecting to collect more samples for online-available solutions, but according to our definition we have to stick to the 45 effective PI solutions according to our best knowledge; For online survey we've collected more than 500 comprehensive examples, nevertheless, as only 15% have move the innovation idea forward, sample size is still limited for analysing innovators that are developing or have developed a solution.

3) Subjective and self-reported data may result in some inaccuracies: The survey includes a certain amount of self-reported data. For open questions such as description of innovation, error may exist compared with real situation; The measurement of effectiveness of treatment, and patients' quality of life before and after the innovation are self-reported data, in which the standards may be biased between individuals; The rating and classification of innovations were done with the help of medical professionals, but still could no fully exclude subjective elements.

Despite the above limitations, we nonetheless consider that our research has contributed to the field of user innovation in the global healthcare sector.

5.3 Future Research

We are pleased to see that the previous research work provided more possibilities for the next stage. In addition, we would suggest the following directions of investigation in the future:

- 1) It would be meaningful to establish contact with patient associations, patient communities and patient forum/ groups, through which we are able to access a larger number of patients and caregivers for first-hand data and information, and focus on specific types of disease when necessary;
- 2) Communication with the innovators: due to the constraints, our current study mainly obtained information passively. It would be extremely helpful if we overcome this barrier in the future and have more interactions (emails, phone interviews, group discussions) with the patient and caregivers, and we strongly believe more detailed and accurate information will be obtained;
- 3) The following areas are worthy of attention: Collaborators, which is also an important category for the PI activities in China; Parents whose kids are born with a suffering from a chronic/ serious disease, which we expected to have potential findings though our current work has found very few examples;
- 4) Lastly, we strongly believe that the PI activities from China would add value to the PI community, and in the future, we will make our effort to have more Chinese contents on the PI platform, and actively promote the sharing of solutions between Chinese PI innovators and those from other countries.

Appendix

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C. Survey for Patient Innovation

Patient Innovation Survey - China 患者创新调查问卷 – 中国

I - General Questions. 一般问题

1. Do you or anyone in your family suffer from a chronic disease? 您或家中有人患有慢性疾病吗?

(If more than one people in your family have chronic disease, please select the patient, whose health condition is mostly affected by the chronic disease 如果您家中有多人患有慢性疾病, 请选择由于慢性疾病, 健康状况受到影响最大的人)

Yes, me 是的, 我自己

No 没有

Yes, a close relative or someone in my family 是的, 我的亲戚和/或家中的亲人

(Please indicate your relationship 请注明你们之间的关系: _____)

2. What is the chronic disease? 您或家人患有哪种慢性疾病?

(If the person has more than one disease, please list from the most to the least influential to the health condition 如果患者有多种慢性疾病, 请按照对健康状况影响最大到最小的顺序列出)

3. For how long has you or the person suffered from that disease? 您或家人患有这种疾病已经多长时间了?

(Please answer according to the first disease in question 2 请根据问题2中的第一个慢性疾病作答)

Less than 12 months 小于12个月

1 year (included) – 3 years 11 months 1年(含) - 3年11个月

4 years (included) – 9 years 11 months 4年(含) - 9年11个月

More than 10 years (included) 10年(含) 以上

Don't know 不确定

4. Does the chronic disease generates negative impacts/ limitations on the patient and caregiver/ family members? Please evaluate the impact/ limitations using 1 to 5. 该慢性病是否给病人或家人/照顾者的生活带来了负面影响和限制? 请用1到5的数字, 评价疾病造成的限制和负面影响。

(If there is more than one caregiver, please choose the one that is most affected to answer the question 如果有超过1位照顾者, 请选择受到影响最大的人进行回答)

1-The effect is very slight, or even negligible 可忽略或极为轻微; 2-The effect is generally slight 轻微的影响;

3-The effect is obvious, at a medium extent 中等程度; 4-The effect is relatively serious 比较严重的影响;

5-The effect is extremely serious and my life has been totally different 极为严重的影响, 无法正常生活

For the patient: 对于病人 1 2 3 4 5

For the caregiver/ family member: 对于家人/照顾者 1 2 3 4 5

5. Do you think the professional medical treatment you or the patient received is effective for the chronic disease? 您认为目前的医学治疗方法对改善病人的症状是否有效? From 1 to 5, please rate the effectiveness of the current medical treatment on the chronic disease 请用1到5的数字, 评价现有医学治疗方法的有效性。

1-Extremely Effective 非常有效, 2- Effective, but have tiny flaws 有效, 但有小的缺陷, 3- Relatively effective but have some flaws 有一定效果, 但有一些缺陷, 4- Little effect and serious flaws 效果很小, 较为严重的缺陷, 5- Extremely serious flaws or ineffective 极为严重的缺陷, 几乎无效

Western Medicine Treatment (Surgery, Medication): 西医疗法 (手术, 药物等) ()1 ()2 ()3 ()4 ()5

Chinese Medicine Treatment (TCM, Acupuncture): 中药疗法 (中药, 针灸等) ()1 ()2 ()3 ()4 ()5

Portable Equipment/ Devices: 便携式医疗仪器/辅助装置 ()1 ()2 ()3 ()4 ()5

6. Are the expenses related with the disease significant? Can you specify a monthly expense? 疾病明显增加了您的花费吗? 每个月增加的费用大体是多少?

