UNIVERSITY OF TURKU

# The Development and Evaluation of E-Management Platform for Patient-reported Outcomes Research Based on Business Process Improvement Theory

Department of Nursing Science
Master's thesis

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# Abstract


**Background**

Patient-reported outcomes (PROs) refer to the health-related information coming directly from patients without any explanation by the doctors or others. It is of great significance for patients to participate in medical decision-making, have a higher quality of care， and have a better medical outcome. Therefore, patient-reported outcomes measurements (PROMs) have important clinical value. Patient-reported Outcomes Measurement Information System (PROMIS) is one of the most accurate PROMs led by NIH and focuses on health-related big data's scientific characteristics. PROMIS advocates cross-population, cross-region, and cross-disease studies and is widely recognized among the research community. PROMIS Health Organization (PHO) now promotes the global implementation of PROMIS by setting up PROMIS National Center (PNC) in various countries, and PNCs organize the research cooperation with many research groups to promote PROMIS. PROMIS China Center is one of the PNCs that takes charge of the PROs cooperative research with many research teams to promote PROMIS in China. Due to the diverse tasks, complex procedures, and low efficiency of the current cooperative management mode of PROMIS China Center, it cannot meet the efficient research management requirements. Therefore, it is necessary to analyze the needs, improve the process, and build an E-management platform under the guidance of business improvement theory to improve the management efficiency of the patient-reported outcome research and eventually promote PROMIS in China.

**Objectives**

The general purpose of this research is to improve the management process of patient-reported outcomes research based on the business process improvement theory and develop an E-Management platform as well as evaluate the usability of the E-management platform.

Purpose one: The need analysis of the E-management platform for the patient-reported outcomes research;

Purpose two: The framework construction of the E-management platform for patient-reported outcomes research;

Purpose three: The development of the E-management platform for patient-reported outcomes research;

Purpose four: The usability evaluation of the E-Management Platform for Patient-reported outcomes research.

**Methods**

The study was comprised of 4 parts：

Part1: The need analysis of the E-management platform for the patient-reported outcomes research

Based on business improvement theory (ESIA theory), the researcher conducted the semi-structured qualitative interviews, including five rounds of focus group interviews with 5 management staffs of the PROMIS China Center and one-on-one interviews with 11 cooperative team members to know the current management process of patient-reported outcomes research, the problems of current management process, and the need for the E-management platform.

Part2: The framework construction of the E-management platform for patient-reported outcomes research

The researcher held a brainstorming discussion with 13 management staffs to improve the current management process based on business improvement theory; Meanwhile, the researcher accomplished the literature study about the patient-reported outcomes research E-management platforms of other countries and analyzed the framework; Then, the researcher combined the results of need analysis, brainstorming, and literature study to draw the preliminary framework of the patient-reported outcomes research E-management platform; Finally, the researcher held an expert group meeting with

7 experts from the field of both nursing research and software engineering to revise the preliminary framework and make a final framework.

Part3: The development of the E-management platform for patient-reported outcomes research

The researchers organized and coordinated close cooperation among experts in different fields. Based on the final framework of the E-management platform formed in the early stage, the researchers adopted the human-centered concept and the agile development method to develop the E-management platform with 3 software engineers.

Part4: The usability evaluation of the E-Management Platform for Patient-reported outcomes research

The researcher implemented the formative usability evaluation during the process of development to find the problems about the interface, like font and module; Then the researcher implemented the summarized usability evaluation by task analysis and semi-structured interviews with 15 users，including 5 management staffs of the PROMIS China Center and 10 cooperative team members. The evaluation outcomes were reported after data analysis.

**Results**

Part1: The need analysis of the E-management platform for the patient-reported outcomes research

The qualitative research results show the: ① PROMIS translation, validation, clinical application management processes, and the researcher presented them in text and flow chart. ② The current process's problems, like the current management process is tedious; the current management process involves too much paper materials; it is difficult for management staffs to supervise the process. ③ the need for the E-management: all the participants said they need the E-management platform and expressed their specific needs.

Part2: The framework construction of the E-management platform for patient-reported outcomes research

The brainstorming efficiently improved the management process, and the improved process was shown with text and flowchart; The literature study presented the framework of the Netherlands PROMIS E-management platform; the researcher drew a preliminary framework of the E-management platform under the guidance of need analysis, improved management process, and Netherlands PROMIS E-management platform, which contains 7 first-level modules, and 5 second-level modules. After the expert group meeting, the final framework was constructed, which includes 6 first-level modules: "Home", " Introduction ", "PROMIS Measurement", "News Center", "Resources", and " Research Cooperation", 16 second-level modules, and the content covered by the second-level modules.

Part3: The development of the E-management platform for patient-reported outcomes research

The researchers demonstrated the preliminary framework of the E-management platform to the software engineers, and we worked jointly to complete the development of the E-management platform after the steps of requirement clarification, design, development, testing, and release.

Part4: The usability evaluation of the E-Management Platform for Patient-reported outcomes research

During the formative usability evaluation, the researcher found many problems, and they were all solved by software engineers; During the summarized usability evaluation, we demonstrated the platform in terms of effectiveness, efficiency, and satisfaction. Based on the scores of the usability evaluation questionnaire after the test: system usefulness is 5.2 (from management staffs) and 5.8 (from cooperative team members), information quality is 6.8 (from management staffs) and 6.0 (from cooperative team members), interface quality is 5.4 (from management staffs) and 5.9 (from cooperative team members), and overall evaluation is 6.0 (from management staffs) and 6.2 (from cooperative team members). Through qualitative interviews, we understand the user experience of the platform. The interview data shows two topics related to usability. By combining quantitative and qualitative outcomes, the researcher thinks that the E-management platform's usability is generally good, but there are still some shortcomings.

**Conclusions**

Both the management staffs and cooperative team members of the PROMIS China Center have a high level of need for the E-management platform. The final framework based on need analysis and process improvement is good guidance for developing the E-management platform. The usability evaluation shows that the E-management platform has a good usability and can help manage the patient-reported outcomes cooperative research. It will be able to enhance the management efficiency of patients-reported outcomes research extensively and accelerate the rapid promotion of PROMIS in China.

**KEY WORDS：** Patient-reported Outcomes, Patient-reported Outcomes Measurement Information System, E-management platform, ESIA Theory, Business Process Improvement

# Abstrakti

**Tausta**

Potilaan raportoimilla vaikutuksilla (patient-reported outcomes PROs) tarkoitetaan terveyteen liittyviä tietoja, jotka tulevat suoraan potilailta, ilman lääkäreiden tai muiden tulkintoja. On tärkeää, että potilaat voivat osallistua lääketieteelliseen päätöksentekoon, saada laadukkaampaa hoitoa ja parempia hoitotuloksia. Siksi asiakkaan raportoimilla vaikutusmittareilla (patient-reported outcome measurements PROMs) on tärkeä kliininen arvo. PROMIS (Patient-reported Outcomes Measurement Information System) on yksi tarkimmista Yhdysvaltojen terveysviraston (National Institute of Health, NIH) johtamista asiakkaan raportoimista vaikutusmittaristojärjestelmistä ja se keskittyy terveyteen liittyvien suurten tietomassojen tieteellisiin ominaisuuksiin. PROMIS tukee eri väestöryhmien, alueiden ja sairauksien välisiä tutkimuksia, ja se on laajalti tunnistettu tutkimusyhteisön keskuudessa. PROMIS Health Organization (PHO) on edistänyt PROMISin maailmanlaajuista käyttöönottoa perustamalla PROMIS National Center (PNC) -keskuksia eri maihin ja järjestämällä tutkimusyhteistyötä useiden tutkimusryhmien kanssa PROMISin edistämiseksi. PROMIS China Center on yksi kansallisista keskuksista (PNC), joka vastaa PROs-yhteistyötutkimuksesta useiden tutkimusryhmien kanssa edistääkseen PROMISin käyttöönottoa Kiinassa. PROMIS China Centerin monipuolisten tehtävien, monimutkaisten menettelytapojen, ja nykyisen johtamisvastuun heikon tehokkuuden vuoksi, se ei pysty täyttämään tehokkaita tutkimusjohtamisvaatimuksia. Siksi on välttämätöntä liiketoimintaprosessien parantamisteoriaan perustuen analysoida tarpeita, parantaa prosesseja ja rakentaa sähköisen johtamisen alusta, jotta voidaan parantaa potilaan raportoimien vaikutusten (PROs) tutkimuksen johtamisen tehokkuutta ja edistää PROMISia Kiinassa.

**Tavoitteet**

Tämän tutkimuksen tarkoituksena on parantaa asiakkaan raportoimien vaikutusten (PROs) tutkimuksen johtamista liiketoimintaprosessien parantamisteoriaan perustuen ja kehittää e-hallinta-alusta sekä arvioida alustan käytettävyyttä.

Tehdään e-hallinta-alustan tarveanalyysi potilaan raportoimien vaikutusten tutkimusta varten;

Rakennetaan viitekehys e-hallinta-alustalle potilaan raportoimien vaikutusten tutkimusta varten;

Kehitetään e-hallinta-alusta potilaan raportoimien vaikutusten tutkimusta varten;

Arvioidaan e-hallinta-alustan käytettävyyttä potilaan raportoimien vaikutusten tutkimuksessa.

**Metodit**

Tutkimus koostui neljästä osasta:

Osa 1: Tarveanalyysi e-hallinta-alustalle potilaan raportoimien vaikutusten tutkimusta varten

Tutkija toteutti liiketoiminnan parantamisteoriaan (ESIA teoria) perustuen puolistrukturoidut haastattelut, joihin kuului viisi kierrosta focusryhmähaastatteluja PROMIS China Center –keskuksen johtotehtävissä olevien henkilöiden (n=5) kanssa ja yksilöhaastattelut yhteistyötiimin jäsenten (n=11) kanssa. Haastattelujen tavoitteena oli muodostaa käsitys potilaan raportoimien vaikutusten tutkimuksen johtamisen tämän hetkisestä tilanteesta, mahdollisista ongelmakohdista tutkimuksen johtamisessa ja tarpeesta e-hallinta-alustalle.

Osa 2: Viitekehyksen rakentaminen e-hallinta-alustalle potilaan raportoimien vaikutusten tutkimusta varten

Tutkija järjesti keskustelutilaisuuden johtotehtävissä olevien henkilöiden (n=13) kanssa, jotta voitaisiin kehittää nykyistä johtamisprosessia liiketoiminnan parantamisteorian (ESIA teoria) perusteella. Tutkija suoritti samanaikaisesti kirjallisuuskatsauksen muiden maiden potilaiden raportoimien vaikutusten tutkimuksessa käytössä oleviin e-hallinta-alustoihin ja analysoi viitekehystä katsauksen tuloksien perusteella. Tutkija yhdisti tarveanalyysin (osa 1), keskustelutilaisuuden ja kirjallisuuskatsauksen tulokset ja muodosti näiden perusteella alustavan viitekehyksen e-hallinta-alustalle potilaiden raportoimien vaikutusten tutkimusta varten. Lopuksi tutkija järjesti kokouksen

hoitotieteen ja tekniikan alana asiantuntijoiden (n=7) kanssa, jossa alustavaa kehystä kehitettiin edelleen, kunnes luotiin lopullinen viitekehys.

Osa 3: e-hallinta-alustan kehittäminen potilaan raportoimien vaikutusten tutkimusta varten

Tutkijat järjestivät ja koordinoivat tiivistä yhteistyötä eri alojen asiantuntijoiden kesken. e-hallinta-alustan viitekehyksen pohjalta tutkijat omaksuivat ihmiskeskeisen lähestymistavan ja ketterän kehittämismenetelmän kehittääkseen e-hallinta-alustan kolmen ohjelmistoinsinöörin kanssa.

Osa 4: e-hallinta-alustan käytettävyyden arviointi asiakkaiden raportoitujen vaikutusten tutkimuksessa

Tutkija toteutti formatiivista käytettävyyden arviointia kehitysprosessin aikana havaitakseen käyttöliittymän ongelmia, kuten fontit ja moduulit. Käytettävyyttä arvioitiin myös tehtäväanalyysin ja puolistrukturoitujen haastattelujen avulla. Haastateltavat olivat alustan käyttäjiä (n=15), joista viisi olivat johtotehtävissä toimivia henkilöitä ja kymmenen yhteistyötiimin jäseniä. Kaikki työskentelivät PROMIS China Center –keskuksessa. Arvioinnin tulokset raportoitiin datan analyysin jälkeen.

**Tulokset**

Osa 1: Tarveanalyysi e-hallinta-alustalle potilaan raportoimien vaikutuksien tutkimusta varten

Laadulliset tutkimustulokset osoittavat: 1) PROMIS käännös-, validointi- ja kliinisten sovellusten hallintaprosessit ovat esitetty tekstissä ja FLOW-kaaviossa. 2) Nykyisten prosessien ongelmien, kuten nykyisen hallintajärjestelmän pitkällisyyden ja hallintaprosessien vaatimien paperisten dokumenttien vuoksi, johtotehtävissä toimivien henkilöiden on vaikeaa valvoa prosessia. 3) Kaikki osallistujat ilmaisivat, että e-hallinta-alustalle on tarvetta ja kuvailivat siihen liittyviä tarpeita.

Osa 2: Viitekehyksen rakentaminen e-hallinta-alustalle potilaan raportoimien vaikutuksien tutkimusta varten

Keskustelutilaisuus paransi tehokkaasti hallintaprosessia ja prosessi on kuvattu tekstissä ja FLOW-kaaviossa. Kirjallisuuskatsauksessa kuvattiin Alankomaiden PROMIS e-management -alusta. Tutkija kehitti alustavan viitekehyksen tähän alustaan, parannettuihin hallintaprosesseihin ja tarveanalyysin tuloksiin perusten. Alankomaiden PROMIS e-hallinta –alusta sisältää seitsemän ensimmäisen tason moduulia ja viisi toisen tason moduulia. Hoitotieteen ja tekniikan alana asiantuntijoiden kokouksen jälkeen, muodostettiin viitekehyksen lopullinen versio, joka sisältää kuusi ensimmäisen tason moduulia: koti, johdanto, PROMIS mittaristo, uutiset, lähteet ja tutkimusyhteistyö. Viitekehys sisältää myös 16 toisen tason moduulia ja sen kattamat sisällöt.

Osa 3: e-hallinta-alustan kehittäminen potilaan raportoimien vaikutuksien tutkimusta varten

Tutkijat esittelivät alustavan viitekehyksen mukaisesti e-hallinta-alustan suunnitelman ohjelmistoinsinööreille. Tutkijat ja insinöörit työskentelivät yhteistyössä e-hallinta-alustan kehityksen loppuun saattamiseksi seuraten seuraavia vaiheita: vaatimusten selvennys, suunnittelu, kehitys, testaus ja julkaisu.

