




# Identifying required data elements for designing mobile-based application for self-care of women living with endometriosis

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## ABSTRACT

**Introduction:** According to WHO, 190 million reproductive-aged women are affected by endometriosis. Using self-care interventions has a significant impact on managing endometriosis-related pain. Despite the enormous potential of different endometriosis applications, the medical professionals' role has been neglected in the process of app development. This study aimed to extract the requirements for developing a mobile-based app for self-care of endometriosis patients through an overview of the literature and validate them according to the expert gynecologists' point of view.

**Material and Methods:** This cross-sectional descriptive study was carried out in two steps. First, endometriosis-related articles were reviewed. Second, a researcher-made questionnaire (Cronbach's alpha=0.98) was designed to validate the identified information elements. Elements that obtained at least an average score of 3.2 (60%) out of 5-point Likert scale, were considered as required data elements for designing an android-based mobile app for self-care of endometriosis patients.

**Results:** Based on the literature review, 36 studies were retrieved and 126 data elements were extracted. The elements were classified into six categories including electronic health record, educational materials, follow-up, pain management, nutritional diet, and lifestyle. All data elements except "using traditional opioids/drugs" were verified.

**Conclusion:** In this study, a minimum data set was achieved for designing an endometriosis mobile app. Since due to the lack of international standards for designing health apps, the results of this research can be beneficial for the design and development of endometriosis apps. In the current research, an effort has been made to study all related references carefully in order to provide a comprehensive data set for designing and developing an app. This data set could be useful not only for designing a mobile-based app but also for the design of any other systems which is related to endometriosis.

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## INTRODUCTION

Endometriosis is an estrogen-dependent, chronic inflammatory disease with aberrant growth of ectopic endometrial tissue [1, 2]. Endometriosis mostly involves the pelvic peritoneum; however, the lesions could also occur in the ovaries and uterosacral ligaments [1]. According to recent statistical reports, endometriosis affects ~10% (approximately 190

million) of reproductive-aged women worldwide [3-5]. Therefore, a personalized life-long management plan should be developed for this chronic condition [6]. According to recent statistical reports, 29% of Iranian infertile women, 1.7 million German women, and 6 million American women suffer from endometriosis [7-9]. Though, owing to the asymptomatic nature of this disease in some cases, a wide range of affected women remain undiagnosed

[10]. Different symptoms and consequences of this disease affect several aspects of a person's life; therefore, the direct and indirect costs of this condition should be considered [11]. Despite the fact that the economic burden of endometriosis is underestimated, extensive studies performed across different countries substantiated that its burden is alike or higher than other chronic diseases such as diabetes and heart disease [12-14].

The pathophysiology of endometriosis is not known yet [15] and its onset and progression may be associated with extraordinary pathogenic mechanisms. Moreover, it is believed that environmental and lifestyle factors may play enormous roles in the pathogenesis of this disease [16]. Endometriosis patients experience a range of symptoms including heavy menstruation, dysmenorrhea, chronic pelvic pain, painful sex, gastrointestinal symptoms such as abdominal bloating, nausea, painful defecation (dyschezia) or dysuria, and psychological symptoms like anxiety or depression [3]. Owing to the debilitating effects of endometriosis such as infertility, and interference with daily life; early diagnosis of endometriosis may prevent its adverse sequelae in patients [16].

Using self-care interventions is highly effective in controlling endometriosis-related symptoms [17]. Endometriosis patients apply various self-care techniques including dietary changes, physical exercise, acupuncture, transcutaneous electrical nerve stimulation (TENS), and herbal remedies to relieve their symptoms [17-20].

Mobile health (mHealth) is a medical and public health practice supported by wireless devices [21]. mHealth has an advantageous effect on the health status of patients with chronic diseases such as chronic pain [22].

According to a recent study, limited access to healthcare services during the COVID-19 pandemic had negative impacts on endometriosis patients' lives. Electronic health tools such as mobile applications (apps) are considered an appropriate alternative for gynecologic care, addressing restrictions in access to health services [15].

The increase in the smartphone technology adoption and usage in health care over last few years, has provided the opportunity to promote efficiency and effectiveness within health care processes [2]. However, despite the enormous potential of different endometriosis apps, there is a concerning absence of evidence-based (EB) and medical professional involvement (MPI) in app development both in self-care and other medical activities, resulting in patient safety issues [2, 23].

