ETHICAL FRAMEWORK ON BREAST SELF-EXAMINATION SYSTEM

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by

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TABLE OF CONTENTS

LIST OF TABLES

Page

LIST OF FIGURES

Page

LIST OF ABBREVIATIONS

(AVE)	Average Variance Extracted
(AVR)	Average Rating Value
(BSE)	Breast Self-Examination
(CFT)	Confidentiality
(CR)	Composite Reliability
(CRG)	Caring
(DV)	Dependent variable
(EV)	Ethical values
(FGD)	Focus Group Discussion
(FRS)	Fairness
(INT)	Interaction
(ITG)	Integrity
(IV1)	Independent variable 1
(IV2)	Independent variable 2
(MV)	Moderation variable
(PRT)	Protection
(RQ)	Research Questions
(TW)	Trustworthiness
(TP)	Trust Propensity
(VIF)	Variance Inflation Factor

APPENDICES

GLOSSARY OF TERMS

Anonymity	An unknown person accessing a system without any identification.
Belief	Justified and should be accepted (acceptable without argumentative support).
Calendar	Calendar (reminder system) for setting menstrual schedule as an alarm system.
Chat room	The interaction or dialog privately between public/user and physician. User able to share her history data on self-exam.
Clinical Result	The clinical result is the diagnosis data or historical data of the patient based on the examination process.
Clinician Judgment	The best clinician outcome on patient health interest.
Communication	The activity of expressing feelings and ideas or providing information to another person.
Competency	The ability of one person to fulfill another person's needs.
Confidence	A feeling of certainty or easiness regarding a belief one holds.
Credibility	The quality of being trusted and believed in.
De-identification	A process of removing identifiers from health information and mitigating privacy risks to individuals.
Engagement	The approach of the physician is to convince the patient.
Expert Advice	A physician's capability in explaining healthcare matters to society. It is part of the trust given to the physician or any healthcare professional.
Faith	The complete trust or confidence in someone or something.
Forum	The interaction or dialog publicly between patient and physician.
History	The function of this feature is to record all activity on breast self-examination.

Honest Information	A physician is honest to all his/her patient in relation to fees, promotion of any product, and any conflict of interest.
Honesty	One that makes good faith agreements, tells the truth, and fulfills any promises made.
Improving Quality	To maintain the quality of clinical care and the healthcare system.
Inequalities	Incomplete medical evidence for physician decisions on patient treatment.
Informed consent	The consent of a person to undertake a medical procedure or any other information.
Knowledge	The knowledge will provide information such as history, breast anatomy, breast cancer, diagnosis, breast self-exam, and treatment.
Location for Treatment	The user has the capability to get a selection of the nearest physician for consultation or treatment. Physicians are being informed by the patient about an appointment.
Look up information	To look up information is to find information on a particular patient's treatment on the internet. It is part of the patient's privacy that is openly accessed in the public environment. It will create a violation and a compromise of trust.
Optimal care	Optimal care is the maximum effort of the physician to take care of the patient until the clinical result/outcome appears.
Patient interest as the priority	The patient is critical in the healthcare world. They put patients as the highest priority compared with a physician.
Refrain harm	Harmful is the condition of causing harm to other people, such as posting unprofessional content.
Reliability	The quality of being trustworthy or of performing consistently well.
Reputation	Part of the social notion of trust or an expectation about an agent's behavior is based on information about the observation of its past behavior.
Respect	Part of respect for a person is the basis of the moral norm.

Responsibility	Part of the education given by the physician on a particular disease.
Safeguard	The system used a secure closed system with data encryption.
Self-Exam Wizard	Users are able to tap/sign/mark on the breast picture to plot the lesion area and share it with the physician. It has the capability to take a photo when a lump appears on the breast surface.
Sharing Information	The process of the physician delivering medical information to the public.
User Account	Privileged access by a user for keeping personal information safe.
Video Tutorial	This tutorial video will be presented visually and show how to do the correct practice of BSE.