Osa 4: e-hallinta-alustan käytettävyyden arviointi potilaan raportoimien vaikutuksien tutkimuksessa

Formatiivisen käytettävyyden arvioinnin aikana tutkija havaitsi useita ongelmia, mutta ohjelmistoinsinöörit ratkaisivat ongelmat. Käytettävyyden arvioinnissa selvitettiin alustan vaikuttavuutta, tehokkuutta ja käyttäjien tyytyväisyyttä. Käytettävyyttä arvioivan kyselylomakkeen perusteella osa-alueet arvioitiin seuraavasti: alustan hyödyllisyys 5,2 (johtotehtävissä toimivien henkilöiden arvioimana) ja 5,8 (yhteistyöryhmän jäsenten arvioimana); tiedon laatu 6,8 (johtotehtävissä toimivien henkilöiden arvioimana) ja 6,0 (yhteistyöryhmän jäsenten arvioimana); käyttöliittymän laatu 5,4 (johtotehtävissä toimivien henkilöiden arvioimana) ja 5,9 (yhteistyöryhmän jäsenten arvioimana) ja kokonaisarvio 6,0 (johtotehtävissä toimivien henkilöiden arvioimana) ja 6,2 (yhteistyöryhmän jäsenten arvioimana). Haastattelujen kautta saavutettiin ymmärrys alustan käyttäjäkokemuksesta. Haastatteluaineiston perusteella käytettävyyteen liittyy kaksi aihealuetta. Yhdistämällä määrälliset ja laadulliset tutkimustulokset, voidaan sanoa, että e-hallinta -alustan käytettävyys on hyvällä tasolla, mutta joitain puutteita voidaan kuitenkin vielä havaita.

**Johtopäätökset**

Sekä PROMIS China Centerin johtotehtävissä toimivilla henkilöillä, että yhteistyötiimin jäsenillä on suuri tarve e-hallinta-alustalle. Tarveanalyysiin ja liiketoiminnan parantamisteoriaan perustuva lopullinen viitekehys on hyvä malli e-hallinta-alustan kehittämiseen tueksi. Käytettävyyden arviointi osoittaa e-hallinta-alustan käytettävyys on hyvä ja sen avulla voidaan edesauttaa potilaan raportoimien vaikutuksien tutkimuksen hallintaa. Alustan avulla voidaan tehostaa potilaan raportoimien vaikutuksien tutkimuksen hallintaa ja nopeuttaa PROMIS-mittaristojärjestelmän käyttöönottoa Kiinassa.

**Asiasanat:** Potilaan raportoimilla vaikutuksilla, Potilaan raportoimilla vaikutuksilla measurement tietojärjestelmä, E-hallinta-alustan, ESIA teoria, Liiketoimintaprosessin parantaminen

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## Abbreviations

| | |
|---|---|
| PROs | Patient-reported Outcomes |
| PROMIS | Patient-reported Outcomes Measurement Information System |
| BPR | Business Process Reengineering |
| BPI | Business Process Improvement |
| ISO | International Organization for Standardization |
| PSSUQ | Post-study System Usability Questionnaire |

## Introduction

Patient-reported outcomes (PROs) refers to information directly from patients about their own health status without interpretation by the doctors or others[1]. PROs follow the concept of patient-oriented care and emphasize the importance of patients' subjective feelings. It is the most direct source of evidence for patients' personal experiences. PROs can be an effective supplement to disease-oriented medical outcomes and one of the most reliable evidence for medical decision-making[1]. Listening to the patients' voices and integrating PROs into medical big data can significantly promote doctor/nursing patient communication, improve patient compliance with treatment, improve disease experience, and improve the quality of care[2], which is listed as a necessary report item for clinical efficacy evaluation and new drug approval by the Food and Drug Administration (FDA) of the United States. PROs have become a hot spot and trend in medical research in recent years, especially in the management of symptoms of patients with chronic diseases, which have been widely recognized and concerned[3]. The systematic use of patient-reported outcome measurement tools has been an effective way to standardize disease care at present, and more and more medical and health institutions are incorporating patient-reported outcome data into clinical practice[4].

The Patient-reported Outcomes Measurement Information System (PROMIS) is a practical implementation of the PROs concept, which was developed by the National Institute of Health (NIH) in 2004 [5]. Its second round of funding was launched in 2010 to expand the scope to children population and longitudinal research, aiming to completely change the selection and application of patient-reported outcome tools in clinical research and practice evaluation, to accurately and efficiently measure patient-reported symptoms and other health outcomes in clinical practice. PROMIS uses the WHO three-dimensional health (physical, psychological, and social health) as a measurement framework [6], integrates the latest and most scientific research methods in many fields such as psychometric metrology, health information technology, clinical research, and qualitative research [1, 7].PROMIS gradually developed into a set of measurement tools including more than 20 symptom concepts and nearly 2000 items. The time duration of development has lasted for 16 years, and PROMIS is still being supplemented and improved [5]. Due to its unique advantages such as comparability, flexibility, openness, and accuracy, PROMIS is currently the most credible self-reported outcome measurement recognized by the international research community[8, 9]. Driven by a large number of researchers and clinical practitioners around the world, PROMIS

has been translated into 62 languages[10-12] at present, and it is supplemented by validation [13-15], calibration[16-18] ,and other methods to prove and ensure its psychometric characteristics. It has been used in different degrees in the background of scientific research or clinical practice.

With the increasing recognition of PROMIS, it has become a general trend to promote patient-reported outcomes cooperative research among research groups. The main reasons are as follows: First of all, PROMIS covers nearly 2000 items and more than 300 short forms constructed from it. Moreover, the work requirements are strict, and the steps are complicated. The research cooperation gathers the scientific research forces from different regions and various hospitals across the country. The researchers work together to carry out the translation, validation, and clinical application of PROMIS, which can significantly speed up the promotion of PROMIS and make PROMIS take root in China as soon as possible. Second, PROMIS emphasizes people's subjective feelings, and the cross-cultural communication of human feelings makes PROMIS uniquely comparable. The patient-reported outcomes research carried out based on this feature makes it possible to compare the feelings of patients who experience in different scientific research situations，which can bring high scientific research value. Third, PROMIS has a characteristic of openness, allowing researchers to develop new items according to their own needs and disease research progress. The implementation of research cooperation realizes extensive cooperative research focusing on the same problem [19], and bring a new and more comprehensive perspective to the development of unique measurements. Fourth, the promotion of PROs is not only the promotion of the concept of patients' feelings but also the promotion of measurement technology. Patient-reported outcomes research is conducive to clinical care and patients' more profound understanding of subjective feelings and objective measurements, including advanced measurement theory, modern measurement form, accurate scoring explanation, etc. It is of deep significance to the promotion of PROs.

The attention to the concept of patient-reported outcome and the introduction of related measurement tools are relatively minor of Chinese researchers, but in recent years, more and more researchers are going to focus on it[20]. They concentrated on the translation of foreign scales and self-developed scales[21].The author is from the research team that was approved to establish the Patient Experience Research Center and the PROMIS China Center in the School of Nursing, Fudan University [22]. As the responsible organization of PROMIS in China, it is committed to promoting PROMIS in China. The PROMIS China Center is currently cooperating and signing agreements with many clinical institutions or academic

institutions, leading and managing the Chinese researchers to conduct cooperative research on patient-reported outcomes.

The management process of this patient-reported outcomes research involves the transmission of a large amount of information (such as confirming research status, translation requirements, etc.) and documents (such as English items of PROMIS, the Chinese version of the PROMIS, etc.). The traditional management channels are WeChat, e-mail, mail, and other media. Management staffs exchange information with cooperative team members in a "one-to-one contact" manner. This conventional management way has hidden dangers such as file loss and information leakage. At the same time, it leads to the increment of management load and decreases cooperation efficiency. Today, with the increasing influence of PROMIS and the increasing number of cooperative teams, it is clear that the current management way can no longer help the patient-reported outcomes research in China.

Since the 1980s, information technology has been developing rapidly, which has had a significant impact on society and personal life. Therefore, researchers from multiple fields began to resort to technological ways to solve problems [23] , especially management problems. At present, various scenarios such as hospitals[24], schools[25], and commerce[26]are actively carrying out informatization construction. The E-management platform, an information technology tool for management-related affairs, has many functions such as changing the traditional management mode, improving management efficiency, reducing costs, and ensuring management standardization. Researchers in the field of medical and educational informatization actively engaged in constructing E-management platforms to help with scientific research and teaching. While, E-management platform for medical care, which plays a considerable role in managing staff, materials, and archives, has been developed in many medical institutions[27].

Therefore, as a nursing master student exploring nursing informatics research in China, the author focuses on the process management of patient-reported outcomes research and considered improving the management efficiency through information technology means. Based on the process improvement theory, the author adopted the methods like literature study, brainstorming, qualitative research, expert working group meeting, usability evaluation to develop the E-management platform of patient-reported outcomes research. The E-management platform can help manage the patient-reported outcomes research so as to

eventually promote the implementation of patient-reported outcomes, improve the patient's disease experience, and bring patients better care quality in China.

# 1 Research background

## 1.1 Definition

(1) Patient-Reported Outcomes (PROs)

PROs is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else [1].

(2) Patient-reported Outcomes Measurement Information System (PROMIS)

PROMIS is a set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. It can be used with the general population and with individuals living with chronic conditions[5].

(3) E-management platform

An E-management platform is a digital platform used to optimize and manage business processes. They are used to model, implement, and automate management workflows with the goal of improving performance by minimizing errors, inefficiencies, and miscommunication.

(4) Usability

The International Organization for Standardization (ISO) defines "usability" as " the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" in the ISO9241-11[28].

(5) PROMIS China Center

PROMIS National Centers make efforts to identify, coordinate, and promote best practices to develop, translate, validate, and utilize PROMIS instruments across countries. PROMIS China Center is the specific center of PROMIS promotion in China which was found in 2018.

(6) PROMIS China Center management staffs

The PROMIS China Center management staffs work for PROMIS China Center to promote PROMIS and patient-reported outcomes research in China by cooperating with various research groups.

(7) PROMIS China Center cooperative team members

The PROMIS China Center cooperative team members are implementing PROMIS translation, validation, and clinical application in China under the guidance of PROMIS China Center management staffs.

## 1.2 Literature review

A review of the literature is conducted to confirm the existing knowledge and gaps on this topic so as to provide direction for this research. In this chapter, the existing literature on the research status of E-management platform as well as business process improvement have been provided. Literature searches using relevant key words were conducted on four databases namely China National Knowledge Infrastructure (CNKI), China Science and Technology Journal Database, Wanfang Data Knowledge Service Platform and The Institute of Electrical and Electronics Engineers (IEEE). The literature search was supplemented with searches of reference lists of primary studies and the internet in general. Manual searches were also conducted using reference lists of the included publications.

### 1.2.1 The research status of E-management platform

As the information technologies became more and more advanced, the electronic means became more and more spread[29]. In the field of process management, electronic means are playing an increasingly important role. The E-management platform can bring benefits to both the process itself and the organization. The benefits of the E-management platform to the process itself are mainly reflected in the following three aspects[30]: First, it can formulate a quick and convenient solution for the process management; second, it can improve the production efficiency while reducing construction costs; third, it can fundamentally meet people's requirements for informatization construction and achieve a satisfactory level of informatization. The critical significance of the E-management platform to the development of the organization is mainly reflected in the following aspects: First, the E-management platform can be used to manage the documents conveniently and fast; Second, it can effectively promote cooperation among multiple user roles; third, it can optimize process management; fourth, it can promote an institution's transformation to information-based institutions. Based on the many benefits mentioned above, various institutions and organizations are actively introducing advanced information technology to optimize the management processes for efficient management.

(1) Research status of the E-management platform related to scientific research and teaching

The construction of the E-management platform related to scientific research and teaching can help improve scientific research and teaching management methods, optimize scientific research and teaching management processes, and meet the requirements of high efficiency, real-time, sharing, and collaboration [31].

Long Yan et al. [32]designed an E-management platform for college students' scientific research and training. The platform's primary function is to make scientific research training and teaching management digital. The platform establishes an interactive platform between teachers and students, and realizes the coordination of process management and target management. Among all the functions, the E-management can help manage: project information (project establishment, project members, instructors, research proposal), process tracking (students can upload experimental data and results regularly, and teachers conduct process supervision), project achievements (students can upload the project papers at the end of scientific research training), project interaction, and project summary.

Similarly, Lin Suna et al. [33] built an E-management platform for hospital scientific research management. The function includes project management, fund follow-up, paper publication upload. It can meet the needs of scientific research management staffs, scientific research applicants, and processing staffs. The E-management platform can help the communication and information exchange among different users: the annual implementation status, project staff or content changes, project information query, project application ratification, project report, scientific research content, and data submission. The E-management platform is in line with the reality of scientific research. Take an existing project management for example, the project leader can inquire about the project's full content in time, and the participants can also know all the information of the project and upload the information in time to ensure the consistency of the online data and the actual work. There are several core steps of the development of an E-management platform. The design process's main steps include role design (including administrators, experts, project leaders, project members, and ordinary visitors), business process presentation (presented the research process in stages according to the actual process), and design of primary business functions.

The construction of the E-management platform for university student file management [34] can efficiently help the work of university teachers and dimmish the rate of errors. This university combines the original documents of paper archives and digital documents uploaded

to the E-management platform, which is also completely integrated with the school's information construction. The E-management platform makes the important document organized and stalled safer, allowing management staffs to retrieve the document conveniently.

Comparing to research and teaching management, the management requirements of the laboratory are complicated, involving multiple steps and roles [35]. The autonomous experimental teaching E-management platform constructed by Mr. Hu et al. [36] makes the whole process of experimental teaching process-specific, informatized, and electronic. This experimental teaching E-management platform can facilitate the information interaction between students and teachers. More importantly, through this platform, students can independently propose experimental projects, make appointments for experimental time and venues, and truly realize the opening in time, space, and equipment [37].

(2) Research status on E-management platforms related to clinical care

Clinical care has the characteristics of complexity and dynamics [38]. The care process involves the information interaction and document transmission of doctors, nurses, pharmacists, patients, and other groups of people. Simultaneously, the interactive information has the characteristics of solid professionalism and high confidentiality requirements, and the E-management platform can be used as a suitable process interaction medium to help the implementation of clinical care.

Henrich et al. [39] constructed an E-management platform based on the actual workflow of electronic brachytherapy. The platform can realize the automatic recording of documents, resources, and other information. The intervention results show that it has played a significant role in improving the work efficiency of medical institutions, reducing the preparation time of surgeons, and reducing treatment errors.

Marzal-Alfaro Maria Belén et al. [40] applied an image-based E-management platform to manage anti-tumor drugs' prescription entry program. Among all processes of 9872 drugs, the total error rate was only 0.8%, which confirmed that the E-management platform could effectively reduce the frequency of drug use errors.

Lin Alex C et al. [41] used a retrospective study to analyze the changes in drug waste rate before and after using an intravenous injection-related E-management platform. The results

showed that the use of this platform could standardize the workflow, improve patients' safety, and have a positive impact on medical costs and health outcomes of patients.

The E-management platform has essential significance for the hospital work efficiency and patient management efficiency. Traditional pathological examination-related data, such as pathological application form, pathological specimen circulation, and pathological report, are all managed by manual paper filing. With the increase of the number of patients and workload, the error rate of the examination is gradually increased[42]. Zuo Lin et al.[43] designed and constructed a case specimen whole process E-management platform through a need analysis of surgeons, operating room nurses, and pathology staff in various positions, as well as investigations on the current status of the circulation of case specimens. The E-management platform effectively reduces the omission of specimens, the mismatch of the specimen and patient information, and improves the hospital's digitization level.