Please answer according to the cost after reimbursed by insurance 请根据医疗保险报销后的费用作答

() No increase 没有增加

() Yes, but less than 100 EUR 是的, 但每月小于800元

() Yes, 100 (incl.) -250 EUR per month 是的, 每月800 (含) -2499元

() Yes, 250 (incl.) -499 EUR per month 是的, 每月2500 (含) -4999元

() Yes, 500 (incl.) -999 EUR per month 是的, 每月5000 (含) -9999元

() Yes, greater than 1000 (incl.) EUR per month 是的, 每月大于10000元

7. Have you ever have an idea, of a potential new or improved solution, that would help you or the patient to deal with the disease/ condition? (example: an idea for a new or improved treatment/therapy, equipment, medical or non-medical devices, behavior, strategy) 您是否曾经有过想法, 或发明、创造出了一种解决方案, 能够帮助你或病人更好地应对疾病, 改善症状? (如, 新的治疗方法、医疗/非医疗装置、一种行为习惯或策略?)

() No, I haven't thought or heard that others have done that 没有想过, 并且也没有听说过这方面的信息

() No, I haven't, but I know others who did this 没有想过, 但我了解过其他人有这样的想法或实践过

If possible, please specify and (or) put the weblink/ contact information of the person 如果可以, 请提供相关信息如网络链接, 联系方式等 _____

(If the answer is "No", please answer the questions in Part 3 如此项回答“否”, 请进入第3部分作答)

() Yes 是

(If the answer is "Yes", please answer the questions in Part 2 如此项回答“是”, 请进入第2部分作答)

2 - Questions about the innovation. 创新发明相关问题

2A – Have idea but not implementing; 2B – Innovator

8. Regarding your idea, a potential new or improved solution (example: an idea for a new or improved treatment/therapy, equipment, medical or non-medical devices, behavior, strategy), which stage does it belong to?

对于你的想法或发明创造（如，新的治疗方法、医疗/非医疗装置、一种行为习惯或策略），目前进行到了哪一个阶段？

If you have more than one idea/ innovation, please choose the one that is most important. 如果您有多个创意或发明，请选择您认为最重要的一个进行作答。

- I never implement it, or I tried but stopped 是的，但我从未实践过，或尝试过但没有继续进行 (2A)
- I'm developing a solution, but haven't finished 是的，我正在创造一个解决方案，但还未完成 (2B)
- I've developed a solution and it worked/ have reached important milestone
我创造了一个解决方案，并取得了成功/ 获得了重要进展 (2B)

(If the answer is "Yes", please answer the questions in Part 2A/ 2B如此项回答“是”，请进入2A/ 2B部分作答)

[Common Question] – 2A/ 2B

9. What does your idea or solution represent? In other words, what product- strategy did you develop?

您的创意或发明是什么？换言之，您希望创造，或创造了怎样的解决方案？

- A medical equipment (please describe) 一种治疗装置（请注明_____）
- A Treatment/Therapy (please describe) 一种治疗方法（请注明_____）
- Yes, a Behavior/ Habit/ Strategy (please describe) 一种生活行为/习惯/策略（请注明_____）
- An auxiliary tool (please describe) 一种辅助装置（请注明_____）
- A food/ drink/ natural product (please describe) 一种食物/饮料/天然产物（请注明_____）
- Others (please describe) 其他（请注明_____）

2A – Have idea but not implementing

10. How far did you go with this idea? 您的创意目前在哪一个阶段?

- I just thought about but never implement it. 我只有过想法，但从未实施
- I have specified this idea in a drawing/ a written description 我做过文字记录或者画过草图
- I have specified this idea in model but not move further 我做过示意模型，但没有进一步进行
- I once started working on my idea but stopped 我曾经实践过，但没有继续进行
- Other status (please specify) 其他状态（请注明）_____

11. Have you ever discussed with other people about your idea? 您和其他人交流过您的创意和想法吗?

Multiple Choice Question (多项选择题)

- No 没有
- Yes, other patients with similar disease 是的，其他病友
- Yes, my family and relatives 是的，我的家人
- Yes, other friends (non- patients with similar disease) 是的，其他朋友（非病友）
- Yes, my doctor (s) 是的，我的医生
- Yes, other people (please specify) 是的，其他人（请注明）_____

12. Why did you stop working on your innovation idea? 是什么原因让您没有继续实施您的创意?

Multiple Choice Question (多项选择题)

