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An Evaluation on Electronic Patient-Reported Outcomes in Ciparay Sub-District, Bandung, West Java

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Abstract

Electronic Patient-Reported Outcomes for children has become more common as a means to collect health data during conception, pregnancy, and childbirth. However, it remains unclear whether the responsive level of the digital divide on the technology. The purpose of this study was to assess the adoption of an Electronic Patient-Reported Outcomes by mothers to monitor the health status of their infants in Ciparay Sub-District, West Java Province. This study also examined the relationship between demographic characteristics on the utilization of the new technology and perceived barriers for usage. A total of 112 patients had registered into an Electronic Patient-Reported Outcomes entitled 'Memobayi' from April to July 2016. Personal and technical factors affected the adoption of electronic technology for recording the health status of their infants. This included lack of knowledge, privacy as well as technical concerns. The result of the study also revealed that although the use of information and communication technologies in Indonesia had overgrown during the last ten years, a considerable gap remained between those with and without access to the adoption of Electronic Patient-Reported Outcomes.

Keywords: Electronic Patient-Reported Outcomes, Digital Divide, Memobayi, Ciparay.

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1. Introduction

Electronic Patient-Reported Outcomes (e-PROs) have overgrown in clinical research and care. In 1994, Landgraf and Abetz [13] had developed the infant/toddler quality of life questionnaire (ITQOL) as an assessment of child health-related quality of life through parent report for children between 2 months and five years old. The United States Food and Drug Administration (FDA) Guidelines for Industry also developed E-PROs since 2009 to ensure the delivery of quality patient care (FDA in Landgraf et al., 2012). The European Medical Association (EMA) acknowledged the need for e-PROs since October 2010 to increase healthier lifestyles and better decision making for doctor and patient (European Commission in Landgraf et al., 2012). Although there was no universal definition of an e-PROs, Parliari et al. (2012) had defined e-PROs as "an electronic application in which individuals can access and manage their health information in a private, secure and confidential environment."

The adoption of e-PROs has potential advantages to maximize the value of health outcomes research. Patients with long term conditions are the most need to track their illness and real-time decision treatments (Parliari et al., 2012). E-PROs may increase partnership between health professionals and patients through sharing information to ensure the delivery of quality patient care ([26], Wu, AW, 2013). Chang (2007) emphasized that e-PROs may reduce the health care cost by identifying patients' symptoms, guiding health prevention, and providing medical intervention. E-PROs can be a useful tool to reach diverse, geographically dispersed and specifically targeted populations [7].

Research on the use of ePROs to conduct health surveillance faced potential issues and challenges. Those issues and problems are privacy as well security concern, digital divide, technical considerations, lack of comprehensive yet clinical relevant PROs measures, health provider burdens, and lack of clinically meaningful analyses ([12], Pangliari et al., 2007, Ekman and Litton, 2006). Lengthy instruments can frustrate and disinterest patients to respond due to time as well as energy consumed, that may cause missing or inaccurate data (Moris et al. in [17], Miller, D, et al., 2015). PROs instruments which have more than 20 variables lead to overburden patients which cause further content redundancy [27].

In Indonesia, despite substantial growth in internet use, the Association of Indonesian Internet Service Providers has estimated that there 48.2 percent of individuals lacked internet access in 2016 [2]. Internet access varies widely by socioeconomic status which leads to digital exclusion (the so-called 'digital divide') [7]. The factors underlying the digital divide may result from socioeconomic barriers to access as well as a lack of desire or ability to use the internet among particular segments of the population (Wagner et al., 2005). Subsequently, the digital divide will be outpaced by those who are ahead in the ability to select and process information (Mason and Hacker, 2003, Wong et al., 2009).

Located in the capital city of West Java Province, Ciparay's Sub-District has recorded as the most populated district in Bandung Region. In 2015, the population reached 148.025 people in which its population density has estimated 19.784 people per km^2 [2]. Ciparay Sub-District has the highest poverty level compared to another district in Bandung area [2]. In 2012, there were one neonatal death (0-6 days) and three infant death in Ciparay's Sub-District [6].