Shi Fenghua et al. [44] built a day surgery E-management platform based on the problems of irrational hospital day surgery procedures and inaccurate data management. The platform's design process incorporates multidisciplinary members, including doctors, nurses, management, information engineers to conduct need analysis of the E-management platform. Combing the outcomes of need analysis, the researcher completed the platform's design using methods of current status investigation, process combing and design. This E-management platform optimizes the process and provides convenience for patients and clinicians.

The E-management platform is used to a considerable extent in the fields of scientific research, teaching, and clinical care. It also involves some scientific methods in the construction process, such as need analysis through interviews with interest-related users, current status surveys of task processes, and process improvement design. The above research methods provide a reference for the implementation of this study.

### 1.2.2 The research status of Business Process Improvement

The meaning of process in the dictionary is a series of related human activities or operations that consciously produce a specific result. In short, it is the order in which we do things for a specific purpose [45]. In 1993, Professor Michael Hammer and James Champy of Massachusetts Institute of Technology (MIT) in the United States put forward a kind of management idea: Business Process Reengineering (BPR) in the book " Reengineering the Corporation: Manifesto for Business Revolution " [46]. BPR refers to the subversive re-

examination and redesign of the business processes of an enterprise, and ultimately achieve the decisive improvement of all the processes of the enterprise [46]. After the concept was put forward, many companies put it into practice. However, due to the thoroughness and violent nature of BPR, it brought risks and challenges to the company's operation. Therefore, the theory of Business Process Improvement (BPI) has been developed. Business Process Improvement means that in order to face the new market environment and solve the bottleneck of enterprise production and operation, the enterprise finds a strategy or method to improve the performance by investigating, analyzing, and improving the existing business process. Finally, the improved process can help reduce the enterprise's operating cost, increase the economic benefits, establish a competitive advantage, and achieve sustainable development [47]. Business process improvement can be used for the entire business process or for some steps of the process[48]. Process improvement aims to improve enterprises' efficiency, improve the quality of cooperation, reduce production costs, reduce energy consumption, reduce labor intensity, promote safe production and reduce pollution emissions. Compared with BPR, BPI's improvement mode is more moderate, avoiding enterprises' inevitable loss by riding fierce ways. Therefore, more and more enterprises adopt it. Business Process Improvement refers to the process of continuous improvement of each enterprise, which is a continuously pursued goal. In essence, it is to review the business process repeatedly, and constantly put forward improvement plans and improvement strategies, even redesign a set of new business processes, so that the critical performance of the enterprise (mainly including product quality, process time and speed, enterprise cost and service effect) all have an improvement [49]. It has been proved that process improvement will contribute more and more to the development of organizations in the 21st century [50]. There are many process improvement applications in the medical field, like establishing a new model of medical institution management to protect the rights and interests of patients, improve patient satisfaction, improve hospital management efficiency, and improve medical service procedures. To a certain extent, the importance of process improvement can be seen by observing and analyzing the connection between business processes and business results. Business processes with different improvement levels can profoundly impact a series of indicators such as product R & D, market response speed, product delivery ability, and overall operating cost. Therefore, enterprises should continuously optimize business processes through innovation to adapt to the environment's changing needs.

Simultaneously, only when the process is visual and transparent can it be possible to monitor and improve the process. In order to achieve the purpose of "visualization" of business processes, it is necessary to carry out information construction for the enterprise [51]. Enterprise information construction refers to the establishment of an E-management platform that reflects information integration and information sharing. Supported by modern information technology, the E-management platform processes, summarizes, and classifies all kinds of information inside and outside the enterprise according to unified data standards and formats, and places them in databases with different confidentiality ranks and levels. The E-management platform enables employees at all levels to make full use of information resources and effectively develop a human-computer interaction system for production and business activities. The construction of an E-management platform has realized the integration and sharing of information among different enterprise departments, internal and external, and between enterprises. It makes the organization's operation tend to be programmed, automated, and electronic and makes the operation of the process break the regional restrictions to meet customers' needs quickly, high quality, and efficiently. Before the enterprise adopts information technology, all business processes are operated manually in a one-to-one management mode. In contrast, business processes improvement is realized by utilizing information technology, which adopts a one-to-many operation mode, allowing the information to be transmitted to multiple departments simultaneously. Therefore, enterprise informatization construction is the technical prerequisite for process improvement. At the same time, optimizing enterprise business processes is the basis for informatization construction. For this reason, if an enterprise applies an E-management platform, it must first adapt to the status quo of enterprise process management and must be conducive to the improvement of enterprise business process management. Therefore, process improvement and E-management platform development are two parallel long-term tasks that promote each other. In daily business, consciously establishing a cost-efficiency-oriented process improvement mechanism to optimize the process and consciously introducing appropriate information methods are two important things for the development of one organization. Process improvement methods include benchmarking method, DMAIC model method[52], ESIA analysis method, ECRS analysis method[53], and D+PDCA cycle method[54].

Since the widespread use of both E-management platform and business process improvement method, and the urgent need to develop a PROs research E-management platform, this research is going to build this platform for further research.

## 1.3 Theoretical basis

The ESIA analysis method was proposed by Joe Peppaxd and C Philip Rowland in 1995, which is a classic model of enterprise service process improvement. The main goal is to improve the process by removing unnecessary activities, simplifying the remaining process, integrating the decentralized process, and realizing the automatic operation of the process[45]. The specific content of ESIA is shown in Table 1 below[53]. See Table 2 for the main content of the of ESIA systematic transformation[55].

Table 1 The specific content of ESIA theory

| Link | English abbreviation | Details |
|---|---|---|
| Process Eliminate | E（Eliminate） | Remove unnecessary activities in the original process |
| Process Simplify | S（Simply） | On the basis of the previous step, the remaining process in further simplified |
| Process Integrate | I（Integrate） | The various decentralized process in tandem, so that the entire process is smooth, coherent, and better meet user needs |
| Process Automate | A（Automate） | Using modern information technology to realize the automatic operation of the process |

Table 2 The main contents of ESIA systematic transformation

| Eliminate | Simply | Integrate | Automate |
|---|---|---|---|
| Over-production | Forms | Jobs | Dirty |
| Waiting time | Procedures | Teams | Difficult |
| Transport | Communication | Customers | Dangerous |
| Processing Inventory | Technology | Suppliers | Boring |
| | Problem areas | | Data capture |
| Defects/failures | Flows | | Data transfer |
| Duplication | Processes | | Data analysis |
| Reformatting | | | |
| Inspection | | | |
| Reconciling | | | |

ESIA theory is a step-by-step process improvement method with a specific and clear definition for reviewing each step in the process to ensure the scientificity and preciseness of the improvement process and the expected improvement results.

First, the non-value-adding (NVA) activities of the process refer to the activities that customers are unwilling to pay but also take time. To eliminate non-value-adding activities, we must first distinguish which are value-adding activities and which are non-value-adding activities. Then try to eliminate non-value-adding activities without affecting the regular operation of the existing cooperation process, so as to improve the distribution of customers in the value chain, thereby enhancing cooperation efficiency[56]. This improvement step is mainly performed by reviewing the entire process and judging whether each step must exist, what problems each step can solve, whether the step can be eliminated, and whether the steps' results are necessary to complete the entire process. Through these questions, it can be judged whether it is a non-value-adding step. If it is a non-value-adding step, it needs to be judged whether it is necessary, and if it is not, it should be eliminated. To improve the process, it is necessary to eliminate or minimize these activities without affecting the process. For example: waiting between activities, the movement of raw and auxiliary materials or finished products, product design defects and errors, redundant activities, repeated product inspections. The elimination of non-value-adding activities in the cooperation process mainly starts from two aspects [56]: First, for a single cooperation node, make sure that the person in charge must have clear responsibilities and the responsibilities cannot be repeated so the cooperation process is simplified and the cooperation efficiency is improved. For example, at present, the approval of cooperation is approved by A and B simultaneously, and their responsibilities are basically the same. Therefore, one of A or B can be removed; if a person must know the business process's relevant content, there will be the default notification or completion notification rather than the notifications from a person in charge of this work. Second, redundant cooperation processes should be eliminated, and one-way flow and interactive flow should be distinguished. The cooperation that can be realized by one-way flow does not need interactive flow.

Second, simplifying the process means simplifying the steps that are too complicated or merge certain activities. Different business processes can be simplified with different contents. Taking the enterprise approval process as an example, it can be simplified from four aspects: forms, procedures, communication, and logistics [56].

Third, integrating process refers to making the cooperation most effortless by adjusting and sorting the activities' activities. The most typical activity adjustment sequence is to use concurrent engineering instead of traditional serial engineering because concurrent engineering ideas can optimize the approval process and significantly shorten the cooperation

period. So, the enterprise can shorten the stagnation time between processes or can operate the two steps simultaneously.

Fourth, process automation is based on information technology to achieve accelerating processes and improve service quality on the basis of process elimination, simplification, and integration [57]. The process automation can help the enterprise make full use of existing resources and solidify the core process. Process automation can be realized through the following methods: fixing the step manager without repeatedly confirming the approval process, significantly improving efficiency. However, it should be noted that once the organizational structure changes, the person in charge of the process needs to communicate with IT staff on time to ensure the latest status of the process; automating the delivery of forms, documents to improve the efficiency of collaboration.

The ESIA method is mainly used in process improvement research, which some domestic scholars have explored. For example, Zhao Jun et al. used the ESIA method to improve the scientific research management process in a university to improve its scientific research management level [58]. Jiang Zhiyi and others used the ESIA method to optimize the library business process to promote the library's modernization. The improved process can help to improve the reader's satisfaction, literature utilization, and resource management level [57]. Hu Dan et al. used the ESIA method to optimize the outpatient service process of top-ranking hospitals, which significantly improved the quality of outpatient service and patient satisfaction [59]. Song Jingbo et al. adopted the ESIA method to optimize and standardize the relevant process of hospital nurses management about their appearance, technical operation, and document writing, which improved the level of nursing and the quality of nursing services [60]. Ma Jiazheng used the ESIA method to optimize governmental departments' assessment and evaluation process and proposed a set of specific improvement schemes by eliminating non-value-adding activities, simplifying necessary activities, integrating scattered processes, and automating tasks [61]. Xue Xiaodong et al. used the ESIA method to improve the administrative examination and approval process for local government investment projects, which brings a new idea for improving the efficiency of administrative examination and approval [62]. The scholars mentioned above follow the four-step process improvement strategy of ESIA to implement the corresponding scientific research and achieve the practical purposes, proving that the ESIA method has a high significance for process improvement.

## 1.4 Research content and roadmap

### 1.4.1 General research purpose

To develop PROs research E-management platform

### 1.4.2 Research questions

(1) What is the need for the E-management platform for patient-reported outcomes research from the perspective of PROMIS China Center management staffs and PROMIS China Center cooperative team members?

(2) How to develop the E-management platform for patient-reported outcomes research based on the need and business improvement theory?

(3) How to evaluate the usability level of the E-management platform for patient-reported outcomes research?

### 1.4.3 Research contents

The study was comprised of 4 parts of content：

Part1: The need analysis of the E-management platform for the patient-reported outcomes research

Based on business improvement theory (ESIA theory), the researcher conducted the semi-structured qualitative interviews to know the current management process of patient-reported outcomes research, the problems of current management process, and the need for the E-management platform.

Part2: The framework construction of the E-management platform for patient-reported outcomes research

The researcher implemented a brainstorming discussion and the literature study to draw the patient-reported outcomes research E-management platform's preliminary framework, which was revised by an expert group meeting to form the final framework.

Part3: The development of the E-management platform for patient-reported outcomes research

Based on the final framework of the E-management platform formed in the early stage, the researchers developed the E-management platform with software engineers.

Part4: The usability evaluation of the E-Management Platform for Patient-reported outcomes research

The researcher implemented the formative usability evaluation during the process of development for finding the problems about the interface and implemented the summarized usability evaluation by task analysis and semi-structured interviews with users to evaluate the usability level of the E-management platform.

### 1.4.4 Roadmap

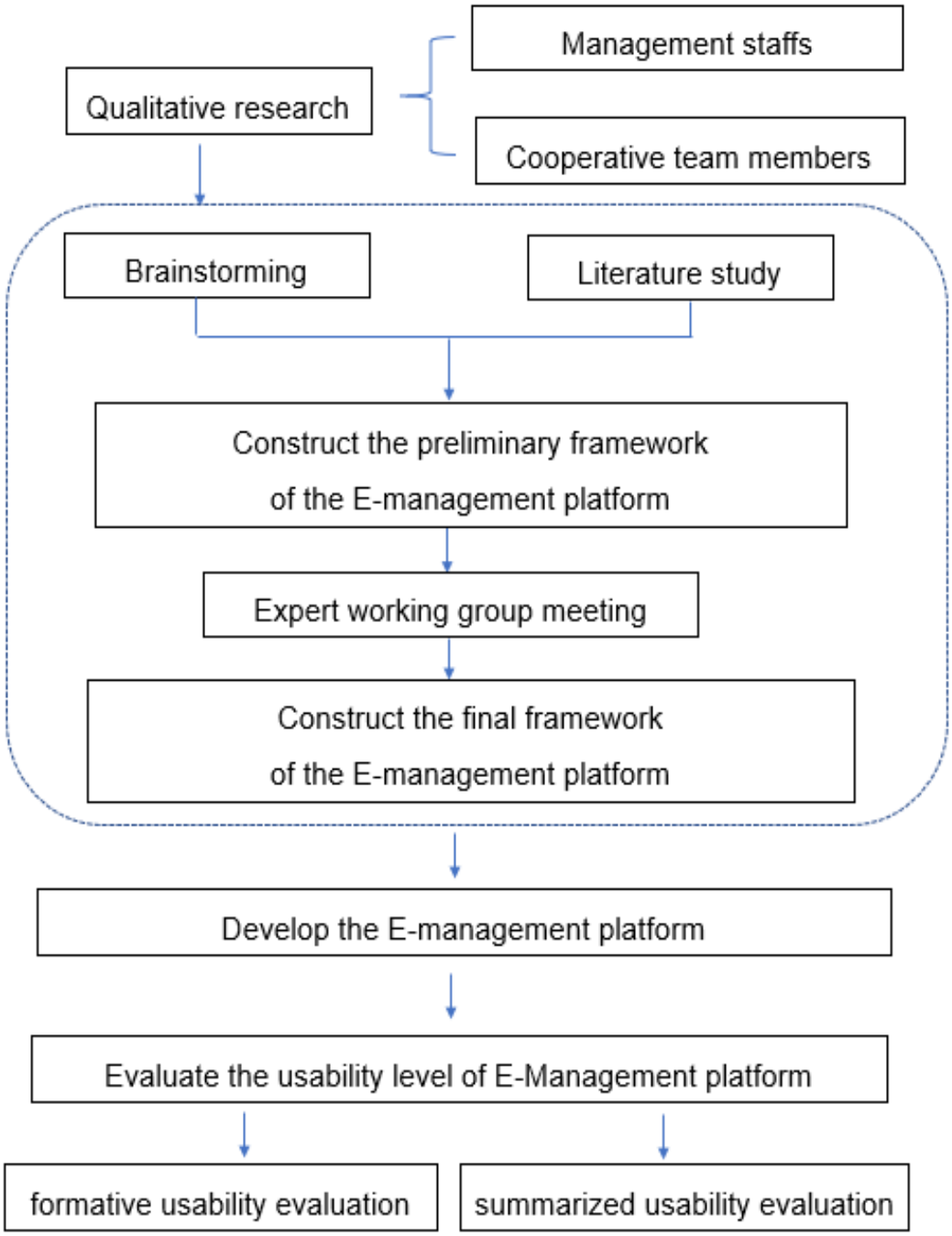


Figure 1 The roadmap of this research

# 2 The need analysis of E-management platform

## 2.1 Research purpose

Following the guidance of the method of qualitative research, the researcher implemented the semi-structured interviews with PROMIS China Center management staffs and PROMIS China Center cooperative team members to know: 1) the current management process of patient-reported outcomes research; 2) the problems of current management process; 3) the need of E-management platform from the perspective of PROMIS China Center management staffs and PROMIS China Center cooperative team members. The flow chart of the current management process can clearly show the process and provide the basis for process improvement. The problems of the current management process can confirm the necessity of the E-management platform development. The need for the E-management platform can guide the construction of the E-management platform framework.