KERANGKA ETIKA SISTEM PEMERIKSAAN SENDIRI PAYUDARA

ABSTRAK

Kanser Payudara adalah penyebab utama kematian wanita di Indonesia. Wanita di Indonesia memerlukan sistem pemeriksaan sendiri payudara (BSE) untuk mendapat maklumat dan berunding kes mereka dengan mana-mana doktor. Walau bagaimanapun, pelanggaran kerahsiaan pesakit, kekurangan kepercayaan pesakit terhadap tingkah laku doktor, dan kekurangan kawalan pesakit ke atas data mereka menjadi masalah utama dalam sistem BSE. Disebabkan ini, suatu sistem BSE yang boleh menjejaki data peperiksaan diri dan komunikasi bulanan antara pesakit dan doktor diperlukan. Dalam pembentukan sistem BSE, nilai etika dan kebolehpercayaan harus wujud sebagai sebahagian daripada kebolehan sistem ini. Suatu kajian tinjauan dijalankan untuk mengenal pasti tentang nilai etika dan kebolehpercayaan yang boleh digunakan dalam sistem BSE. Oleh itu, matlamat penyelidikan ini adalah untuk mengenal pasti nilai etika, tentukan faktor kebolehpercayaan yang sesuai serta mencadangkan suatu rangka kerja etika yang selaras bagi pembangunan sistem BSE. Kaedah gabungan penjelasan dijalankan dengan tinjauan kuantitatif terhadap 772 responden. Perbincangan kumpulan fokus kualitatif dijalankan dengan 32 peserta dalam menghasilkan kepentingan rangka kerja etika yang digunakan dalam sistem BSE ini. Hasil kajian menunjukkan nilai etika secara positif mempengaruhi sistem BSE dengan nilai $p < 0.001$, kebolehpercayaan secara positif mempengaruhi sistem BSE dengan nilai $p < 0.001$, dan rangka kerja etika adalah penting untuk dilaksanakan dalam sistem BSE disebabkan oleh pekali penentuan (R2) = 0.509. Implikasi penyelidikan telah menghasilkan rangka kerja etika untuk mewujudkan sistem BSE yang beretika. Kerangka etika juga memperkenalkan pembolehubah baharu

nilai Etika untuk pengesahan sistem dan Kebolehpercayaan sebagai alat ukuran kepercayaan pesakit terhadap doktor. Sistem BSE adalah antara sistem penjagaan kesihatan yang berkait rapat dengan data sulit pesakit, oleh itu penyelidikan ini memberi impak kepada keperluan nilai-nilai etika dan kebolehpercayaan disertakan dalam mana-mana sistem penjagaan kesihatan yang menggunakan data sulit pesakit.

ETHICAL FRAMEWORK ON BREAST SELF-EXAMINATION SYSTEM

ABSTRACT

Breast Cancer is the leading cause of mortality for females in Indonesia. There is a need for women in Indonesia to have a breast self-examination system (BSE) where they can seek information and consult their cases with any physician; However, violation of patient confidentiality, lack of patient trust in physician conduct, and lack of patient control over their data pose a major problem in the use of BSE system. For this reason, there is a need to design a BSE system that can track self-exam data and allow communication between patient and physician. In developing a BSE system, ethical and trustworthiness values should exist as a part of the system's ability. A survey was conducted to identify the ethical and trustworthiness values that can be applied to the BSE system. Therefore, this research aims to identify ethical values, determine the suitable trustworthiness factors, and propose an ethical framework that suits the development of the BSE system. The explanatory mixed-method carried quantitative survey with 772 respondents. A qualitative focus group discussion is conducted with 32 participants leading to the importance of an ethical framework being used in the healthcare system. The findings indicate that ethical values positively influence the BSE system with a p-value < 0.001, trustworthiness positively influences the BSE system with a p-value < 0.001, and an ethical framework is essential to implement in the BSE system due to the coefficient of determination (R^2) = 0.509. The research implication has produced an ethical framework for creating an ethical BSE system. The ethical framework also introduces a new variable of ethical values for system validation and trustworthiness as a measurement tool of a patient's trust in a physician. BSE system is a healthcare system

that deals with the patient's sensitive data; therefore this research impacts the need for ethical and trustworthiness values to be included in any healthcare system that uses patient's sensitive data.

CHAPTER 1 INTRODUCTION

1.1 Introduction

Cancer is the leading cause of death in economically developed countries and developing countries (Bray et al., 2018). Whereas, Indonesia as a developing country facing dilemmas of mortality cases reached almost 10 % of 270 million people (WHO, 2020).