Considering the fact that identifying the required

data elements for designing a science-based application, and then validate them according to expert's point of view are the basic and also most important phases of developing a system/software. This study aimed to first identify the requirements for designing a mobile-based app for self-care of endometriosis patients through an overview of the literatures, and second validate the requirements with respect to gynecologists' opinions and perspectives.

## MATERIAL AND METHODS

This cross-sectional descriptive study was carried out in two phases in 2022. First of all, a review in the literature was conducted in five electronic databases including PubMed, Scopus, Web of Science, ScienceDirect, and Google Scholar (manual search). Additionally, endometriosis guidelines of European Society of Human Reproduction and Embryology (ESHRE) and National Institute for Health and Care Excellence (NICE) and gynecology-related reference textbooks were reviewed.

### First phase

#### Search strategy

The search strategy included the following keywords: "endometriosis", "mobile apps", and "self-care" in the title or abstract of the article (Table 1). The search string used on PubMed is presented in table 2. The following inclusion criteria were applied: (1) published in English; (2) published from 2003 to 2022; (3) full-text journal articles; (4) most relevant to the concept of self-management of endometriosis; (4) review and systematic review articles. Articles that reported self-care in other gynecological diseases were excluded.

**Table 1: Literature search terms**

Item	Category name	Search terms
1	Endometriosis	"Endometriosis" OR "Endometrioma" OR "Endometrioses" OR "Endometriomas" OR "Endometrio*"
2	Self-care	"self-care" OR "self-management"
3	Mobile Apps	"Mobile Apps" OR "mobile application" OR "smartphone" OR "mHealth" OR "mobile health" OR "Minimum Data Set" OR "data elements" OR "information elements" OR "E-health" OR "electronic health"
4		[1] AND [2]
5		[1] AND [3]
6		[1] AND [2] AND [3]

**Table 2: PubMed Search string**

1	("endometrio**"[Title/Abstract]) AND ("self-care"[Title/Abstract] OR "self-management"[Title/Abstract])
2	("endometrio**"[Title/Abstract]) AND ("mobile apps"[Title/Abstract] OR "mobile application"[Title/Abstract] OR "smartphone"[Title/Abstract] OR "mHealth"[Title/Abstract] OR "mobile health"[Title/Abstract] OR "minimum data set"[Title/Abstract] OR "data elements"[Title/Abstract] OR "information elements"[Title/Abstract] OR "E-health"[Title/Abstract] OR "electronic health"[Title/Abstract])
3	((("endometrio**"[Title/Abstract]) AND ("self-care"[Title/Abstract] OR "self-management"[Title/Abstract]) AND ("mobile apps"[Title/Abstract] OR "mobile application"[Title/Abstract] OR "smartphone"[Title/Abstract] OR "mHealth"[Title/Abstract] OR "mobile health"[Title/Abstract] OR "minimum data set"[Title/Abstract] OR "data elements"[Title/Abstract] OR "information elements"[Title/Abstract] OR "E-health"[Title/Abstract] OR "electronic health"[Title/Abstract]))

Endometriosis-related mobile apps were searched on App Store and Google Play Store using the keyword "endometriosis" both in English and Persian. 17 endometriosis-related apps in English were found (presented in table 3). However, there was no endometriosis mobile app in Persian for Iranian women.

**Table 3: Endometriosis-related mobile apps**

App	Operating system	
	iOS	Android
Endometrix	✓	✓
SORA	✓	
Endo, PCOS & menopause	✓	
Luna endometriosis	✓	✓
My endometriosis team	✓	✓
EndoWheel	✓	
NEZHAT	✓	✓
AAGLEndo Classification	✓	✓
Phendo	✓	✓
Endometriosis+	✓	
SurrEndo	✓	
Endometriosis Diary	✓	
Endobaby	✓	
Beyond the Invisible AR	✓	
Endometriosis Treatment		✓
The adventures of Detective Coli – "Endometriosis"		✓
TED/The Endometriosis Diet	✓	
My Endo App (Early access)	Under development	

## Second phase

In the second phase, a researcher-made

questionnaire was designed based on the data derived from the literatures to validate the extracted data elements.