## 2.2 Participant

The researcher used the purposive sampling method to select the participants.

(1) Inclusion criteria for PROMIS China Center management staffs:

① Person who is familiar with PROMIS;

② Person who understands the development methodologies PROMIS;

③ Person who has participated in the management of the PROMIS China Center for more than 3 months.

(2) Inclusion criteria for PROMIS China cooperative team members:

① Person who is familiar with PROMIS;

② Person who understands the development methodologies PROMIS;

③ Person who has experience about PROMIS translation, validation and clinical application.

From November 2019 to December 2019, a total of 5 management staffs were included in 5 rounds of focus group interviews, and 11 cooperative team members were included in the one-on-one interviews. Since the 5 management staffs are taking management responsibility

and know clearly about the management process, they can provide enough information to meet data saturation requirements.

## 2.3 Research methods

(1) Interview outline

The researcher wrote the preliminary version of the interview outline combined with ESIA theory and then sent it to experts of the mentor group. Three of experts revised it, and the final interview outline was decided. The final interview outline is shown as follows:

① What is the current management process of patient-reported outcomes research?

② Are there any drawbacks in the current management process?

③ Is it necessary to develop an E-management platform to improve the management process, like eliminating unnecessary steps, simplifying some complex steps, integrating some steps, or realizing the automatic operation of the process? If the answer is yes, what are your suggestions on the E-management platform?

(2) Data collection

The researcher contacted the participants before the interview, and made a brief introduction about the research purpose and methods. After receiving their content, the researcher determined the interview date and place. The place was usually the PROMIS China Center Office. The researcher conducted the interview according to the interview outline. If necessary, the researcher would make some adjustments about the outline and ask more questions related to their answers and meaningful to the result. Each focus group interview lasted for about 60 minutes, and each one-on-one interview lasted for about 30 minutes, and the whole interview process was recorded with the participants' permission. The researcher observed the facial expressions and body language of the participants, and made interview notes carefully. The recording of the interview was transcribed into a written manuscript by the two people and sent to participants. The participants read the written manuscript to make sure it was right. The researchers summarized the information in the written manuscript and made sure that the data was saturated.

(3) Data analysis

The researcher analyzed the interview data by content analysis method[63].

## 2.4 Research results

The characteristics of the 5 management staffs is shown in Table3 and the characteristics of the cooperative team members is shown in Table 4

Table 3 Characteristics of the management staffs

| No. | Gender | Age | Education background | Professional title | Management duration |
|---|---|---|---|---|---|
| S1 | female | 28 | master | research assistant | 6 months |
| S2 | female | 30 | doctor | post-doctoral | 18 months |
| S3 | female | 50 | doctor | professor | 3 years |
| S4 | female | 34 | doctor | lecturer | 12 months |
| S5 | female | 27 | doctor | lecturer | 6 months |

Table 4 Characteristics of the cooperative team members

| No. | Gender | Age | Education background | Professional title | PROMIS research duration |
|---|---|---|---|---|---|
| F1 | female | 51 | master | nursing professor | 6 years |
| F2 | female | 34 | master | supervisor nurse | 2 years |
| F3 | female | 36 | master | supervisor nurse | 2 years |
| F4 | female | 41 | doctor | associate professor | 2 years |
| F5 | female | 39 | master | associate nursing professor | 3 years |
| F6 | female | 33 | master | associate professor | 4 years |
| F7 | female | 40 | doctor | associate nursing professor | 3 years |
| F8 | female | 29 | master | senior nurse | 3 years |

| No. | Gender | Age | Education background | Professional title | PROMIS research duration |
|---|---|---|---|---|---|
| F9 | female | 33 | bachelor | Senior nurse | 3 years |
| F10 | female | 35 | bachelor | supervisor nurse | 3 years |
| F11 | female | 29 | master | senior nurse | 2 years |

(1) The current management process of patient-reported outcomes research

1) PROMIS translation

The current management process of PROMIS translation is shown in Figure 2. The researcher describes it the text: ① The cooperative team members consult with management staffs about the progress of PROMIS translation. ② The management staffs answer the questions. ③ If the cooperative team members want to apply for translating PROMIS, the management staffs will send the registration form to the cooperative team members, which can help management staffs know the research background, scale translation ability, and research capacity of cooperative team members. ④ The cooperative team members fill in the registration form and send it to management staffs. ⑤ The management staffs confirm the research background of the applicant. ⑥ The management staffs and send them the application form. ⑦ The cooperative team members fill in the application form and send it to management staffs. ⑧ The management staffs review the application form and make a decision to cooperate with the applicants. ⑨ The management staffs send the agreement to cooperative team members. ⑩ The cooperative team members fill in agreement and post it to the management staffs. ⑪ The management staffs fetch the parcel and seal the agreement. ⑫ The management staffs send the PROMIS English scale to cooperative team members. ⑬ The cooperative team members translate the English scale into Chinese and send the Chinese version of the PROMIS scale to management staffs. ⑭ The management staffs review the Chinese scale.

2) PROMIS validation

The current management process of PROMIS validation is shown in Figure 3. The researcher describes it the text: ① The cooperative team members consult with management staffs about the progress of PROMIS validation. ② The management staffs answer the questions. ③ If the cooperative team members want to apply for validating PROMIS, the management staffs will

send the registration form to the cooperative team members, which can help management staffs know the research background, and research capacity of cooperative team members. ④ The cooperative team members fill in the registration form and send it to management staffs. ⑤ The management staffs confirm the research background of applicant. ⑥ The management staffs and send them the application form. ⑦ The cooperative team members fill in the application form and send it to management staffs. ⑧ The management staffs review the application form and make a decision to cooperate with the applicants. ⑨ The management staffs send the agreement to cooperative team members. ⑩ The cooperative team members fill in agreement and post it to the management staffs. ⑪ The management staffs fetch the parcel and seal the agreement. ⑫ The management staffs send the Chinese version of PROMIS to cooperative team members. ⑬ The cooperative team members collect the data with PROMIS according to their research purpose and send the data to management staffs. ⑭ The management staffs review the data.

3) PROMIS clinical application

The current management process of PROMIS clinical application in is shown in Figure 4. The researcher describes it the text: ① The cooperative team members consult with management staffs about the progress of PROMIS clinical application. ② The management staffs answer the questions. ③ If the cooperative team members want to apply for PROMIS clinical application, the management staffs will send the registration form to the cooperative team members, which can help management staffs know the research background, and research capacity of cooperative team members. ④ The cooperative team members fill in the registration form and send it to management staffs. ⑤ The management staffs confirm the research background of applicant. ⑥ The management staffs and send them the application form. ⑦ The cooperative team members fill in the application form and send it to management staffs. ⑧ The management staffs review the application form and make a decision to cooperate with the applicants. ⑨ The management staffs send the agreement to cooperative team members. ⑩ The cooperative team members fill in agreement and post it to the management staffs. ⑪ The management staffs fetch the parcel and seal the agreement. ⑫ The management staffs send the Chinese version of PROMIS to cooperative team members. ⑬ The cooperative team members collect the data with PROMIS, and send the data to management staffs. ⑭ The management staffs review the data.