Breast cancer is a key determinant of death for females across the globe (Bray et al., 2018) and in Indonesia (WHO, 2020). In this study, breast cancer is chosen because of the female capability of detecting and identifying cancer themselves. This is due to the visibility of the disease symptoms shown on the physical surface of the female breast. Screening for breast cancer could be done with the help of medical practitioners or the usage of screening tools. One of the screening tools is Breast self-examination (BSE) invented by Cushman Haagensen in 1950 (Thornton & Pillarisetti, 2008). BSE is an independent regular self-diagnostic technique conducted by a female in observing any suspicion and alterations such as lumps on the breast by means of a mirror (Longe, 2005). In employing a BSE tool, the need for medical practitioners could further confirmed a self-diagnostic exercise being done by the female. BSE is adopted worldwide including Indonesia.

BSE is a web-based system that can be integrated with social media sites such as Facebook. A large number of people suffering from breast cancer sought information and performed discussions with the physician on social media (Della Rosa & Sen, 2019; Denecke et al., 2015; Hale et al., 2014). Both Nastasi et al. (2018) and Della Rosa & Sen

(2019) had adopted social media. Nastasi et al. (2018) adopted Twitter in discussing the physician-patient interaction regarding healthcare issues. Out of 1345 tweets being made, almost 68% were discussing breast cancer screening guidelines. Meanwhile, the rest of the discussions were on other health issues. Similarly, Della Rosa & Sen (2019) shows that 70% out of 7029 Facebook posts were related to healthcare information and awareness of breast cancer. One study on the BSE system in social media demonstrates that, out of 1001 women who participated, 84% were attending the web-based breast screening successfully (Roberto et al., 2020). BSE system which was on growth to facilitate the needs of breast health knowledge and to decrease breast cancer worry is part of social media because it is a web-based services platform that allows users to be active in online exchanges. However, while the BSE tool is being adopted on either social media sites or independent web platforms, there are concerns relating to ethics such as violation of patient confidentiality (Chretien & Kind, 2013; Passat & Israhadi, 2021), lack of patient-physician trust accessing patient data (Mouslim et al., 2020), and lack of patient's control over their own data (Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018).

Referring to the BSE examination in Indonesia, the physician's conduct on patient data could lead to the patient's data being counterfeited by Indonesia's physicians (Vatikawa & Amnawaty, 2018). There is a lack of legal protection in terms of patients' privacy rights and data privacy protection in Indonesia (Nasser, 2013; Passat & Israhadi, 2021). This contributes to cases of medical disputes such as loss of medical records confidentiality.

In terms of aggressive social media usage in Indonesia, the lack of privacy protection would be harmful to patients' sensitive data. An example published in The Jakarta Post with the headline "Covid-19 patients become victims of Indonesia's Lack of

Privacy Protection" has shown the downside effect of social media on privacy breaches. Indonesia's first Covid-19 patients claim due to the media coverage and discussion on social media; had left them mentally drained (Shakriah et al., 2020). The impact has taken a greater toll on them than the disease itself.

A patient's medical record data could be manipulated by physicians even though the records appear as part of health services and as a legal basis on the facts of the patient's condition. The problem lies in the patients' medical records counterfeited by physicians in Indonesia in terms of ethics and law aspect (Vatikawa & Amnawaty, 2018). The patient's data privacy could be treated in an ethical manner even though unlawful. But when the emphasis is on the unlawfulness of the physicians, they are automatically considered unethical. Therefore, ethics should be officially educated to the physicians and applied to the system so as to minimize malpractice since counterfeiting the patient's medical record data indicates a part of violation of the patient's confidentiality.

The confidentiality of patients' data is legal protection of patients' privacy rights. A patient's medical record itself is a file of notes and documents covering the patient's identity, examination, treatment, actions, and other services (Vatikawa & Amnawaty, 2018). In Indonesia, ethics guidelines are well maintained and protected under the Minister of Health Regulation no. 269/Menkes/Per/III/2008 concerning medical records (Passat & Israhadi, 2021). Protection of personal data in the electronic system has been declared by the ministry of communication and informatics of the Republic of Indonesia since 2016. Under Article 2, personal data protection is clearly defined as the law to be followed (Sari, 2016). There is one example that Indonesia's women will feel ashamed if their breast cancers are disclosed by physicians (Solikhah et al., 2020). They need an

ethical system that really protects their private data or confidentiality. However, as a fact, most healthcare systems do not implement ethics guidelines into their system (Mouslim et al., 2020; Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018) because there are no specific guidelines for the healthcare system. The existing ethics guidelines were based on ethics for medical practice (AMA, 2001; Beauchamp & Childress, 2009) and ethics guidelines for electronic mail (Bovi, 2003).