The purpose of this study was to evaluate patients who access the Primary Health Care in Caray's Sub-District to the adoption of Electronic Patient-Reported Outcomes.

Therefore, this study was designed to address the following questions:

1. Are there any significant demographic differences among Ciparay's patients about their adoption of emerging patient-reported outcomes?

2. To what extent are patients in Caray's Sub-District fill in various types of variables in the patient-reported outcomes technology?

3. What barriers to the adoption of patient-reported outcomes in Ciparay's Sub-District? staff

2. Methods

The study design is a cross-section, analyzed by the descriptive way as part of an evaluation of Memobayi.com, an EPROM technology. This study included a convenience sample of patients who have access Ciparay's Primary Health Care during April to July 2016. Participants informed that by filling out the EPROs, they would give informed consent and had agreed to participate in this research voluntarily.

Patients were approached during their consultation in the Ciparay's Primary Health Care and were asked to complete the patient-reported outcomes. They are given a written statement regarding the research goal and objectives, which stated that by filling the Memobayi.com. Those patients had consented to take part in the research project. It also said that if they decided not to take part in not complete the survey, it would not affect their right or benefits in any way. Initially, those patients had assisted in filling in the Memobayi.com. Afterward, the patients had to fill in the Memobayi.com itself. A year after the research has conducted in Ciparay, several patients had been re-contacted by email and phone on August 2017 to have feedback on Memobayi.com.

Theoretical concepts from Roger's Diffusion of Innovations Theory guided the development of patient-reported outcomes [21]. Roger describes five characteristics of an innovation namely, relative advantage, compatibility, complexity, trialability and observability. The theory has also suggested that the users' perception of the attributes of change determines the extents of uptake of new technology [21].

The project team developed a Memobayi.com, an EPROM which included 114-variables to assess the health status of children. Demographic information in the Memobayi included age, educational background, marital status, parent's height, parent's weight, and occupation. Data on infants included name, gender, date of birth, place of birth, parity, birth history, perinatal history, parenting history, disease history, neonatal screening, and obstetric history.

3. Results

A total of 112 patients in Ciparay's Primary Health Care has filled Memobayi.com. Only 6 percent of the patients have a private email. Therefore, those patients have been assisted in creating their email since private email is mandatory to register into Memobayi.com.

All patients have fully responders to fill in selected variables e.g. name of the user, user's email, date of birth, marital status, user's address, phone number, medical personnel handling, place of health service, sex of their infants, activation date, birth weight, birth length of their infants, Apgar value and birth condition of their infants. Nearly 95 percent of the responders have registered into Memobayi.com for one month after their babies are born. The majority of those infants have normal birth weight (more than 2.500 gram) whereas only 6 percent of the infants have low birth weight (less than 2.500 gram).

ATTACHMENT NO. 1: Completion Rate of Memobayi.com, Ciparay's Sub-District, 2016.

	Number of responders	Completion Rate (in %)
Demographic characteristics of the parents		
User's Name	112	100
Email's Address	112	100
User's Date of Birth	112	100
User's Educational Background	112	100
Marital status	112	100
Address	112	100
User's occupation	112	100
Phone number	112	100
Health provider	112	100
Institution	112	100
Registration Date	112	100
The blood type of user	95	84.82
User's Height	0	0
User's Weight	0	0
Infant's Data		
Infant's name	112	100
A medical record number of the infant	112	100
Infant's sex	112	100
Activation Date	112	100
Birth History		
Place of birth	112	100
Infant's Date of Birth	112	100
Delivery Process	112	100
Birth Weight of Infant	112	100
Birth Length	112	100
Apgar Value	112	100
Birth Attendant	109	97.32
Initial Breastfeeding	108	96.43
Birth Complication	107	95.54
Head Circumference	106	94.64
Babies cry directly	105	93.75
Injection of Vitamin K	105	93.75
Infant Bluish	104	92.86
The blood type of infant	13	11.61