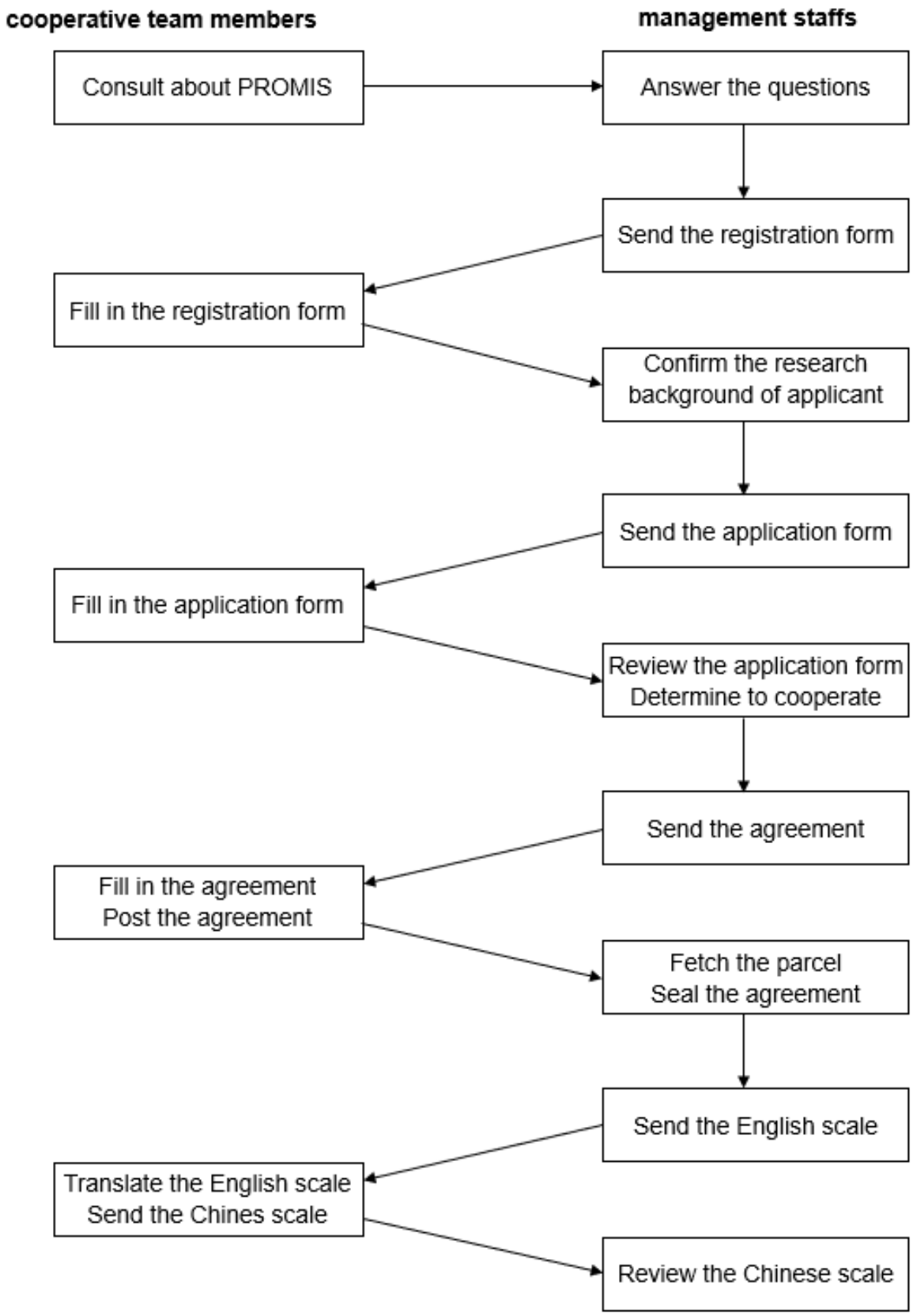


Figure 2 PROMIS translation management process

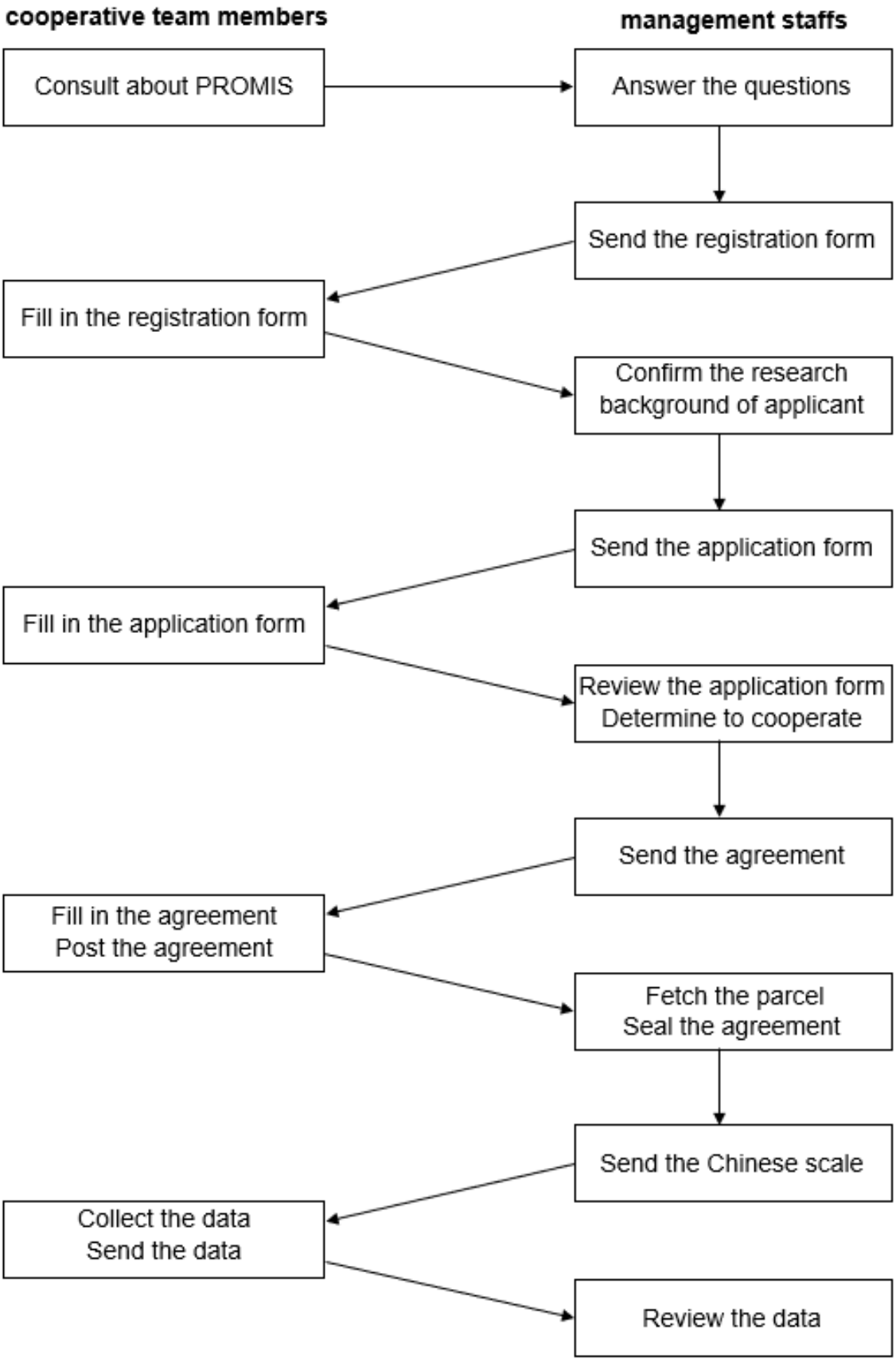


Figure 3 PROMIS validation management process

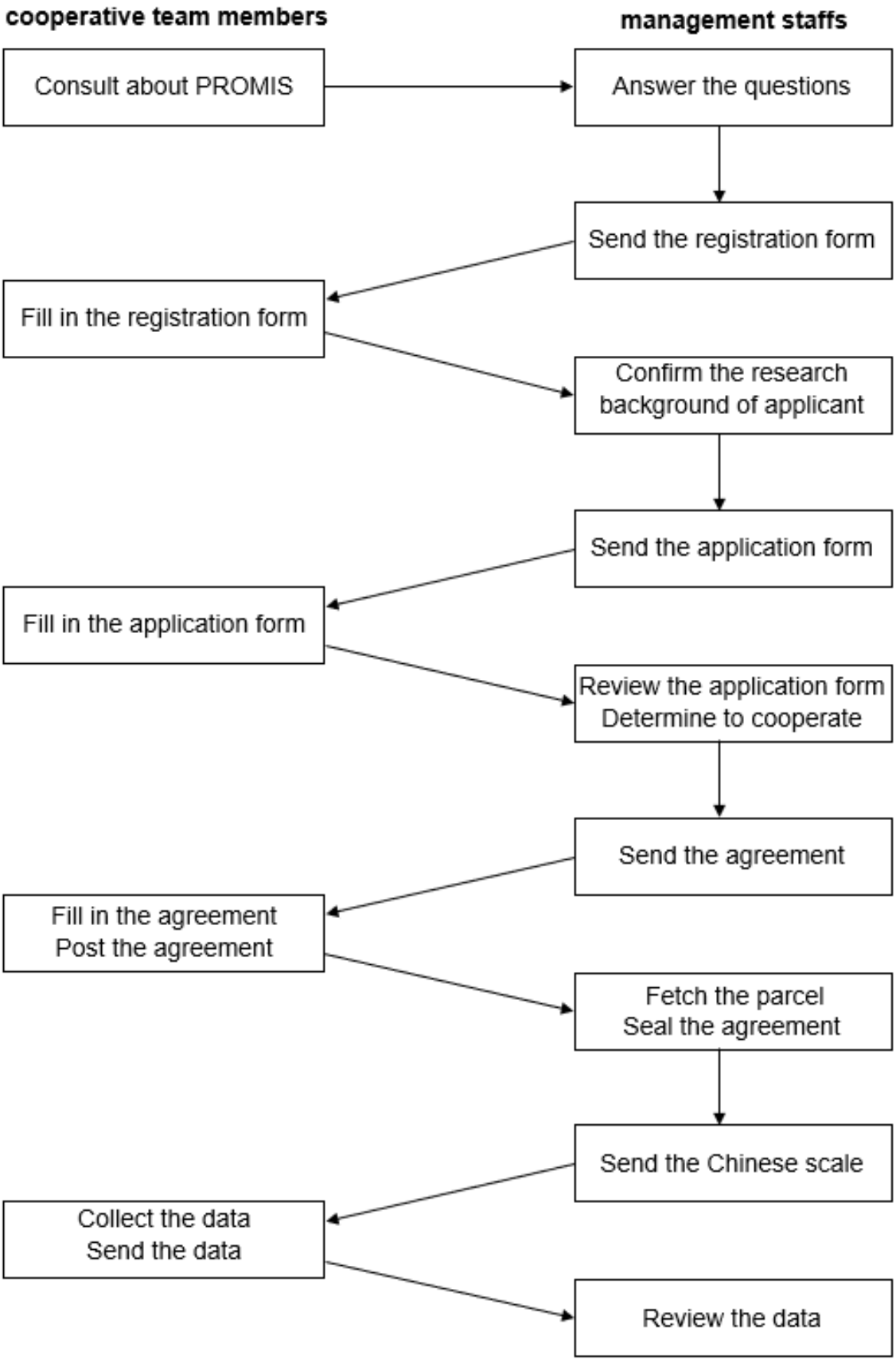


Figure 4 PROMIS clinical application management process

(2) The problems of current management process

① The current management process is tedious.

S4: The cooperative team members send the agreement. I have to go to fetch the parcel. It's not convenient.

S5: There are a lot of documents such as agreements and registration forms. Every time I have to find the corresponding documents on the computer and then send them to cooperative team members.

F2: Both the management staffs and cooperative team members need to do a lot of work in the current process.

F4： I am not clear about the progress of PROMIS in China, so I need to ask management staffs. It is really time-consuming.

F10: I applied to translate 8 short form scales, but even 2 years after I have submitted the file, 6 of them haven't been verified, and I don't know the process status.

F11: I don't know the current development status, like what PROMIS China Center wants us to do? The research plan? So I just explore PROMIS-related research by myself, and I find it really difficult.

② The current management process involves too much paper materials.

S1: It is challenging to manage all the paper materials, such as the registration form, application form, and agreement.

S2: There are too many paper materials in my office. The paper materials make my office seem more and more crowded.

S5: It is hard for me to look for one agreement or application form. Sometimes I want to summarize and analyze the development trend of cooperation, and paper material makes this work really cumbersome.

F6: I need to post the agreement to PROMIS China Center staffs. I think it adds the workload of cooperation.

③ It is difficult for management staffs to supervise the process.

S1: In the agreement, we make it clear that cooperative team members need to submit the data to us. However, there is only a small number of cooperative team members submit it to us. Data is valuable.

S4: It is hard to notify cooperative team members the deadline of data submission and remind them to send us the data. Likewise, I cannot quickly get the Chinese version of PROMIS except for asking cooperative team members to submit it.

S5：I am not very clear about which team should hand over the data to me, let alone their research period. It is pretty challenging to manage the process.

(3) The need of E-management platform from the core users

When the researcher asked whether it was necessary to develop an E-management platform for process elimination, process simplification, and process integration, all the 10 participants answered, "Yes, it is necessary." Hence, there is an urgent need for an E-management platform.

① The E-management platform should have a clear interface and be easy to operate

S2: The E-management platform is developed to assist the process of the PROMIS China Center. It should be easy to use, and therefore management staffs can complete the work quickly.

S3: The current management process is too complex. So I do not want the E-management platform is too complicated to operate.

F1: Don't make the platform too complicated. There are some too complex E-management platforms, and I don't really want to use them.

F3: The E-management platform is mainly for cooperation services. I hope it highlights the critical information so that it is easy to find.

F5: I hope that the main points in the process can be clearly presented so it will be convenient for management staffs and cooperative team members.

F7: It should have an unmistakable icon for me to apply for research cooperation. That is the most important thing, I think.

② The E-management platform should present professional learning materials

F2: PROMIS is too professional, and it is difficult for me to understand. I don't understand a lot of things, so I need to find information by myself. I would appreciate that if I can download some learning materials from the platform.

F4: I learned PROMIS by reading articles in PubMed, but there were too many articles in it, and I didn't know how to screen them. It would be better if there were professional and high-quality learning materials on this platform.

③ The E-management platform should present research progress

S3: More and more people come to ask me about the status of PROMIS and the progress of translation, validation, and clinical application, so I have to explain it one by one, which is very troublesome. I want to post the research progress on the platform.

F5: It is better for the E-management platform to present all the PROMIS scales clearly. If I click on the scale, I can see the translation, validation, and clinical application process.

F8: I should see the progress of PROMIS in China, which team is validating it, and which team is applying it so that I can learn from them.

F9: Funding is an essential thing for research, and I want the E-management platform can show some content about PROMIS-related funding news, so I can easily catch the research trend.

## 2.5 Discussion

(1) The management process of PROMIS translation, validation, and clinical application is shown in the figure and text are complex and need to be improved. There are 14 steps in each management process, and most of the steps involve the exchange of paper materials, including registration form, application form, agreement. The current management process depends on social media, such as Wechat, mail, and e-mail, which is time-consuming. Simultaneously, both management staffs and cooperative team members hold the review that the current

management process is unsatisfying. Therefore, it is critical that the researcher need to optimize the management process.

(2) The management staffs and cooperative team members think that the E-management platform's development is of great importance for process improvement. Nevertheless, their need is different. The management staffs tend to manage paper materials by it, allowing them to save working time. The cooperative team members want to learn more knowledge and get more information from it, which can help them get a deeper understanding of PROMIS and psychometric methodology. Since the E-management platform is developed for two groups of people, it is necessary to consider both core users' needs.

# 3 The framework construction of the E-management platform for patient-reported outcomes research

## 3.1 The improvement of the management process of patient-reported outcomes research

### 3.1.1 Research purpose

Considering the complexity and problems of the current management process presented in the last part of this dissertation, the researcher aimed to improve the process by brainstorming[64]. People who participated in the group discussion could ask questions and come up with some ideas in a free, happy, and open atmosphere, stimulating creativity and bringing more constructive inspirations to management process improvement. And The improved process can be the basis for the E-management platform.

### 3.1.2 Participants

The researcher used the purposive sampling method to select the participant.

(1) Inclusion criteria:

① Person who is familiar with patient-reported outcomes research;

② Person who understands the PROMIS development methodologies;

③ Person with strong analytical and inferential skills.

### 3.1.3 Research methods

(1) Brainstorming outline

① With the help of an E-management platform, which of the step of the process can be eliminated to improve the process?

② With the help of an E-management platform, which of the steps of the process can be simplified to improve the process?

③ With the help of an E-management platform, which of the steps of the process can be integrated together to improve the process?

(2) Data collection

The brainstorming was held in the office room to ensure the discussion take place in a quiet environment with no distractions. Everyone had pens, paper, or a computer to write down whatever came to their mind. Before the discussion, the researcher introduced the theme of discussion and the current management flowchart. The brainstorming lasted for about 90 minutes. During the meeting, the researcher presented the brainstorming outline, recorded the discussion with the participants' permission, and made the discussion notes. The recording of brainstorming was transcribed into a written manuscript.

(3) Data analysis

The researcher analyzed the manuscript and summarized the creative, practical, and beneficial ideas. Then the researcher combined the ideas and drew the improved processes with text and figure.

### 3.1.4 Research results

(1) The characteristics of the participants is shown in Table 5

Table 5 Characteristics of the brainstorming participants

| No. | Gender | Age | Education background | Professional title | PROMIS research duration |
|---|---|---|---|---|---|
| B1 | female | 28 | master | research assistant | 2 years |
| B2 | female | 30 | doctor | associate professor | 3 years |
| B3 | female | 50 | doctor | professor | 3 years |
| B4 | female | 34 | doctor | lecturer | 2 years |
| B5 | female | 27 | doctor | lecturer | 6 years |
| B6 | female | 30 | master | senior nurse | 3 years |
| B7 | female | 29 | master | senior nurse | 2 years |
| B8 | female | 24 | bachelor | nurse | 2 years |
| B9 | male | 24 | bachelor | nurse | 1 year |
| B10 | male | 23 | bachelor | nurse | 1 year |

| No. | Gender | Age | Education background | Professional title | PROMIS research duration |
|---|---|---|---|---|---|
| B11 | female | 23 | bachelor | nurse | 1 year |
| B12 | female | 23 | bachelor | senior nurse | 3 years |
| B13 | female | 35 | bachelor | supervisor nurse | 3 years |

(2) The improved management process of patient-reported outcomes research

1) PROMIS translation

The improved management process of PROMIS translation is shown in Figure 5. The researcher describes it the text: ① The cooperative team members read the platform to know progress of PROMIS translation, and fill in the online registration, which can help management staffs know the research background, scale translation ability, and research capacity of cooperative. ② The management staffs confirm the research background of applicant. ③ The cooperative team members fill in the online application form. ④ The management staffs review the application form and make a decision to cooperate with the applicants. ⑤ The cooperative team members download and fill in the agreement. Then scan and upload it. ⑥ The management staffs download the filled agreement and seal it. ⑦ The cooperative team members download the PROMIS English scale, translate it into Chinese, and upload the Chinese version of the PROMIS scale. ⑧The management staffs review the Chinese scale.

2) PROMIS validation

The improved management process of PROMIS validation is shown in Figure 6. The researcher describes it the text: ① The cooperative team members read the platform to know progress of PROMIS translation, and fill in the online registration, which can help management staffs know the research background, scale translation ability, and research capacity of cooperative. ② The management staffs confirm the research background of applicant. ③ The cooperative team members fill in the online application form. ④ The management staffs review the application form and make a decision to cooperate with the applicants. ⑤ The cooperative team members download and fill in the agreement. Then scan and upload it. ⑥ The management staffs download the filled agreement and seal it. ⑦ The

cooperative team members download the Chinese version of PROMIS, collect the data with PROMIS according to their research purpose, and upload the data. ⑧The management staffs review the data.

3) PROMIS clinical application

The improved management process of PROMIS clinical application is shown in Figure 7. The researcher describes it the text: ① The cooperative team members read the platform to know progress of PROMIS translation, and fill in the online registration, which can help management staffs know the research background, scale translation ability, and research capacity of cooperative. ② The management staffs confirm the research background of applicant. ③ The cooperative team members fill in the online application form. ④ The management staffs review the application form and make a decision to cooperate with the applicants. ⑤ The cooperative team members download and fill in the agreement. Then scan and upload it. ⑥ The management staffs download the filled agreement and seal it. ⑦ The cooperative team members download the Chinese version of PROMIS, apply it in the clinical context, and upload the data. ⑧The management staffs review the data.