The content validity of the questionnaire was evaluated by a team of four experts (three specialists in medical informatics and health information management, and one gynecologist). The reliability of the questionnaire was calculated using SPSS version 26 (Cronbach's alpha = 0.98). The Answers were measured on a 5-point Likert scale ranging from 1 to 5 (1= unimportant, 2= low importance, 3= neutral, 4=important, and 5= very important). The statistical population of this study consisted of 32 obstetric-gynecologic specialists working at Yas hospital affiliated to Tehran University of Medical Sciences. After visiting the hospital in person for one-week and using the random-access sampling method, the questionnaires were distributed to 25 gynecologists based on the Morgan sample size table.

Collected data were analyzed with descriptive statistics using SPSS software version 26. The information elements that obtained at least an average score of 3.2 (60%) were considered practicable elements for designing a mobile-based application for self-care of women living with endometriosis.

## RESULTS

### First phase

293 documents were retrieved according to the search method applied in the mentioned databases (Fig 1). The search was limited to title/abstract, duplicate articles were removed, and then by applying inclusion criteria, 36 articles were selected. By reviewing selected articles, ESHRE and NICE endometriosis guidelines, and gynecology-related reference books, 126 data elements were identified. According to the research team concurrence, identified elements were assorted into six parts. These items were classified into six subcategories including electronic health record (57 items), pain management (19 items), lifestyle (19 items), educational materials (12 items), nutritional diet (10 items), and follow-up (9 items). (By visiting in person, the health information management department, the raw forms of patients' medical records were checked to categorize the data in the electronic health record (EHR) section of the questionnaire.

The results of this step could be divided into two parts; the first part containing studies focused on just one self-care strategy, and the second part including studies investigating a group of self-care strategies.

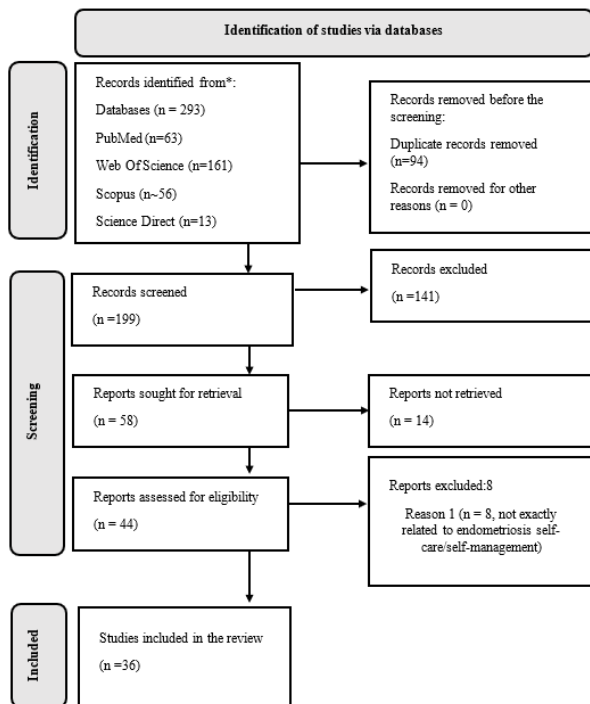


Fig 1: PRISMA diagram

The geographical distribution of the included articles in this study was as follows: Australia (n=7), Germany (n=2), Hungary (n=2), Canada (n=2), Iran (n=2), Brazil (n=1), Norway (n=1), Netherland (n=1), South Africa (n=1), UK (n=1), Italy (n=1). 17 of the articles were review articles and studies conducted in different countries.

App Store and Google Play were searched to find endometriosis-related apps and also for scanning their features. Most of the mentioned mobile apps were focused on one or two aspects of endometriosis like dietary recommendations, symptoms tracker, pain trackers, or pain management recommendation. As an example, “TED/The Endometriosis Diet” concentrates on providing comprehensive nutrition guidelines for patients, Therefore, it is only focused on the aspect of dietary recommendations. This research has tried to consider all the extracted features as much as possible, in order to obtain a complete data set.

**Second phase**

In this phase, the distributed questionnaires were collected. Two of the questionnaires were omitted due to some unanswered questions. Respondents included six fellowships in minimally invasive gynecologic surgery (hysteroscopy and laparoscopy), five gynecologists (OB/GYN specialists), and 12 obstetrics and gynecology residents. Table 4 shows the frequency analysis of the participants’ demographic information.