- Physical constraints (disease related) 疾病和身体原因
- Time constraints 个人时间限制
- Economic constraints (e.g. cost is high) 经济原因（如，实践需要较高的成本）
- Perceive it's difficult to execute it 感到执行起来非常困难
- I've talked with others but they think it's not interesting 我与其他人交流过，但他人认为意义不大
- Other reasons (please specify) 其他原因（请注明）_____

2B - Innovator

13. How long does it takes you (or expected to take) to develop the innovation? 您完成整个发明大概经历了，或者预计经历多长时间？

If you have improved the innovation, please refer to the latest version 如进行过改进，以最新版本完成的时间为准

- Less than 6 months 小于6个月
- 6 months (included) – 1 years 11 months 6个月（含）- 1年11个月
- 2 years (included) – 4 years 11 months 2年（含）- 4年11个月
- More than 5 years (included) 5年以上
- Don't know 不确定

14. How much does it cost (or expected to cost) to develop the innovation? 您完成整个发明大概花费了，或者预计花费多少费用？

_____ RMB 元

15. Does the innovation improved the life quality of the patient? 创新发明是否提高了病人的生活质量？

From 1 (non-existing) to 7 (excellent) how do you rate the quality of life of the patient. 请用从1到7的数字，评价病人生活质量的变化

(1- Non-existing 几乎没有改变, 2- Improved a little 微小的改变, 3- Improved more than a little but less than medium 小到中等程度的改变, 4- Improved to a medium extent 中等程度的改变, 5-较大的改变 Improved relatively significant, 6-很大的改变 Improved significantly, 7-巨大的改变, 几乎和正常人一样 Improved tremendously, almost become normal)

If the patient hasn't try the solution, please select the same scale. 如病人尚未尝试该发明，请选择相同数值。

Before the innovation: 创新发明之前: 1 2 3 4 5 6 7

After the innovation: 创新发明之后: 1 2 3 4 5 6 7

16. Has someone helped you to develop the solution? 您在创新发明过程中是否得到了其他人的帮助？

Multiple Choice Question (多项选择题)

- No 没有
- Yes, my family member and relatives 是的，我的家庭成员和亲戚
- Yes, my friends 是的，我的朋友
- Yes, primary/ middle/ high/ school or university students 是的，研究生/大学/中学/小学学生
- Yes, entrepreneurs and companies 是的，企业家和企业
- Yes, other kind-hearted people 是的，其他热心和好心人

(If possible, please specify the person/ people/ school/ company that helped you 如果可以，请分享帮助人/ 学校/ 企业的信息: _____)

17. Have you discussed/ showed your idea/ innovation to others? 您和其他人交流或演示过您的发明吗?

Multiple Choice Question (多项选择题)

- No 没有
- Yes, other patients with similar disease 是的, 其他病友
- Yes, my family and relatives 是的, 我的家人
- Yes, other friends (non- patients with similar disease) 是的, 其他朋友 (非病友)
- Yes, my doctor (s) 是的, 我的医生
- Yes, other people (please specify) 是的, 其他人 (请注明) _____

18. Have you learned knowledge by yourself to develop the solution?

您是否学习了相应的知识和技能, 以完成您的发明?

- No 没有
- Yes, I've learned a little but not much 是的, 学习了一点, 但不是很多
- Yes, I've learned a lot 是的, 学习了很多人
- Yes, I've learned a huge amount and intensively/ consistently 是的, 学习了非常多, 并且持续学习

19. Have you already did, or willing to share your innovation with others?

您是否已经或者愿意把发明分享给其他人?

- I've already shared and it worked on others 我已经分享给他人, 并且对他人有效
 - I've talked and about to share with others 我已经和他人沟通过, 即将分享给他人
 - I'm happy to share with others, but haven't yet due to constraints 我愿意分享给他人, 但因条件所限, 暂未
 - Currently haven't considered sharing 暂时还没有分享给他人的想法
- (Indicate reason if possible 如果可以, 请注明原因: _____)

20. Has your innovation heard by the public and won corresponding awards? 您的发明是否被公众得知, 并获得一定荣誉?

Multiple Choice Question (多项选择题)

If you have participated in multiple competitions and exhibitions, please refer to the one you think is most important

如果您曾经参加过多个竞赛或展览, 请选择您认为最有意义的一个

- No 没有
- Yes, participated in international competition/ exhibition 是的, 参加过国际竞赛 (展览)
- Yes, participated in national/ regional competition/ exhibition 是的, 参加过国内或地方竞赛 (展览)
- Yes, reported by newspaper/ internet/ other media 是的, 被报纸或网站报道过

If the answer is "Yes", please specify the name and whether you've won an award, preferably with links

如回答为“是”, 请提供竞赛 (展览) / 媒体名称, 获得奖项等 (最好可附上网络链接)