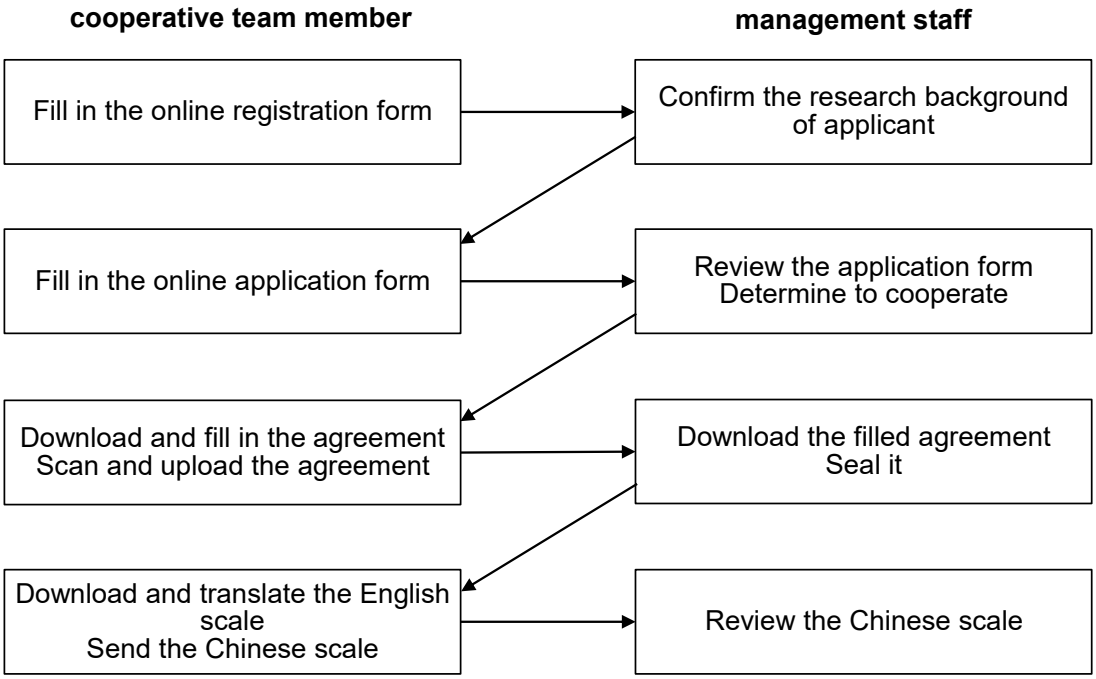


Figure 5 The improved management process of PROMIS translation

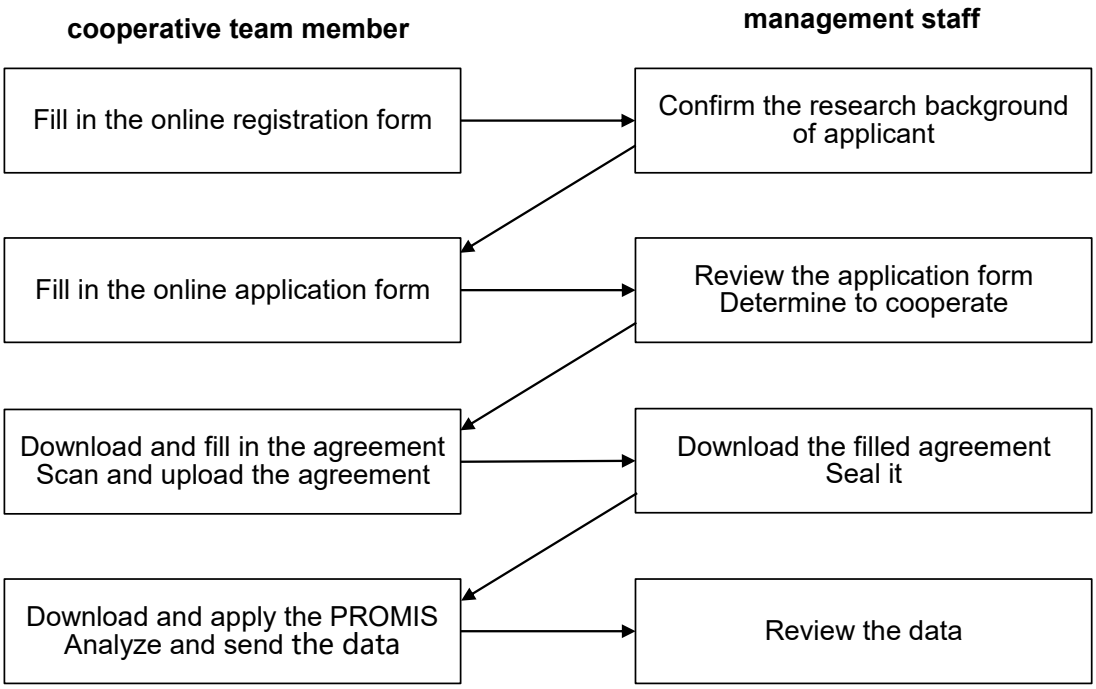


Figure 6 The improved management process of PROMIS validation

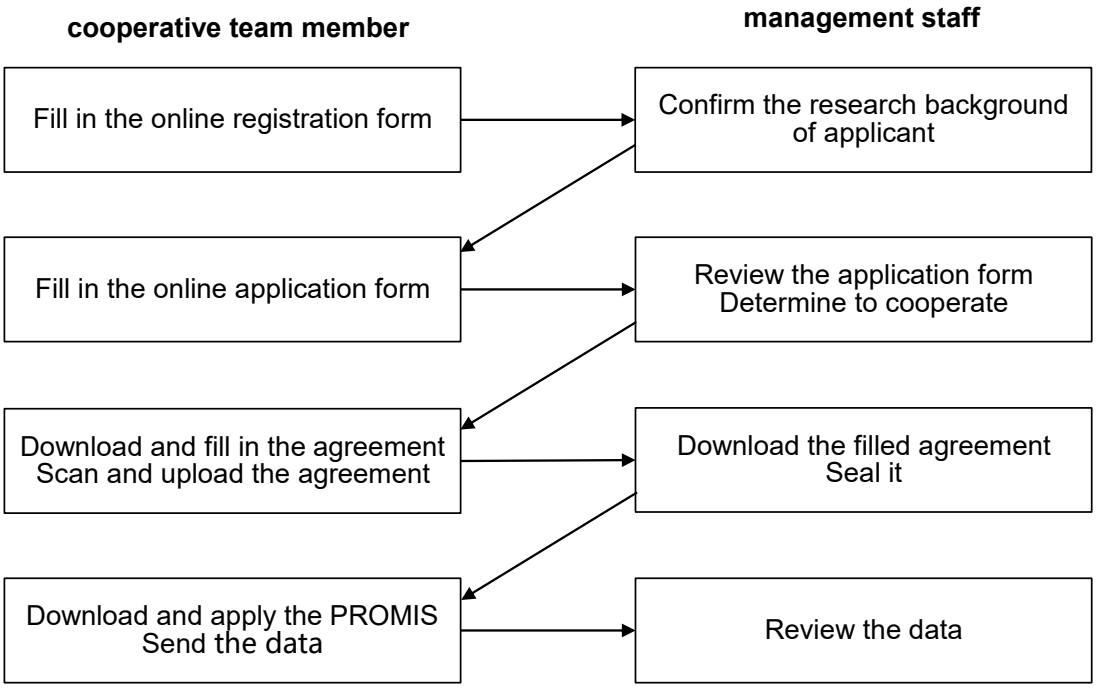


Figure 7 The improved management process of PROMIS clinical application

## 3.2 The literature study of the E-Management Platform for Patient-reported

### 3.2.1 Research purpose

To construct the framework of the E-Management Platform for Patient-reported outcomes research, it is necessary to learn from the existing PROMIS E-management platforms. In this part of study, the researcher focused on the existing PROMIS E-management platforms and summarized the menus and models to provide a reference to framework construction.

### 3.2.2 Research methods

The researcher searched Google, Baidu, and other search engines to find the patient-reported outcomes research E-Management Platform from all over the world. At the same time, the researcher read the information on HealthMeasures [6], PROMIS Health Organization[65] to find the links of other PROMIS E-Management Platforms, which can be models for the E-Management Platform we were going to develop.

### 3.2.3 Research results

The PROMIS National Center is the organization to implement the promotion of PROMIS in various countries. At present, some PROMIS national Centers have developed their E-management platforms, like PROMIS Netherlands Center [66], PROMIS Germany Center [67], PROMIS Hungary Center [68], PROMIS Canada Center[69], and PROMIS Poland Center [70]. Because PROMIS Netherlands Center has a long research history, and its platform is the most advanced one, the researcher took it as an example to guide the framework construction of the E-management platform. The researcher listed the modules of its first-level menu and second-level menu, as well as the content of each module. The PROMIS Netherlands Center platform includes 6 first-level modules and 23 second-level modules. The framework of the PROMIS Netherland Center platform is shown in Table 6 and Figure 8 as below:

Table 6 The framework of the PROMIS Netherland Center platform

| First Level | Second Level | Content |
|---|---|---|
| What is PROMIS | ①Dutch-Flemish PROMIS Group<br>②Mission<br>③What is innovative about PROMIS | Introduce PROMIS, test forms, and aims |
| Concepts | ①Conceptual module<br>②Self-reported health<br>③Physical health | Show the domains that can be measured with the |

| First Level | Second Level | Content |
|---|---|---|
| | ④Mental health<br>⑤Social health | PROMIS instruments |
| Instrument | ①Development of item banks<br>②Dutch-Flemish item banks<br>③Short forms<br>④Computer Adaptive Testing<br>⑤Instrument details | Show the aim and process of developing item bank |
| Research | ①Translation<br>②Validation<br>③Development of new PROMIS instruments<br>④Norm data<br>⑤Publications<br>⑥Presentations<br>⑦Congresses | Dutch-Flemish PROMIS scales and the application status of it |
| PROMIS in use | ①PROMIS for value-based care<br>②Conditions | The available form of Dutch-Flemish PROMIS |
| Contact | ①Contact | The links to PROMIS Health Measure and E-mail of PNC representative |

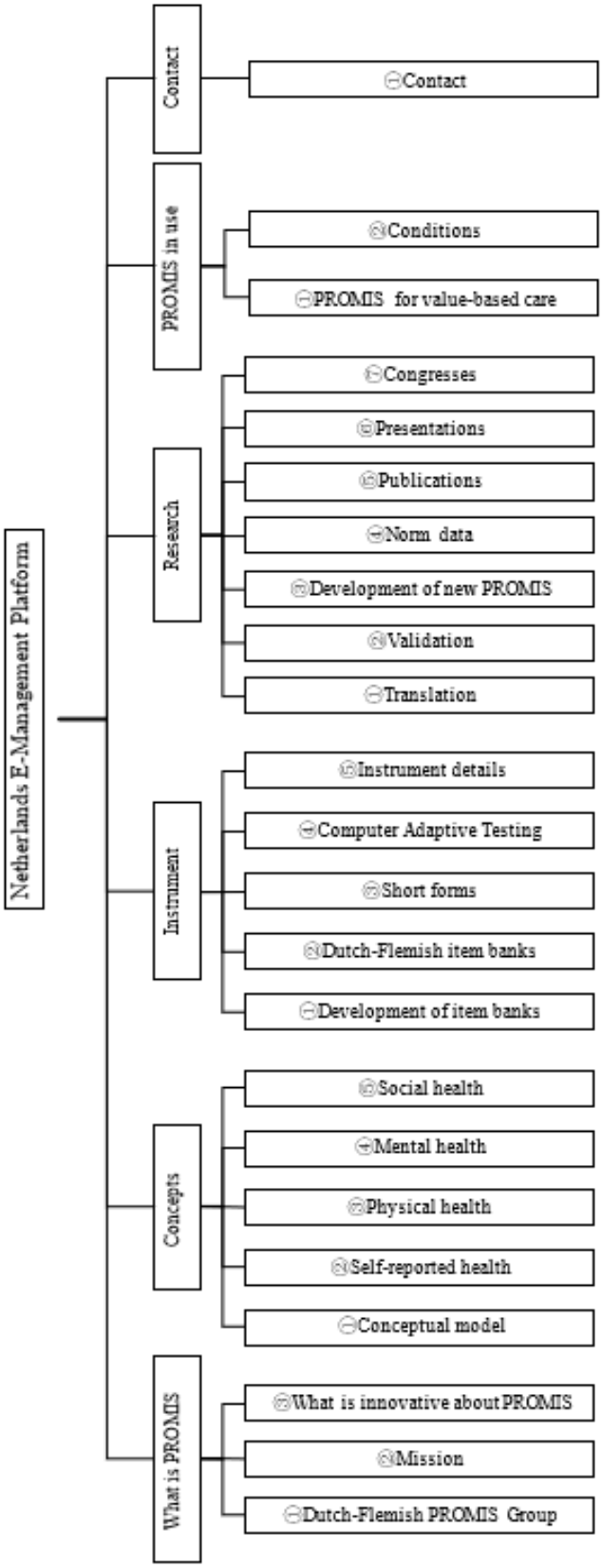


Figure 8 The framework of the PROMIS Netherland Center platform

## 3.3 The preliminary framework construction of the E-management platform for patient reported outcomes research

### 3.3.1 Research purpose

This part of study was implemented to design the preliminary framework of the E-management, including the first-level modules and second-level modules as well as the content.

### 3.3.2 Research methods

Based on the results of need analysis, process improvement, and literature study, the researcher constructed the preliminary framework of the E-management platform, which includes 7 first-level modules and 5 second-level modules. It is shown in Table 7.

### 3.3.3 Research results

Table 7 the preliminary framework of E-management platform

| First level | Second level | Content |
|---|---|---|
| Home | | Introduce the core content of "news", "resources" and other modules |
| About platform | ① management staffs introduction<br>② tasks of PROMIS China Center<br>③ the innovations of PROMIS | Introduce the management framework and tasks of PROMIS China Center; the basic information of PROMIS |
| Progress of Cooperation | ① Adult PROMIS<br>② Pediatric PROMIS | Show the progress of PROMIS Chinese version |
| News | | Show the information of events, upcoming training courses and PROMIS international conferences |

| First level | Second level | Content |
|---|---|---|
| Contact and consultation | | Name and contact information of the management staffs |
| Resources | | Documents involved in the process, such as application form, registration form, agreement, etc. |
| Application | | The cooperation process management |

## 3.4 The final framework construction of the E-management platform for patient-reported outcomes research

### 3.4.1 Research purpose

To demonstrate and revise the E-management platform's preliminary framework for patient-reported outcomes research, the researcher held the expert working group meeting with experts in the fields of nursing and software engineering. Experts expressed their suggestion from the aspects of the management experience and requirements of patient-reported outcomes research E-management platform.

### 3.4.2 Participants

Following the principles of voluntariness and informed consent, the researcher included 5-10 experts in the fields of nursing research or software engineering.

Experts need to meet one of the following requirements:

① Researcher who has rich experience in PROMIS research.

② Software engineer who has engaged in any E-management development program and has rich experience in this field.

### 3.4.3 Research methods

(1) Meeting process

The Expert working group meeting was held on August 18, 2020. One week before the meeting, the researchers sent the preliminary framework and discussion outline to the experts. The experts would think about it and make some preparations to improve the discussion efficiency. Before the meeting, the researcher informed the experts that the whole meeting would be recorded. The researcher briefly introduced the research background and discussion outline, and then experts were free to discuss.

(2) Discussion outline

① What are your opinions and suggestions on the improvement of the first-level modules?

② What are your opinions and suggestions on the improvement of the second-level modules?

③ What are your opinions and suggestions on the improvement of the content of each module?