Even though ethical values dealing with confidentiality seem to have common sense; people still failed to seriously adopt the values within any healthcare solutions being developed. The study is essential to formulate a comprehensive ethical framework for a web-based online healthcare system especially BSE since most of the currently existing online healthcare systems have no or limited ethical features. The newly proposed ethical framework would be beneficial to increasing public trust in the medical profession and eliminating ethical dilemmas in the healthcare system.

1.2 Analysis of the Existing Healthcare System on Facebook

Seven healthcare systems are being observed on Facebook and the website is being analyzed on its ethical guidelines and policies. Table 1.1 demonstrates the analysis of ethical values that appear in the healthcare systems which are being hosted by social media specifically the Facebook platform and website portal. Ethical values consist of six indicators such as *interaction, integrity, confidentiality, protection, caring, and fairness*.

Interaction is defined as the value of communication in interpersonal interaction between patient and physician while *integrity* is the quality of being honest and having strong moral principles. *Confidentiality* on the other hand is the obligation of persons who receive information in the context of the intimate relationship, which respects the privacy

interests of the person-related data and keeps data safe. *Protection* is the act of protecting somebody/something from any harm and whereas, *caring* is the quality of care by a physician to the patient, either through direct interaction or an online approach. Finally, *fairness* is the quality of treating people equally or in a way that is right or reasonable. The analysis is done by identifying the meaning of every sentence on each guideline and policy provided by the healthcare system and the relationship to the ethical values.

Among the healthcare systems which integrated ethical values such as confidentiality, protection, and fairness within their existing guidelines are the Memorial Healthcare System (MHS, 2021) and Genesis Healthcare System (GHS, 2021). Meanwhile, Keep-A-Breast (Mendoza, 2021) healthcare system had embedded ethical values related to protection and fairness. However, other listed healthcare systems presented in Table 1.1 are still lacking any ethical values embedded within their systems.

Table 1.1 Overview of existing Healthcare System Guidelines

Existing Healthcare System on Facebook	**Guidelines/ Policy/Law**	**Ethical values**					
		interaction	**integrity**	**confidentiality**	**protection**	**caring**	**fairness**
Memorial Healthcare System (MHS, 2021)	Social media	x	x	√	√	x	√
	Website/mobile	x	x	√	√	x	√
Genesis Healthcare System (GHS, 2021)	Social media	x	x	√	√	x	√
	Website	x	x	√	√	x	√
Bunda Medik Healthcare System (BMHS, 2021)	Social media	x	x	x	x	x	x
	Website	x	x	x	x	x	x
Halodoc (Halodoc, 2021)	Social media	x	x	x	x	x	x
	Website/mobile	√	x	x	x	x	x
MAKNA (Makna(LUDIc), 2017)	Social media	x	x	x	x	x	x
	Website/mobile	x	x	x	x	x	x
The Breast Control (BC, 2021)	Social media	x	x	x	x	x	x
	Website/mobile	x	x	x	x	x	x
Keep-A-Breast (Mendoza, 2021)	Social media	x	x	x	x	x	x
	Website/mobile	x	x	x	√	x	√

Note: √= exist, x = not exist

In addition, the ethical values being added are also not comprehensive and misleading. For example, even though the value of confidentiality appears on Memorial Healthcare System (MHS, 2021) and Genesis Healthcare System (GHS, 2021) Facebook