21. What's your attitude towards your innovation and the process? 您怎样看待自己的发明/创新活动?

Multiple Choice Question (多项选择题)

- I am proud of myself and improved my confidence 我感到骄傲，并提高了自信
- I am planning to improve it further 我计划对其进行更多的改进和完善
- I would like to share for free or with marginal cost 我愿意免费或成本费用与他人分享
- I would like to turn it into a business 我希望能够从事与之相关的商业活动，并获得利润
- Others (please specify) 其他（请注明_____）

* Answer this question if you choose "I would like to turn it into a business" in Q22, otherwise please skip it.
如您在21题中选择“我希望能够从事与之相关的商业活动，并获得利润”，请回答此题，否则跳过此题

21.1 What's your plan on starting a business out of your innovation?

您对商业活动的规划是怎样的?

- I already started my own company 我已经成立了公司，并开展经营
If so, indicate name and year of founding 如选择此项，请注明公司名称，成立年份_____
- I am planning to start/ cofound my company soon 我正在计划成立公司
- I am collaborating with the manufacturer to produce 我与生产商合作生产产品
- I am looking for manufacturer to produce 我正在寻找合适的生产商
- I am not taking active action but open to collaboration 我暂未采取行动，但对新机会会有兴趣

22. Have you applied or planning to apply for patents?

您是否已经，或打算为您的发明申请专利?

- No, and I'm not planning to do that 没有，暂无此方面的打算
- No, but I'm planning to do that 没有，但我计划这样做
- Yes, I have applied patent but not yet granted 是的，我已经申请了专利，但暂未获批
- Yes, the patent has been granted 是的，我已经获得了专利

3 - Demographic questions. 人口统计学相关问题

23. Birth year of the patient? 病人出生于哪一年?

24. Gender of the patient? 病人的性别?

Female 女性

Male 男性

25. Birth year of the innovator? 发明者出生于哪一年?

If the patient is the innovator, please use the same information as Q23; if there is no innovator, please leave it blank 如果病人是发明人, 请填写与Q23中相同的信息, 如果没有发明创造, 此项请留空

26. Gender of the innovator? 发明者的性别

If the patient is the innovator, please use the same information as Q24 if there is no innovator, please leave it blank 如果病人是发明人, 请填写与Q24中相同的信息, 如果没有发明创造, 此项请留空

Female 女性

Male 男性

27. Location & administrative division of residence: 居住地区划属性

State-owned cities, capital of provinces and special economic zones 直辖市、省会城市和经济特区

Other prefecture-level cities 其他地级市

County-level cities, counties and towns 县级市、县城和城镇

Countryside 乡、村

Overseas: Please specify country/ city 海外 (请注明国家/ 地区_____)

28. Employment status: 经济状况

Student 学生

Employed 在职

Unemployed 失业

Retired 退休

Housewife 家庭主妇/男

Other: 其他 (请注明_____)

29. Education level? 教育状况

- Primary or below 小学及以下
- Middle & High School 中学
- Bachelor 本科
- Master or above 硕士及以上
- Others: 其他

30. Field of study? 专业领域

- Exact Sciences 精确科学
- Natural Sciences 自然科学
- Engineering & Technology 工程技术
- Agricultural Sciences 农业
- Social Sciences 社会科学
- Art 艺术

31. Marital Status? 婚姻状况?

- Single 单身
- Married 已婚
- Divorced 离婚
- Cohabitation 同居
- Widower 守寡

32. Are you (or a member of your family) member of another chronic/ rare disease association?

您或您的家庭成员是否参与了慢性病/罕见病协会?

- No 没有
- Yes (If yes, which?): 是的 (组织的名称是什么? 请注明_____)

33. Are you (or a member of your family) usually visit disease related forums and groups, and share/ exchange information with other patients or caregivers? 您或您的家庭成员是否经常访问疾病相关的论坛和小组, 并与其他病人和照顾者分享解决方案?

- No 没有
- Yes, but only visited but not posting 是的, 但我只是浏览但不发言
- Yes, we exchange information occasionally 是的, 我们偶尔交换信息
- Yes, we exchange information very often 是的, 我们经常交换信息

If you choose "yes", please specify the name of the forum/ group 如选择“是”, 请注明论坛/小组的名称

4 - ICT Related Questions. 信息技术相关问题

34. Do you have access to internet? 您能每天使用互联网吗?

- No 不能
- Yes 能

35. What social networks do you use? 您使用什么社交网络?

Multiple Choice Question (多项选择题)

- WeChat 微信
- QQ 腾讯 QQ
- SINA Blog 新浪微博
- Video Websites 视频网站
- Others 其他 (Please specify 请注明_____)

36. We've developed a platform where patients of chronic and rare disease can share among them experiences and solutions for their pathologies (<https://patient-innovation.com>). Would you join such platform and share your innovative solutions with patients and caregivers around the world?