### 3.4.4 Research results

（1）The characteristics of experts

There were 7 experts participating in the meeting, including 4 researchers of PROMIS and 3 software engineers. The details of the experts are shown in Table 8:

Table 8 The characteristics of experts

| No. | Gender | Age | Education background | Research field | Technical Title | Working years |
|---|---|---|---|---|---|---|
| 1 | female | 50 | doctor | nursing research | professor | 25 |
| 2 | female | 30 | doctor | nursing research | associate professor | 3 |
| 3 | female | 28 | doctor | nursing research | lecturer | 2 |
| 4 | female | 27 | master | research assistant | research assistant | 3 |
| 5 | male | 39 | doctor | Software engineering | engineer | 13 |
| 6 | male | 41 | bachelor | Software engineering | engineer | 15 |

| No. | Gender | Age | Education background | Research field | Technical Title | Working years |
|---|---|---|---|---|---|---|
| 7 | male | 28 | bachelor | Software engineering | engineer | 4 |

The key points of the results of the expert group meeting

① The "About platform" module aims to introduce “the management framework of and tasks of PROMIS China Center; the basic information of PROMIS” . Experts pointed out that the word "platform" made users mistakenly believe that this module is an introduction to an E-management platform, rather than an introduction to a patient-reported outcomes research, so it is recommended that it be adjusted to " Introduction ". Moreover, the second-level module is unclear and confusing, so it is recommended to introduce them level by level according to the management framework, like from PROMIS Health Organization, to PROMIS National Center, to PROMIS China Center.

② The "Progress of Cooperation" module aims to introduce the progress of translation, validation, and clinical application of the PROMIS Chinese version. Experts pointed out that "Progress of Cooperation" focuses too much on the management staff's work while ignoring other user's perspectives, such as cooperative team members. Based on the fact that the whole module focuses on the introduction of PROMIS, it is suggested to adjust it to "PROMIS Measurements". At the same time, the introduction of PROMIS needs to follow the indispensable logical prerequisite for presenting the progress. Therefore, from all users' perspectives, it is suggested to set up a second module "Overview of PROMIS" under the first-level menu. The other two second modules "Adult PROMIS" and "Pediatric PROMIS" were then set up to introduce the corresponding measurements for the two categories of group. Finally, another second module of "PROMIS Chinese Version Progress" needs to be established.

③ The two first modules "News" and "Resources" should categorize the expected presentation content to make the categories clearer and easier to read. And it is better to change the "News" to "News Center".

④ The "Resources" module aims to publicly present the documents involved in the management process, such as application forms, registration forms, agreements, etc. Experts emphasized that the documents mentioned above have been embedded in the corresponding

steps in the "application" module, and there are download entrances. Simultaneously, second-level modules need to be set up, making materials to be presented in a more reasonable manner.

⑤ The “Contact and consultation” is of little importance because users can see the contact information in the “home”.

⑥ The purpose of the "Application" module is to provide a quick entry for cooperation applications. It is clicking on this module to enter the three major cooperation processes of PROMIS translation, validation, and clinical application. Experts pointed out three comments on this module: First of all, the design of the preliminary framework merges the three major cooperation together, which can easily mislead new cooperative team members and cause false applications; Second, the name of the module should show its function more straightforwardly and clearly, which can be called as "Research cooperation"; Finally, the entire "application" module does not show the details, requirements, specifications, etc. It is recommended to give a brief introduction to the details of cooperation.

(2) The revised E-management platform framework

After repeated revisions, the framework of the E-management platform for the patient-reported outcomes research was finally formed. The platform framework includes 6 first-level modules: "Home", "Introduction", "PROMIS Measurements", "News Center", "Resources" and "Research Cooperation", under which 16 second-level frameworks are determined, which are shown in Figure 9 and interpreted as follows:

Module1: Home

In the form of an image carousel on the homepage, this part presents photos of the PROMIS China Center cooperation and the research meetings' process, which plays a role of brief introduction. At the same time, combined with the brief introduction of the "News Center", and "Resources", "home" quickly introduces the core content of the E-management platform, and provides websites links that are related to PROMIS for readers to grasp the status of PROMIS efficiently.

Module2: Introduction

① Introduction of PHO:

Introduces the development history, cooperation goals, and core organizational framework of PHO.

② Introduction of PROMIS National Center:

Introduces the development status and organizational framework of PROMIS National Center and gives examples to illustrate the PROMIS national Centers' cooperation status.

③ Introduction of PROMIS China Center:

Introduces the development history and cooperation status of PROMIS China Center.

④ Framework of PROMIS China Center:

Introduces the person in charge of the PROMIS China Center and the person in charge of various cooperation of the patient-reported outcomes research.

Module 3: PROMIS Measurements

① Overview of PROMIS:

Introduces the background of PROMIS development history, construction process, conceptual framework, measurement form, scoring interpretation, innovation points and so on.

② Adult PROMIS:

Present the major health fields in the order of adult physical health, mental health, social health, overall health, and profile, and each item bank is presented from high to low according to the usage frequency and importance of it to clearly and comprehensively display all the adult PROMIS measurements.

③ Pediatric PROMIS:

Present the major health fields in the order of pediatric physical health, mental health, social health, overall health, and profile, and each item bank is presented from high to low according to the usage frequency and importance of it to clearly and comprehensively display all the pediatric PROMIS measurements.

④ Progress of the PROMIS Chinese version:

Introduce the current status and latest developments of the Chinese PROMIS' translation, validation, and clinical application to help users analyze and understand the hot trends of domestic patient-reported outcome research.

Module 4: News Center

① News bulletin:

Display important events and research progress related to PROMIS.

② Announcements:

Publicize important information such as the upcoming PROMIS-related training courses and PROMIS international conferences.

Module 5: Resources

① Learning materials:

Share the learning materials related to the theoretical knowledge of PROMIS, such as the comparative characteristics of IRT and CTT, and the application status of CATs, etc.

② Achievements display:

Display important thesis and books related to international and domestic PROMIS development.

Module 6: Research Cooperation

① About research cooperation

Present the research cooperation status, and cooperation requirements (such as agreement signing, details of data submission).

② PROMIS translation cooperation

Help cooperative team members to apply for the translation cooperation by following the improved management process of PROMIS translation.

③ PROMIS validation cooperation

Help cooperative team members to apply for the validation cooperation by following the improved management process of PROMIS validation.

④ PROMIS clinical application cooperation

Help cooperative team members to apply for the clinical application cooperation by following the improved management process of PROMIS clinical application cooperation.

## 3.5 Discussion

(1) The improved process is much more concise

The brainstorming discussion inspired a lot of valuable suggestions and was an efficient way for process improvement. The previous process includes 14 steps and the improved process includes only 8 steps. Simultaneously, the improved process revolves in fewer paper materials exchanges, making the interaction between the management staffs and the cooperative team members more practical.

(2) The amount of PROMIS E-management platforms is small

Following the methods of literature study, the researcher found all the existing PROMIS E-management platforms. However, there are only five PROMIS E-management platforms. Most of them cannot present enough information and are not advanced enough to manage the process. Therefore, it is urgent to accomplish the development of this platform. It can be a model for further research in this field.

(3) The final framework of the E-management platform is more reasonable

The experts from the group meeting offered a lot of constructive suggestions about the preliminary framework constructed by the researcher. The researcher decided on the final framework by following the recommendation of experts. The final framework is richer in content and more suitable to the need of the core users of the platform, which can efficiently guide the development of the E-management platform.

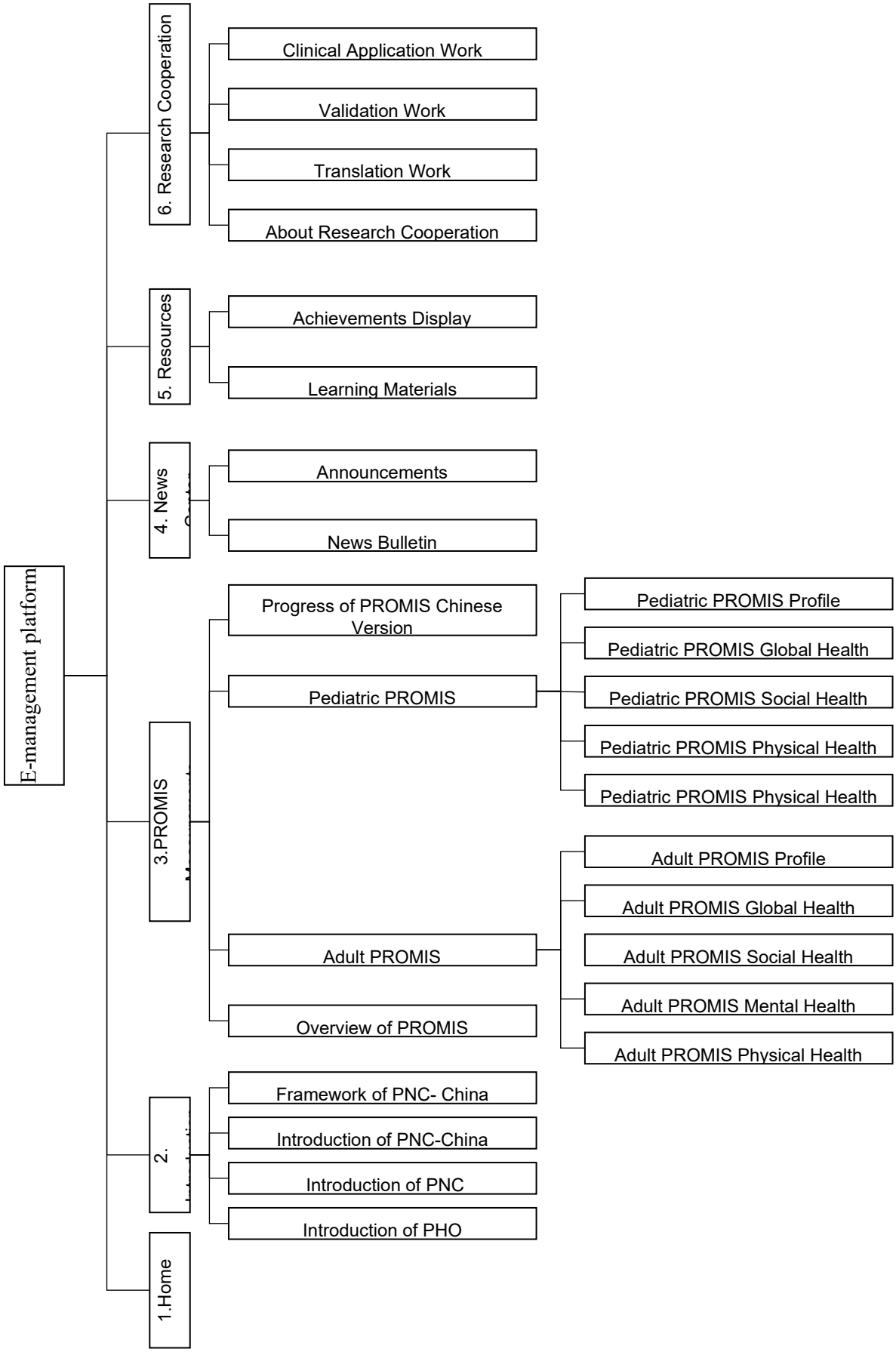


Figure 9 The final framework of the E-management platform

# 4 The development of the E-management platform for patient-reported outcomes research

## 4.1 Research purpose

According to the final framework of the E-management platform, the researchers collaborated with the software engineers to develop it based on the human-centered concept and agile development method.

## 4.2 Research methods

(1) Requirement clarification: The researcher communicated with software engineers over the final framework of the E-management platform, and make sure that the engineers have understood the requirement.

(2) Design: The interface designer designed the human-computer interaction, operation logic, and interface aesthetics of the E-management platform.

(3) Development: According to the design for the E-management platform, the software engineers wrote and modified the platform's front-end code and back-end code.

(4) Testing: After developing the E-management platform, the engineer submitted the source code. Then, the researcher tested it repeatedly and feedbacked the deficiencies. The engineer amended it depending on feedback.

(5) Release: With engineers' assistance, the E-management platform will be accessible to the public.

## 4.3 Research results

### 4.3.1 Technological points of development

The technological points of development are shown in table 9.

Table 9 Technological points of development

| | **front-end** | **back-end** |
|---|---|---|
| development language | Vue.js | java |
| development environment | windows | windows |
| development tools | vscode | IntelliJ IDEA |

| | front-end | back-end |
|---|---|---|
| coding mode | Utf-8 | Utf-8 |

### 4.3.2 The user interfaces and functions

The user interface and functions are shown in Figure 10 to Figure 18

Figure 10 the home module of the E-management platform

Figure 11 the introduction module of the E-management platform

Figure 12 the PROMIS measurement module of the E-management platform

Figure 13 the news center module of the E-management platform

Figure 14 the resources module of the E-management platform

Figure 15 the research cooperation module of the E-management platform

Figure 16 the PROMIS translation cooperation management process

Figure 17 the PROMIS validation cooperation management process

Figure 18 the PROMIS clinical application cooperation management process

# 5 The usability evaluation of E-Management Platform for Patient-reported outcomes research

## 5.1 The formative usability evaluation of E-Management Platform for Patient-reported outcomes research

### 5.1.1 Research purpose

Implement the formative usability evaluation to evaluate user interface and module designs during the process of development.

### 5.1.2 Research methods

The researchers conducted functional tests on the accomplished modules and recorded the testing process of the E-management platform entirely. The researcher wrote down the shortcomings and problems, and feedbacked them to the software engineers. This process was repeated until all the problems were fully solved.

### 5.1.3 Research results

Take the results of formative usability on January 12th,2021 for example, which is shown in table 10.

Table 10 the results of formative usability on January 12th, 2021

| The usability problem | Results |
|---|---|
| 1) The main color of the page should be dark blue, not light blue | solved |
| 2) Menu styles should be modified to make the categories more obvious | solved |
| 3) Delete one of them on the “home”: E-mail or mail | solved |
| 4) The online registration form should add more questions, like age, gender, education background, telephone | solved |

## 5.2 The summarized usability evaluation of E-Management Platform for Patient-reported outcomes research

### 5.2.1 Research purpose

The usability testing and semi-structured interview are implemented to understand the usability problems. The usability testing is reported with the time duration of the task

completion，the task's completion rate，the score of the PSSUQ. The user interview is conducted to let users report their experience and give their opinions to guide the E-management platform's optimization.

### 5.2.2 Participants

The participants were included by purposive sampling method：

① The management staffs of the PROMIS China Center were selected as the participants. During February 2021, a total of 5 management staffs were included.

② The cooperative team members who are familiar with PROMIS were selected as the participants. During February 2021, a total of 10 participants were included.

### 5.2.3 Research methods

（1）Evaluation Criteria：

To examine the quality of the users tasks completion, the researcher adopted the ISO 9241-11 framework[71]. There are three components in the framework[72]:

① Effectiveness: examine the users' ability to complete the given tasks. Participants are asked to complete six tasks, and the success or failure rate of completing each task is measured to evaluate the E-management platform's effectiveness. Task completion is considered successful when the user completed the task without error or asking for assistance.