	Number of responders	Completion Rate (in %)
Perinatal History		
Weight at returning home	98	87.50
Congenital abnormalities	95	84.82
Room in between mother and newborn	83	74.11
Prematurity status	83	74.11
When the baby has a yellow appearance	38	33.93
Light therapy	30	26.79
Bilirubin level	1	0.89
Parenting history		
Parenting history	81	72.32
Number of older sister/brother	51	45.54
Breastfeed history	48	42.86
Solid food consumed	46	41.07
Formula milk history	44	39.29
Number of younger sister/brother	1	0.89
Disease History Among Parents		
Disease history of the parents: Asthma	83	74.11
Disease history of the parents: Allergy to food	83	74.11
Disease history of the parents: Allergy to Medicine	83	74.11
Disease history of the parents: Obesity	83	74.11
Disease history of the parents: Diabetes Mellitus	82	73.21
Disease history of the parents: Hypertension	82	73.21
Disease history of the parents: Tuberculosis	81	72.32
Disease history of the parents: Thalassemia	78	69.64
Disease history of the parents: Other	0	0
Disease History of the Child		
Disease history of the child: Congenital Abnormalities	97	86.61
Disease history of the child: Convulsions	97	86.61
Disease history of the child: Allergy on Medicine	97	86.61
Disease history of the child: Asthma	97	86.61
Disease history of the child: Tuberculosis	95	84.82
Disease history of the child: allergy to food	83	74.11

	Number of responders	Completion Rate (in %)
Disease history of the child: dermatitis/eczema	82	73.21
Disease History of the Child: Measles	79	70.54
Disease History of the Child: Hepatitis B	79	70.54
Disease History of the Child: Malaria	79	70.54
Disease History of the Child: Typhoid	77	68.75
Disease history of the Child: chicken pox	76	67.86
Convulsions	75	66.96
Tuberculosis history of the child: Doctor	3	2.68
Tuberculosis history: duration	2	1.79
Disease History of the Child: Other	1	0.89
Tuberculosis history of the child: age	1	0.89
Chickenpox history of the child: Age	0	0
Neonatus Screening		
Neonatus: Other Screening	81	72.32
G6PD enzyme's deficiency	80	71.43
Congenital Hypothyroidism	80	71.43
Neonatus - Hb	75	66.96
Laboratorium - Blood sugar	75	66.96
Left Congenital Deafness	0	0
Right Congenital Deafness	0	0
Obstetric History		
Obstetrik - Hb	82	73.21
Complication During Pregnancy	80	71.43
Duration of pregnancy	80	71.43
HIV	80	71.43
Hypertention & preeclamsia	79	70.54
Premature Rupture of Membranes	79	70.54
Examination on K1	79	70.54
Examination on K4	77	68.75
Bleeding	77	68.75
Infection	77	68.75
Upper Arm Circumference	46	41.07
Lactation Visit	41	36.61
Weight Gain	32	28.57
Rubella	7	6.25
pre-screening development questionnaires - 15 months	2	1.79
pre-screening development questionnaires-3 months	1	0.89

	Number of responders	Completion Rate (in %)
pre-screening development questionnaires- 6 months	1	0.89
pre-screening development questionnaires - 9 months	1	0.89
pre-screening development questionnaires- 12 months	1	0.89
pre-screening development questionnaires - 18 months	1	0.89
pre-screening development questionnaires - 21 months	1	0.89
pre-screening development questionnaires - 24 months	1	0.89
pre-screening development questionnaires - 30 months	1	0.89
pre-screening development questionnaires - 36 months	0	0
pre-screening development questionnaires - 42 months	0	0
pre-screening development questionnaires - 48 months	0	0
pre-screening development questionnaires - 54 months	0	0
pre-screening development questionnaires - 60 months	0	0
pre-screening development questionnaires - 66 months	0	0
pre-screening development questionnaires - 72 months	0	0
Toxoplasma	0	0
Syphilis	0	0
Cytomegalovirus	0	0
Herpes simplex	0	0

Source. Data recorded by ePROs Memobayi.com, 2016.

However, none of those patients have to fill in several variables such as parent's height, parent's weight, child's disease history on chicken pox, toxoplasma's status, syphilis's status, herpes simplex's status, congenital deaf's status, and pre-screening development questionnaires (refer to attachment no. 1). These conditions lead to missing data and bias for the research's analysis [18].