我们建立了一个慢性病的病人及看护者能够分享他们的经验和解决方案的平台 (<https://patient-innovation.com/>)。您是否愿意加入这个平台，与其他病友共享解决方案?

- No 不
- Yes 是的

D. Fixation of PI China Survey Data

1) Samples missing important data or not in the range of our analysis are removed

#747 – No disease type

#478 – Belongs to the collaborator type

#81 – Missing Demographic and ICT information

#57, #51 – Missing ICT information

2) Samples missing genders of the patients are recovered based on relationship information

#792, #778, #674, #668, #651, #629, #565, #511 are recovered

#541, #561 – Could not be recovered, so we've removed them

Besides, we've recovered the birth year and gender information in Q25 and Q26, when the respondent is a patient, however, this method does not apply to the case where the respondent is a caregiver. Due to the missing information of birth year and gender information of the respondents and other constraints, we've finally decided to exclude the gender and birth year of respondents in our analysis.

7 out of 509 samples in PI China survey were removed, and the rested 502 are applied for statistical analysis.

E. List of valid PI Examples from Survey

Id	Type	Classification	Description	Rate
620	Innovation	A Treatment/ Therapy	A method to completely cure diabetes	PI - Good Example
588	Innovation	A Behaviour/ Habit/ Strategy	Change life schedule to reduce frequency of occurrence	PI - Ordinary Example
430	Innovation	A medical equipment	Heart Starter	PI - Good Example
323	Innovation	A Behaviour/ Habit/ Strategy	Avoid spicy and salty food, light diet	PI - Good Example
464	Innovation	A food/ drink/ natural product	Water	PI - Good Example
142	Innovation	A Behaviour/ Habit/ Strategy	Take care of health	PI - Good Example
745	Innovation	A food/ drink/ natural product	A drink to treat diabetes	PI - Good Example
60	Innovation	A Behaviour/ Habit/ Strategy	Reduce a certain type of antihypertensive drugs	PI - Good Example
50	Innovation	A Treatment/ Therapy	Combined with medical treatment	PI - Good Example
463	Innovation	A Treatment/ Therapy	Medication	PI - Ordinary Example
709	Innovation	A medical equipment	Respirator to treat athema	PI - Good Example
678	Innovation	A food/ drink/ natural product	Reduce salt intake	PI - Ordinary Example
460	Innovation	A Treatment/ Therapy	A treatment method aim to alleviate the pain	PI - Good Example
697	Innovation	A Treatment/ Therapy	Medical treatment in combination with diet	PI - Ordinary Example
110	Innovation	A food/ drink/ natural product	A food that help to maintain a stable condition	PI - Good Example
129	Innovation	A medical equipment	Chemotherapy apparatus	PI - Good Example
696	Innovation	A Behaviour/ Habit/ Strategy	Balanced nutrition & low sugar diet	PI - Good Example
395	Innovation	A Treatment/ Therapy	Foods that can ease diabetes in daily life	PI - Good Example
205	Innovation	A food/ drink/ natural product	A drink that could cure the disease	PI - Good Example
76	Innovation	A Behaviour/ Habit/ Strategy	Through exercise and sports	PI - Good Example
351	Innovation	A Behaviour/ Habit/ Strategy	Take more walks	PI - Ordinary Example
152	Innovation	A Behaviour/ Habit/ Strategy	Exercise everyday	PI - Ordinary Example
13	Innovation	A Treatment/ Therapy	Combination of Western and Chinese medicine treatment	PI - Ordinary Example
524	Innovation	A Behaviour/ Habit/ Strategy	Proper diet and living style	PI - Good Example