② Efficiency: examine the required user resources to complete the tasks. For evaluating the efficiency of the E-management platform, the researcher records the time (in seconds) that participants took to complete each task. Each task is initiated by expressing the word "start" and finished when the user mentioned the end.

③ Satisfaction: record the users' opinions and feedback. It is used to evaluate the system's overall usability through Chinese version Post-study system usability questionnaire translated from English version of PSSUQ[73,75] (Appendix), which is a usability assessment questionnaire which has been used in many Chinese studies[74-76] and with high reliability[76] and validity[77]. The questionnaire is a seven-point Likert scale in which scale 1 indicates

“totally disagree”, and scale 7 indicates “totally agree”. PSSUQ contains three evaluation dimensions: system usefulness, information quality, and interface quality.

（2）Process of implementation：

①Tasks construction: based on the E-management platform's core functions and the typical and necessary operations of management staffs, the researcher designed the core evaluation tasks. The tasks were viewed by experts and shown in Table 11 (for management staffs) Table 12 (for cooperative team members)

Table 11 tasks for usability testing from the perspective of management staffs

| Task | Name |
|---|---|
| 1 | Open the E-management platform |
| 2 | Delete the first piece of brief introduction |
| 3 | Upload the PROMIS physical function-fatigue item bank |
| 4 | Release a piece of news |
| 5 | Review and approve an application |
| 6 | Upload the translation agreements |

Table 12 tasks for usability testing from the perspective of cooperative team members

| Task | Name |
|---|---|
| 1 | Open the E-management platform |
| 2 | Find and read the latest piece of news |
| 3 | Download the learning material “IRT and CAT” |
| 4 | Register an account |
| 5 | Apply for translating PROMIS physical function-fatigue item bank |
| 6 | Check the notification |

② Equipment and environment preparation: For the convenience of testing, the testing room was the current office room of PROMIS China Center. Besides, testing in this room could provide the staffs with the feeling of working in a real scene. The videotape recorder and the computer were set in advance.

③ Preparation of researcher, recorder, and participants: The researcher informed the participants about the aim of testing and its process. The recorder recorded the facial expression, words, and gestures of the participants. The researcher practiced saying instructions several times.

④ Start the testing: The researcher read the task instructions for the participants. After the participants began the operation, the recorder started to record each task's time duration, the participants' mistakes, and participants' expressions or actions. The researcher was silent and was not allowed to send participants any signals about the mistakes. If the participants cannot complete the task, it is suitable to skip to the next task.

⑤ After the testing: Participants finished the PSSUQ. Then， the researcher conducted an interview. The Interview outline: How do you feel about using the E-management platform? How does this E-management platform help you manage patient-reported outcomes research? Do you gain any good experience from the E-management platform? Does this E-management platform have any shortcomings or drawbacks? How to improve it? Do you have any other feedback?

（3）Data collection

① Observation: pay close attention to the participant’s action but do not interfere with the operation and record the usability problems.

② Audio and video recording: record the screen operation and words said by participants.

⑤ Time record: the whole process will be recorded manually.

（4）Data analysis

Analyze user action indicators through descriptive statistics. The categorical data were analyzed as count and percentage, and the continuous data were expressed as the mean. Two researchers analyzed the interview data independently by Colaizzi method [78].

### 5.2.4 Research results

(1) results from management staffs

The characteristics of the participants are shown in table 13.

Table 13 characteristics of the participants (management staffs)

| No. | Gender | Age | Education background | Professional title | Management duration |
|---|---|---|---|---|---|
| M1 | female | 28 | master | research assistant | 6 months |
| M2 | female | 30 | doctor | post-doctoral | 18 months |
| M3 | female | 50 | doctor | professor | 3 years |

| No. | Gender | Age | Education background | Professional title | Management duration |
|---|---|---|---|---|---|
| M4 | female | 34 | doctor | lecturer | 12 months |
| M5 | female | 27 | doctor | lecturer | 6 months |

① Effectiveness

Effectiveness from management staffs data is shown in table 14

Table 14 Effectiveness from management staffs data

| | Task1 | Task2 | Task3 | Task4 | Task5 | Task6 |
|---|---|---|---|---|---|---|
| Complete number | 5 | 5 | 5 | 5 | 5 | 4 |
| Complete rate | 100% | 100% | 100% | 100% | 100% | 80% |

② Efficiency

During the usability test, the completion time duration of each task was shown by Mean Time (MT), Maximum Duration (Max D), and Minimum Duration (Min D). The statistics are shown in the table 15.

Table 15 Efficiency from management staffs data

| | Task1 | Task2 | Task3 | Task4 | Task5 | Task6 |
|---|---|---|---|---|---|---|
| MT | 3.12 | 12.99 | 56.06 | 35.61 | 19.07 | 54.97 |
| Max D | 3.70 | 17.31 | 65.34 | 45.24 | 22.57 | 62.75 |
| Min D | 2.71 | 10.38 | 47.20 | 31.29 | 15.39 | 45.00 |

③ Satisfaction

PSSUQ results show: system usefulness is 5.2，Information Quality is 6.8，Interface Quality is 5.4, Overall Evaluation is 6.

（2）Results from cooperative team members

The characteristics of the participants are shown in table 16

Table 16 characteristics of the participants (cooperative team members)

| No. | Gender | Age | The research duration of PROMIS |
|---|---|---|---|
| N1 | female | 23 | 2 years |
| N2 | female | 23 | 2 years |

| No. | Gender | Age | The research duration of PROMIS |
|---|---|---|---|
| N3 | female | 22 | 1 year |
| N4 | female | 21 | 1 year |
| N5 | male | 21 | 1 year |
| N6 | male | 24 | 2 years |
| N7 | female | 34 | 3 years |
| N8 | female | 24 | 2 years |
| N9 | female | 25 | 2 years |
| N10 | female | 25 | 2 years |

① Effectiveness

The effectiveness from cooperative team members data is shown in table 17.

Table 17 Effectiveness from cooperative team members data

| | Task1 | Task2 | Task3 | Task4 | Task5 | Task6 |
|---|---|---|---|---|---|---|
| Complete number | 10 | 10 | 10 | 10 | 10 | 10 |
| Complete rate | 100% | 100% | 100% | 100% | 100% | 100% |

② Efficiency

The efficiency from cooperative team members data is shown in table 18.

Table 18 Efficiency from cooperative team members data

| | Task1 | Task2 | Task3 | Task4 | Task5 | Task6 |
|---|---|---|---|---|---|---|
| MT | 3.01 | 6.56 | 13.25 | 47.31 | 70.34 | 3.55 |
| Max D | 3.50 | 10.88 | 23.35 | 50.21 | 89.32 | 4.64 |
| Min D | 2.43 | 4.21 | 7.53 | 33.98 | 47.73 | 2.31 |

③ Satisfaction

PSSUQ results show: System usefulness is 5.8，Information Quality is 6.0，Interface Quality is 5.9, Overall Evaluation is 6.2.

(3) interview results

The results are summarized as follows:

(1) Advantages and benefits

The E-management platform makes management work more efficient, and it is generally easy to use.

N1: I think it's easy to operate, and the contents, I think the contents are very clear.

M2: The advantage, I think the first is cleanliness, I mean compared with paperwork It's important, especially for me.

N3: It's helpful, mainly for people who are not familiar with PROMIS. It's beneficial to post some crucial things.

M4: I'm able to observe the data, like the amount of application of this month or this year. I don't need to search for the paperwork to know the current situation.

M5: I can eventually post the learning material on this platform, and I don't need to send them to cooperative team members.

N8: This information is very useful in helping me to complete the application.

N7: The information can help me effectively to learn psychometrics.

(2) Disadvantages and obstacles

There are still some problems with the E-management platform.

N1: The platform is not beautiful enough, I think.

M2: It would be easier to make this platform link to phone message since some people would not check the notification on the platform frequently.

M3: I cannot change some of the photos on this platform. I want to change it sometimes.

N4: We need to design the interface about the front or other thing which can make it looks more advanced.

N9: The interface of this platform was not pleasant enough, I think.

N10: The picture on the screen is stretched out.

## 5.3 Discussion

(1) The overall evaluation of the usability of the platform

Participants were actively engaged in the evaluation and had a good user experience about the platform's function and framework. The platform has high effectiveness and efficiency. The information is about the brief introduction and professional material, which is rated as high quality. However, the system usefulness and interface quality are relatively low, and need further optimization. The E-management platform's framework is classified in an orderly manner, and the module setting is logical, which improves the efficiency of applications, information browsing and searching, and cooperation. It is excellent in human factors design and has a high significance for managing patient-reported outcomes research.

(2) The effects of the E-management platform for patient report outcomes research

The complex process and complicated contents of PROMIS research have hindered the promotion and application of PROs in China. However, this study's E-management platform is completely following the cooperation content and cooperation process, which avoids many problems in the previous cooperation process. According to the management staffs, the platform facilitates a clear and concise presentation of the background knowledge of PROMIS, as well as the information for collaboration, which facilitates the process. It helps the cooperation process and is of great significance to the promotion of PROMIS in China.

(3) The limitations and optimization strategies of the platform

According to the results of qualitative research, we find some problems of this platform. In the future, we need to beautify the platform and make it easier for users to modify photos or materials.

# 6 Conclusion

## 6.1 Conclusion

(1) Analyzed the need of the E-management platform for the patient-reported outcomes research

Based on business improvement theory (ESIA theory), the researcher conducted the semi-structured qualitative interviews to know： ① the current management process of patient-reported outcomes research. ② The current process's problems, like the current management process is tedious; the current management process involves too much paper materials; it is difficult for management staffs to supervise the process. ③ the need for the E-management. Those results can be the basis for the development of the E-management platform.

(2) Constructed the framework of the E-management platform and developed it

The researcher held a brainstorming discussion to improve the current management process based on business improvement theory; Meanwhile, the researcher accomplished the literature study about the patient-reported outcomes research E-management platforms of other countries and analyzed the framework; Then, the researcher combined the results of need analysis, brainstorming, and literature study to draw the preliminary framework of the patient-reported outcomes research E-management platform; Finally, the researcher held an expert group meeting to revise the preliminary framework and make a final framework. The logical process of framework construction provided solid instruction for the successful process of development.

(3) Evaluate the usability of the E-management platform

The researcher implemented the formative usability evaluation and helped to solve all the usability problems. The summarized usability evaluation shows the platform has high effectiveness and efficiency. The information is of high quality. However, the system usefulness and interface quality are relatively low, and need further optimization. The E-management platform can bring the users a lot of good benefits. It is excellent in human factors design and has a high significance for managing patient-reported outcomes research.

## 6.2 Innovation

(1) Use ESIA theory to optimize the nursing related scientific research process

In this study, the researcher adopted ESIA theory, emphasized the research process, eliminated non-value-adding activities, adjusted and integrated core value-adding activities, and improved the process's integrity and coherence level. The improved process was consistent with the practical work of patient-reported outcome research, which can provide reference for the process improvement related to nursing and scientific research.

(2) Promote the implementation of patient-reported outcomes in China

This study focuses on the patient-reported outcomes research, and the constructed E-management platform promotes convenient and efficient patient-reported outcomes cooperation, which has substantial significance for the promotion of PROMIS in China.

## 6.3 Research deficiencies and future prospects

(1) Aesthetic deficiency of the E-management platform

Due to the limitation of research time and workforce, this researcher focuses on whether the E-management platform's functions can meet the needs, without much consideration of the color scheme, font selection, and decorative elements of user interface. The follow-up researcher should further explore and optimize the usability and aesthetics of the platform interface.

(2) The need to develop online testing for patients

The current E-management platform focus on two groups of users: PROMIS China Center management staffs and cooperative team members. There is an urgent need to develop the online testing function for patients, allowing patients themselves to evaluate their health status whenever they need it.

(3) The need to develop patient-reported outcomes large database.

The current E-management platform can only help collect data, allowing cooperative team members to submit the data quickly and conveniently. However, data analysis is also an essential part of nursing research, and the management staffs can gain more benefits from this

function. Future studies can explore a more suitable way to combine all the data to a large database and analyze the data for more findings.

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# Appendix

Post-study System Usability Questionnaire (English Version)

Dear users,

After using the platform, please evaluate the platform for the following questions. Each item has 7 options, ranging from strongly disagree -- strongly agree is marked as 1-7, and please tick "√" on the corresponding score.

You are：☐management staff ☐cooperative team member

| | | Totally disagree | | | Agree | | Totally agree | |
|---|---|---|---|---|---|---|---|---|
| System Usefulness | Overall, I am satisfied with how easy it is to use this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | It was simple to use this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | I was able to complete the tasks and scenarios quickly using this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | I felt comfortable using this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | It was easy to learn to use this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | I believe I could become productive quickly using this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Information Quality | The platform gave error messages that clearly told me how to fix problems. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | Whenever I made a mistake using the platform, I could recover easily and quickly. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The information (such as online help, on-screen messages, and other documentation) provided with this platform was clear. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | It was easy to find the information I needed. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | This information is very useful in helping me to complete the corresponding tasks | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The organization of information on the platform screens was clear. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The interface of this platform was pleasant. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | I liked using the interface of this platform. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | | Totally disagree | | | Agree | | Totally agree | |
|---|---|---|---|---|---|---|---|---|
| Interface Quality | This platform has all the functions and capabilities I expect it to have. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The word display on the platform is easy to read | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The color contrast of the platform is well designed | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | The picture on the screen is very clear | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | I will still remember how to operate the platform next week | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Overall Evaluation | Overall, I am satisfied with this system. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

# 评估患者报告结局测量信息化管理平台可用性评价问卷

# (Chinese Version)

尊敬的用户您好！请您在使用该平台后，针对以下问题对平台进行评价，每条内容有7个选项，从“强烈不同意”—“强烈同意”分别标记为1-7，请根据您的体验在相应数值上打“√”。

**一．基本信息**

您的身份是：□管理人员　□合作团队成员

**二．可用性评价问卷**

| | | 强烈不同意 | | | 同意 | | | 强烈同意 |
|---|---|---|---|---|---|---|---|---|
| 系统有用性 | 1.总体来说，我很满意该平台的易用性 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 2.应用该平台非常简单 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 3.使用该平台能很快的完成指定任务 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 4.使用该平台我感到很舒适 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 5.学习使用该平台很容易 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 6.我相信使用该平台我能变得更高效 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 信息质量 | 7.平台出现错误信息后能够清晰的告诉我如何修复这些问题 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 8.当我使用该平台犯了错误时，我能很快很容易的纠正 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 9.该平台提供的信息是很清楚的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 10.寻找我需要的信息是很容易的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 11.这些信息在帮助我完成相应任务时是十分有效的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 12.该平台对信息的布局是很合理的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 界面质量 | 13.平台的界面显示是友好的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 14.我喜欢该平台的界面 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 15.平台包含了我期望的所有功能 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 16.平台上的字词显示易于阅读 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 17.平台的颜色对比设计很好 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 18.屏幕上的图片很清晰 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | 19.下一周我依旧能清楚记得平台是如何操作的 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 总体评价 | 20.总的来说，我很满意该平台 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## Original publications and academic conferences

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Academic Conferences

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