Table 4: Frequency distribution of participants’ demographic information

Demographic Information	Categories	Frequency (N)	Percent (%)
Age	30-39	16	69.6
	40-49	5	21.7
	50-59	2	8.7
Degree	Ob /gyn resident	12	52.2
	Ob/gyn specialist	5	21.7
	Fellowships in MIGS	6	26.1
Experience (year)	1-4	14	60.9
	5-9	1	4.3
	10-14	5	21.7
	15-19	1	4.3
	20 ≤	2	8.7

Abbreviations: MIGS, minimally invasive gynecologic surgery; Ob/gyn: Obstetrics and gynecology.

According to the survey respondents, all data elements except “using traditional opioids/drug” obtained at least an average score of 3.2 (60%). Therefore, 125 elements were verified as required data for designing endometriosis self-care app. Among the items of EHR category, three items including age, ethnicity, and BMI got the highest mean score (4.87). “Dysuria and dyschezia” got a mean score of 4.57 in the clinical subcategory. Other data elements that achieved high scores include: “diagnostic imaging” and “laparoscopy” (4.04) in educational materials, “chronic pain” and “reminder for taking medicine” (4.17), in follow-up, “rest” (3.91) in the pain management strategies, “vitamin D” (4.17) in diet changes, and “hot shower in menstruation” (4.04) in the lifestyle subcategory. Tables of data elements’ categorization and their mean are presented in [online supplementary material](#). Data element categories, the number and percentage of items in each category, and their average score are presented in Fig 2.

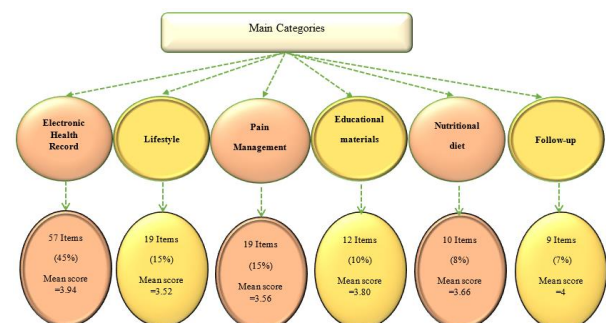


Fig 2: Data element categories, number and percentage of items in each category, and their average score

**DISCUSSION**

In this descriptive-analytical study we aimed to determine the required data for designing an

android-based app for the self-care of endometriosis patients in two steps. In the First step, the required data elements were identified by reviewing articles, gynecology-related reference books and guidelines; and in the second step, the elements were validated through conducting a survey of experts.

Studies demonstrate that patients living with endometriosis use a range of numerous strategies for managing the symptoms of their condition such as pain, and physical, psychosocial, or psychological-sexological issue [16, 19, 24, 25]. There are some strategies that are considered effective strategies for these patients. Acupuncture, acupressure, and heat are commonly used and rated as effective for endometriosis-related pain [26]. There is evidence that there may be an increase in endometriosis risk with increased red meat consumption and a decrease in risk with increased consumption of fish oils, green vegetables, fruits (especially citrus fruits), and dairy products. A gluten-free diet showed a significant positive effect in reducing pain symptoms in endometriosis patients [27, 28]. regardless of negative effects, some herbal drugs use is another self-care strategy for alleviating endometriosis-related pain [29-31].

In this study, data elements were classified into six major categories (Electronic Health Record, Lifestyle, Pain Management, Educational materials, Nutritional diet and Follow-up), whilst in another study aimed for designing a preeclampsia mobile app, data elements were classified into seven major parts containing demographic information, health history, life style, reminder, educational points, Laboratory findings and getting reports through the app [32, 33]. In this study “age” was the most important element in demographic information part, In the current study “age” got the highest score (4.87 out of 5) among the elements of the EHR category as well which was in accordance with the mentioned study. In health/medical history section, “Age at Menopause/Date of Last Menstruation” was the most important data, whilst in present study, “age at menarche” and “dysmenorrhea” got the highest score (4 out of 5).

Similarly, in a study conducted by Safdari et al., aiming to determine data elements for developing a mobile-based app for self-care of females having pelvic floor disorders, “age” was considered the most important element of the “personal information” section (mean score=4.63/5) [34]. The “number of pregnancies” got the highest score in the “medical history” subcategory in the mentioned study (mean=4.86). On the contrary, the “number of pregnancies” got 3.48 average score in this study and “fertility method” (mean score=3.74) was the most important component of the “obstetrics & sterility history” subcategory. Again, in the mentioned study, “prevention” was a significant element of “educational contents”. However, in current study,

“diagnostic information” was important.