141	Innovation	A Behaviour/ Habit/ Strategy	Chinese medicine assisted with proper diet	PI - Good Example
658	Innovation	A medical equipment	A portable device to cure Asthma	PI - Ordinary Example
384	Innovation	A Treatment/ Therapy	Habits that reduce patient from suffering	PI - Ordinary Example
300	Innovation	A Behaviour/ Habit/ Strategy	Relieve diabetes	PI - Ordinary Example
273	Innovation	A Behaviour/ Habit/ Strategy	Not specified	PI - Ordinary Example
654	Innovation	A medical equipment	Highly-efficient treatment device	PI - Good Example
689	Innovation	A Behaviour/ Habit/ Strategy	Reasonable health (?)	PI - Ordinary Example
556	Innovation	A Behaviour/ Habit/ Strategy	Pay attention to diet	PI - Good Example
700	Innovation	A Behaviour/ Habit/ Strategy	Keep warm and avoid strenuous exercise	PI - Ordinary Example
640	Innovation	A Treatment/ Therapy	Combination of Western and Chinese Medicine/ Treatment	PI - Ordinary Example
380	Innovation	A Behaviour/ Habit/ Strategy	Diet	PI - Ordinary Example
286	Innovation	A Behaviour/ Habit/ Strategy	Proper & reasonable diet	PI - Ordinary Example
54	Innovation	A Behaviour/ Habit/ Strategy	Adequate physical exercises	PI - Ordinary Example
20	Innovation	A Behaviour/ Habit/ Strategy	Exercise more, take proper type of physical exercise	PI - Ordinary Example
526	Innovation	A Treatment/ Therapy	Hypnosis	PI - Good Example
427	Innovation	A Behaviour/ Habit/ Strategy	Regulate diet habit	PI - Good Example
194	Innovation	A Behaviour/ Habit/ Strategy	Strengthen your physical capacity	PI - Good Example
21	Innovation	A Treatment/ Therapy	Relieve the condition (Pharyngitis)	PI - Good Example
670	Innovation	A Behaviour/ Habit/ Strategy	Acupressure	PI - Ordinary Example
130	Innovation	A food/ drink/ natural product	Food that helps alleviate the condition	PI - Ordinary Example
542	Innovation	A Behaviour/ Habit/ Strategy	Exercise more	PI - Ordinary Example
450	Innovation	A food/ drink/ natural product	Hypotensive tea	PI - Ordinary Example
712	Innovation	A food/ drink/ natural product	Fruit & vegetable drink	PI - Good Example
724	Innovation	A Behaviour/ Habit/ Strategy	Running/ Jogging	PI - Ordinary Example
183	Innovation	A Behaviour/ Habit/ Strategy	A reasonable diet and regular exercise	PI - Ordinary Example
222	Innovation	A Behaviour/ Habit/ Strategy	Pay attention to diet	PI - Good Example

540	Innovation	A Behaviour/ Habit/ Strategy	More exercise, less desire and intake of unhealthy food	PI - Good Example
221	Innovation	Others	Not specified	PI - Good Example
74	Innovation	A Treatment/ Therapy	Food therapy	PI - Good Example
3	Innovation	A Behaviour/ Habit/ Strategy	Good living habit & customs	PI - Ordinary Example
163	Innovation	A food/ drink/ natural product	Exercise and food therapy	PI - Ordinary Example
656	Innovation	A Behaviour/ Habit/ Strategy	Pay attention to weather changes	PI - Good Example
650	Innovation	A Behaviour/ Habit/ Strategy	Exercise deligently and properly	PI - Good Example
327	Innovation	A Behaviour/ Habit/ Strategy	Enable patient to live happily in the hospital (?)	PI - Good Example
299	Innovation	A Behaviour/ Habit/ Strategy	Ensure peace of mind, wear a mask, keep away from dust	PI - Good Example
225	Innovation	A Behaviour/ Habit/ Strategy	Pay attention to hygiene, exercise more daily	PI - Good Example
70	Innovation	A Behaviour/ Habit/ Strategy	Plan a better living style	PI - Good Example
47	Innovation	A food/ drink/ natural product	Polycarpaea corymbosa (L.) Lam.	PI - Good Example
37	Innovation	A Behaviour/ Habit/ Strategy	Pay attention to the diet (modify according to one's ongoing condition)	PI - Good Example
5	Innovation	A Behaviour/ Habit/ Strategy	Oxygen therapy	PI - Good Example
642	Innovation	A Behaviour/ Habit/ Strategy	Eat more fruits and vegetables	PI - Ordinary Example
252	Innovation	A Behaviour/ Habit/ Strategy	Eat less salt	PI - Ordinary Example
188	Innovation	A Behaviour/ Habit/ Strategy	Work and rest regularly	PI - Ordinary Example
172	Innovation	A Behaviour/ Habit/ Strategy	Eat more nutritional food	PI - Ordinary Example
714	Idea	A medical equipment	A portable device to prevent occurance/ onset	PI - Good Example
706	Idea	A Behaviour/ Habit/ Strategy	Meditation	PI - Good Example
682	Idea	A Behaviour/ Habit/ Strategy	Improve gout through a set of useful exercises	PI - Good Example
671	Idea	A Behaviour/ Habit/ Strategy	Pay attention to diet and mood	PI - Good Example
662	Idea	A Behaviour/ Habit/ Strategy	Avoid strong emotions (e.g. anger)	PI - Good Example
473	Idea	A medical equipment	A device to help patient breath smoothly	PI - Good Example
405	Idea	A food/ drink/ natural product	Spirulina	PI - Good Example
370	Idea	A food/ drink/ natural product	Celery (Lower blood pressure)	PI - Good Example