Table 1 reveals the demographic characteristics of the responders in Ciparay's Sub-District in 2016. The responders were predominantly housewives (89.3%) with 6.25% responders working informal sector and 4.5% responders working in the intimate area. Half (51.8%) of the participants had senior high school graduated whereas only 6.2 percent indicating they had a graduate degree, 27.72 percent patients had junior high school graduated, and 14.29 percent patients had elementary school graduated. Almost

half of the responders at the age of 31-40 years old (45.54%), 21-30 years old (34.82%), less than 20 years old (11.61%) and more than 41 years old (8.04%).

Table 1: Sociodemographic characteristics of the parents.

	N	%
Demographic characteristics		
Education		
Graduate degree	6	6.3
Senior High School Graduated	58	51.8
Junior High School Graduated	31	27.72
Elementary School Graduated	6	14.29
Profession		
Working in the formal sector	7	6.25
Working in the informal sector	5	4.5
Stay at home	100	89.3
Age group (years)		
≤20	13	11.61
21-40	90	80.36
≥ 41	8	8.04
Source. Data recorded by ePROs Memobayi.com, 2016		

There were notable differences among age groups about complete ePROs (indicated by fill in more than 50% of its variables). The result of chi-square analyses showed that there were statistically significant relationships between age group and completion more than 50% variables of Memobayi.com (X^2 = 7.99, p = 0.018) (table 2).

Table 2: Differences among age groups for completing 50% of Memobayi's variables.

	Completion (%)*		Chi-square	p-value
	Yes	No		
Age group (years)				
≤ 20	81.2	18.8	7.990	0.018
21-40	69.4	30.6		
≥ 41	100.0	0.0		
**Responders completed in more than 50% of Memobayi.com's variables.*				
Source. Data recorded by ePROs Memobayi.com, 2016.				

After a year, those patients have been re-contacted by phone to identify their willingness to fill in all variables in Memobayi.com. Several feedbacks have occurred such as the font in the application is too small, unfamiliar with medical terms, variables that have to fill are too much, and too busy (RY, 30; T,19).

4. Discussion

This study assessed the extent to which parents were ready to implement emerging electronic technology to monitor their infant's health status. The findings indicated that most respondents had less access personally to the internet thus they were not comfortable to fill in Memobayi. The key to success to increase the completion rate of a survey that is an adequate number of questions, respondent-friendly questionnaire design, and occupant-addressed correspondence (Fung & Hays, 2008).

Furthermore, technology adoption suggested that in some health settings, a variety of training programs have been initiated both for health providers and patients. Some studies revealed that the passage of ePROs needs more than five times training programs to be accepted among the patients [1]. If the basic approaches to such initiatives are slow to be taken, more creative practices are reluctant to be attempted.

Promoting ePROs by health providers may increase the completeness of ePROs. Doctors need to encourage the ePROs data into the health consultation by conducting reference to the fact that the patient had completed the ePROs' questionnaire, either through stating the patient had completed the questionnaire, thanking the patient for completing the questionnaire or asking how the patient had 'got on with' or 'found' completing the questions [10].

A review of the demographic profiles of patients in this study may suggest some possible reasons for non-utilization of web-based communications. Over 50 percent of the patients were staying at home while highly educated (50 percent had earned a graduate degree). This accomplishment did not translate to advanced internet proficiency. The findings point out the importance of acknowledging the digital divide among generations when new Electronic Patient-Reported Outcomes technologies introduced.

5. Conclusion

The study reveals that there still challenges for responders in Ciparay's Sub-District in adopting an ePROs, Memobayi.com. Not all patients are comfortable or knowledgeable with even the underlying technology. Although the intervention strategy has conducted group and one-on-one training to facilitate the adoption of technology in the health domain, these strategies still not entirely successful in promoting the adoption of electronic medical records filled by the patients. Active communication pathways to encourage disease prevention for the children need to be adopted both by health-care providers and their patients to increase the completeness of the pros. Furthermore, given the potential role of health-care provider in providing an ePROs technology to attract and influence patients' awareness. It would be essential to continue this line of electronic communication and outreach by engaging a broader population, particularly the digital divide.

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Conflict of Interest Statement

All authors have no potential conflicts of interest to report.

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