Langarizadeh et al. detected and validated the requirements for developing a nutrition education mobile app for infertile women through a researcher-made questionnaire. The questionnaire contained three sections including educational part, demographic data elements, and app required capabilities [35]. Similar to current study, “age” got the highest mean score percentage (93.3%) in the demographic section. Moreover, in the mentioned research, “menstrual status”, “menstrual duration” and “menstrual severity” were considered necessary data elements for the nutrition educational app. Similarly, in present study “irregular menstruation”, “dysmenorrhea”, and “heavy menstrual bleeding” got 4.13, 4, 3.74 out of 5, respectively. In Langarizadeh et al. study, all participants pointed that “taking medication” is an important element in the educational content, however, in this study, diagnostic imaging and laparoscopy (both having a mean score of 4.04/5) were the most important elements.

Another study by Langarizadeh et al. determined the requirements for developing an educational app for women at risk of endometriosis [36]. In this study, the extracted data elements were divided into two parts: educational requirements and capabilities/features of the application whereas, in the current study, data elements were classified into 6 parts. And technical features were considered in each part separately (if needed), like reminders in the follow-up section or BMI calculation in the EHR section for instance). In Langarizadeh et al. study, most of the respondents (82%) mentioned that “Chronic pelvic pain”, “infertility”, “overview of endometriosis” and “endometriosis symptoms” are necessary data elements for this educational App. In present study more than 60% of participants pointed that the mentioned elements are required data elements; so current study was in accordance with Langarizadeh et al study.

Ahmadi et al. investigated the requirements for developing a breast cancer-related lymphedema (BCRL) app [37]. The requirements were classified into categories including demographic information, lifestyle, clinical information, and the app functions (including six subcategories of drug use, exercise, nutrition, communication, smoking cessation, and reminder for test time) [37]. Demographic and clinical data elements were classified in the EHR category in current study. Similarly, “lifestyle” was one of the main divisions in the mentioned study. However, the classification of the other elements was different.

Whilst most of the studies consider the nutritional recommendations as a part of lifestyle section [32, 34, 37], in current study nutritional diet was regarded as a separate category and lifestyle category focused on

physical activity, sexual behaviors and health habits.

### Strengthen and Limitation

Fortunately, ease of access to experts (gynecologists) and their great cooperation with the research team facilitated the research process. In the first step of the study (literature review), we made an effort to have a complete survey in PubMed, Web of Science, Scopus, and ScienceDirect, Google Scholar (manual search). 56 records were retrieved after the initial search in Scopus. Owing to a short gap during in this study, the search was conducted again in order to double-check the records and ensure no missed records. Unfortunately, Scopus became inaccessible in Iran at that time. Therefore, some Scopus articles may be missed.

### CONCLUSION

To the best of our knowledge, this is a comprehensive study that has reviewed endometriosis-related studies. The minimum data set proposed here is useful for identifying important variations in the information requirements for designing a mHealth app for endometriosis. Since there are no international standards to develop mHealth apps, the data set presented in this paper can be beneficial for the design and development of any other apps. In the current research, an effort has been made to study all related references carefully in order to provide a comprehensive data set for designing and developing an app. This data set could be useful not only for designing a mobile-based app but also for the design of any other systems which is related to endometriosis. Investment in this study would improve the quality of care thereby reducing the burden and cost of endometriosis. Investment in the first and second phases of this study would improve the quality of care thereby

reducing the cost and burden of endometriosis, especially in developing countries.

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### AUTHOR'S CONTRIBUTION

ZS performed literature review, data collection and data analysis, and drafting the main manuscript. FS participated in data collection and FS and JS contributed to data validation, Review and editing. SP performed editing the manuscript drafts, reviewing, editing, and approving the final manuscript. RS performed Project administration, supervision, analysis, Review.

All authors contributed to the literature review, design, data collection and analysis, drafting the manuscript, read and approved the final manuscript.

### CONFLICTS OF INTEREST

The authors declare no conflicts of interest regarding the publication of this study.

### FINANCIAL DISCLOSURE

No financial interests related to the material of this manuscript have been declared.

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