349	Idea	A medical equipment	A wheelchair that could monitor the body status	PI - Good Example
215	Idea	A medical equipment	Asthma pressure reducer	PI - Good Example
211	Idea	A Behaviour/ Habit/ Strategy	Proper/ reasonable diet and exercise consistently	PI - Good Example
116	Idea	A Behaviour/ Habit/ Strategy	Auxiliary diet and take more exercise	PI - Good Example
100	Idea	A Behaviour/ Habit/ Strategy	Acupuncture and massage	PI - Good Example
92	Idea	A medical equipment	Ventilator	PI - Good Example
77	Idea	A medical equipment	Auto detection device	PI - Good Example
34	Idea	A Behaviour/ Habit/ Strategy	The influence of lifestyle on diabetes, and how to improve	PI - Good Example
22	Idea	A Behaviour/ Habit/ Strategy	Healthy diet, formulating scientific & reasonable recipes	PI - Good Example
18	Idea	A Behaviour/ Habit/ Strategy	Healthy eating, regular lifestyle, diligent exercise	PI - Good Example
729	Idea	A Behaviour/ Habit/ Strategy	Take more exercise	PI - Ordinary Example
699	Idea	A food/ drink/ natural product	Food that contains less sugar but delicious	PI - Ordinary Example
677	Idea	A food/ drink/ natural product	Eat more fruit and vegetables, etc.	PI - Ordinary Example
666	Idea	A Behaviour/ Habit/ Strategy	Go to bed early and get up early	PI - Ordinary Example
661	Idea	A Behaviour/ Habit/ Strategy	Eat less meat	PI - Ordinary Example
660	Idea	A Behaviour/ Habit/ Strategy	Keep positive mood and work/ sleep properly	PI - Ordinary Example
619	Idea	A Behaviour/ Habit/ Strategy	Feet bath everyday	PI - Ordinary Example
602	Idea	A food/ drink/ natural product	A food that can cure laryngitis	PI - Ordinary Example
590	Idea	A medical equipment	A device to relieve pain of patients	PI - Ordinary Example
534	Idea	A food/ drink/ natural product	Eat adequate food to improve the condition, strictly follow a plan	PI - Ordinary Example
499	Idea	A Treatment/ Therapy	Reduce the amount of exercise	PI - Ordinary Example
498	Idea	A Behaviour/ Habit/ Strategy	Avoid from strong emotions	PI - Ordinary Example
482	Idea	A Behaviour/ Habit/ Strategy	Free from alcohol	PI - Ordinary Example
475	Idea	A Behaviour/ Habit/ Strategy	Exercise, take a walk, fitness	PI - Ordinary Example
456	Idea	A food/ drink/ natural product	Plants in the nature that can improve the condition/ health	PI - Ordinary Example
448	Idea	A Behaviour/ Habit/ Strategy	Go to bed early and get up early	PI - Ordinary Example

447	Idea	A Behaviour/ Habit/ Strategy	Food therapy	PI - Ordinary Example
444	Idea	A Behaviour/ Habit/ Strategy	Diet or rest properly to regulate blood pressure	PI - Ordinary Example
426	Idea	A Behaviour/ Habit/ Strategy	Keep health care/ wellness	PI - Ordinary Example
424	Idea	A Behaviour/ Habit/ Strategy	Go to bed early and get up early	PI - Ordinary Example
386	Idea	A Treatment/ Therapy	Exercise Improves Immunity	PI - Ordinary Example
352	Idea	A Behaviour/ Habit/ Strategy	Eat and sleep on time/ regularly	PI - Ordinary Example
346	Idea	A Behaviour/ Habit/ Strategy	Keep a good habit of exercise	PI - Ordinary Example
328	Idea	A food/ drink/ natural product	Apple	PI - Ordinary Example
317	Idea	A Behaviour/ Habit/ Strategy	Sleep early and get up early	PI - Ordinary Example
289	Idea	A Behaviour/ Habit/ Strategy	Take exercises often	PI - Ordinary Example
277	Idea	A food/ drink/ natural product	Eat sugar-free food	PI - Ordinary Example
265	Idea	A Behaviour/ Habit/ Strategy	Wear a mask when going outside	PI - Ordinary Example
260	Idea	A Treatment/ Therapy	Avoid taking medicine, relieve by massage instead	PI - Ordinary Example
232	Idea	A Treatment/ Therapy	Accupunture treatment	PI - Ordinary Example
228	Idea	A Behaviour/ Habit/ Strategy	On diet (Reduce intake)	PI - Ordinary Example
227	Idea	A Behaviour/ Habit/ Strategy	Go to bed early and get up early	PI - Ordinary Example
207	Idea	A Behaviour/ Habit/ Strategy	Eat more fruit	PI - Ordinary Example
202	Idea	A Behaviour/ Habit/ Strategy	Reduce salt intake	PI - Ordinary Example
200	Idea	A food/ drink/ natural product	Inhibition of asthma	PI - Ordinary Example
193	Idea	A Behaviour/ Habit/ Strategy	Conduct a sugar-free diet plan	PI - Ordinary Example
180	Idea	A food/ drink/ natural product	A food therapy method	PI - Ordinary Example
165	Idea	A Behaviour/ Habit/ Strategy	Exercise more	PI - Ordinary Example
161	Idea	A Behaviour/ Habit/ Strategy	Eat light food, exercise more	PI - Ordinary Example
147	Idea	A food/ drink/ natural product	Fruit	PI - Ordinary Example
114	Idea	A Treatment/ Therapy	Nutritional diet	PI - Ordinary Example
109	Idea	A Behaviour/ Habit/ Strategy	Take more exercise	PI - Ordinary Example

99	Idea	A food/ drink/ natural product	Healthy food/ food therapy	PI - Ordinary Example
87	Idea	A medical equipment	A device to relieve pain	PI - Ordinary Example
64	Idea	A Behaviour/ Habit/ Strategy	Eat foods that help to improve coronary heart disease every day	PI - Ordinary Example
53	Idea	A Behaviour/ Habit/ Strategy	Healthy food/ diet	PI - Ordinary Example
52	Idea	A Behaviour/ Habit/ Strategy	Improve living habits	PI - Ordinary Example
38	Idea	A Behaviour/ Habit/ Strategy	Good and health living habits	PI - Ordinary Example
10	Idea	A Behaviour/ Habit/ Strategy	Diet and healthy recipes	PI - Ordinary Example
Table S1. List of valid PI activities in China (from survey)				

F. Influencing factors of PI Activities in China

Respondents with Innovative ideas and Innovative solutions were considered as either independent or same group, the three groups included in our analysis are [Ideas VS. None] and [Solutions VS. None] and [Idea + Solutions VS. None] (in SPSS, 4 variables for group identification were established to reduce errors).

For scale and ordinal variables, we've used 1-way ANOVA analysis plus post-hoc method, therefore [Ideas VS. None] and [Solutions VS. None] were calculated in one model to reduce Type I error, as shown in Table S2.

<i>P-Value</i>	<i>Ideas</i>	<i>Solutions</i>	<i>Ideas + Solutions</i>
<u>No. of diseases</u>	0,458	0,300	0,241
<u>Disease Duration</u>	0,321	0,911	0,733
<u>Negative Impact of Disease</u>	0,007*	0,070***	0,003*
<u>Treatment Efficiency</u>	0,646	0,211	0,259
<u>Increase in expense</u>	0,266	0,124	0,081***
<u>No. of social media used</u>	0,054***	0,080***	0,016**

Table S2. Significance of Scale and Ordinal Factors for PI activities

(Calculated using 1-way ANOVA (with post-hoc) analysis in SPSS; * $p < 0,01$, ** $p < 0,05$, *** $p < 0,1$)

Nominal variables (including disease type) were analysed using Chi-square, results are shown in Table S3 and S4, where [Ideas VS. None] and [Solutions VS. None] were calculated in 2 models as the difference between “Innovative Ideas” and “Innovative Solutions” are not in the range of our study.

<i>P-Value</i>	<i>Ideas</i>	<i>Solutions</i>	<i>Ideas + Solutions</i>
<u>Marital Status</u>	0,175	0,734	0,333
<u>Field of Study</u>	0,378	0,000*	0,000*
<u>Employment Status</u>	0,132	0,167	0,121
<u>Location of Residence</u>	0,030**	0,009*	0,000*
<u>Educational Level</u>	0,180	0,000*	0,000*
<u>Member of Patient association of group</u>	0,872	0,000*	0,000*
<u>Access to Internet</u>	0,197	0,188	0,077***
<u>Would like to join PI</u>	0,142	0,228	0,073***

Table S3. Significance of Nominal Factors for PI activities

(Calculated using Chi-square analysis in SPSS; * $p < 0,01$, ** $p < 0,05$, *** $p < 0,1$)

<i>P-Value</i>	<i>Ideas</i>	<i>Solutions</i>	<i>Ideas + Solutions</i>
<u>Hypertension</u>	0,555	0,235	0,243
<u>Hyperlipemia</u>	0,776	0,787	0,720
<u>Hyperglycaemia</u>	0,391	0,387	0,223
<u>Diabetes</u>	0,219	0,368	0,849
<u>Heart diseases/ CVD</u>	0,002*	0,547	0,091***
<u>Asthma</u>	0,695	0,843	0,898
<u>Osteoporosis</u>	0,218	0,660	0,266
<u>Cervical/ lumbar diseases</u>	0,595	0,454	0,932
<u>Rheumatoid/ rheumatism</u>	0,686	0,219	0,620
<u>Otolaryngology disease</u>	0,717	0,282	0,611
<u>Gastrointestinal disease</u>	0,555	0,920	0,753
<u>Respir track inflammation</u>	0,630	0,814	0,881
<u>Gout</u>	0,521	0,839	0,576
<u>Malnutrition</u>	0,932	0,032**	0,160
<u>Hepatitis/ other liver diseases</u>	0,933	0,333	0,570

Table S4. Significance of diseases for PI activities

(Calculated using Chi-square analysis in SPSS; * $p < 0,01$, ** $p < 0,05$, *** $p < 0,1$)