sites; both systems do not employ any mechanism for informed consent in accessing sensitive patient data. One approach to invoke informed consent is the usage of one-time approval. Without any approach used to enforce confidentiality, it is against the principles of ethics in which informed consent must be obtained each time when patient's data is being accessed (Beauchamp & Childress, 2009). In addition, the lack of integrity indicator within the healthcare system means there is no honesty and trust in physician-patient interactions. As a result, patients are unable to provide any good rating in evaluating the physician's performance. As well as with the lack of protection indicators within the healthcare system simply means that patient data could be disrupted, modified, and disclosed to unauthorized personnel at any time. Based on Table 1.1 analysis, the minimum protection and lack of confidentiality value will cause patients to lose control over their data as well. Based on seven healthcare systems being reviewed in Table 1.1, it can be concluded that most of the systems (BC, 2021; BMHS, 2021; GHS, 2021; Halodoc, 2021; Makna(LUDIc), 2017; Mendoza, 2021; MHS, 2021) are still without any ethics indicators and for that healthcare system that integrated only a few ethics indicators (GHS, 2021; Mendoza, 2021; MHS, 2021); still, fail to comply to the ethical principles. A more in-depth discussion on the existing healthcare system in Table 1.1 will be presented in Chapter 2; section 2.2.2.

A lack of integrity value will avoid the patient to view the physician's performance and a lack of protection and confidentiality will generate the uncontrolled ability of patient's data as stated in Table 1.1.

1.3 Research Problems

BSE system has become an essential aspect of a female's life. Females are curious about getting information on their diseases before going to a physician and prefer to seek health information from social media (Mouslim et al., 2020; Prochaska et al, 2017). On the other hand, the physician adopts the BSE system to assist patients' treatment and consultation (Attai et al., 2015; Brown, 2014; Hardavella et al., 2017; Prochaska et al., 2017). The social media context is a platform of the BSE system used by patients who are looking for treatment and consultation with a physician.

Social media such as Facebook have brought health data privacy and confidentiality lapses (Chretien et al, 2009; Fisher & Clayton, 2012; George & Bhila, 2019; Greysen et al., 2013; Kind et al, 2012; Passat & Israhadi, 2021; Shakriah et al., 2020; Vatikawa & Amnawaty, 2018). Patients and healthcare leaders expect healthcare data to be protected. Unfortunately, these expectations are hard to be achieved due to the absence of ethical guidelines and policies within the healthcare systems. As the result, data protection for patients could not be achieved (Schechner & Secada, 2019; Sharp, 2019).

The analysis of the existing healthcare system in social media as mentioned in Table 1.1 has shown the lack of patient confidentiality, lack of trust in physician conduct, and lack of control over patient data.

The confidential communication between patients and physicians in the BSE system should employ ethical guidelines for data protection. These guidelines should be able to secure the data being communicated between patient and physician. Therefore, based on the analysis presented in Table 1.1; the research gaps are identified.

1.3.1 Violation of patient confidentiality

Patients prefer to discuss their breast cancer disease in the BSE system as a convenient venue (Denecke et al., 2015; Mouslim et al., 2020; Prochaska et al., 2017; Roberto et al., 2020). Physician tends to use the BSE system for assisting, treating, and consulting patients on cancer (Brown, 2014; Chretien & Kind, 2013; Mouslim et al., 2020; Prochaska et al., 2017; Roberto et al., 2020). The analysis of the existing healthcare system on Facebook as mentioned in Table 1.1 shows that the healthcare systems lack ethical values such as interaction, integrity, confidentiality, protection, caring, and fairness.

Most of the systems do not employ any mechanism for informed consent in accessing sensitive patient data. Supposedly, it should be compulsory to get a patient's informed consent before the use of the patient's data (Beauchamp & Childress, 2009; Chretien & Kind, 2013). Out of seven healthcare systems being analyzed, only two systems had embedded confidentiality value within their guidelines. A healthcare system that does not protect its data of confidentiality would lead to unethical usage of patient-sensitive data by unauthorized personnel. Without any approach used to enforce confidentiality, it is against the principles of ethics in which informed consent must be obtained each time when patient's data is being accessed (Beauchamp & Childress, 2009). Therefore, the confidentiality of patients' medical data in the BSE system is an essential factor in enforcing ethical healthcare systems (Chretien & Kind, 2013; Decamp, 2015; Passat & Israhadi, 2021; Tariq & Hackert, 2021; Ventola, 2014).

1.3.2 Lack of Trust in Physician Conduct on patient's data

Issues related to the conduct of a physician on a patient's medical data are focusing on communicating sensitive data with other unauthorized third parties and counterfeiting

medical patients' records (Chretien & Kind, 2013; Greysen, Chretien, Kind, Young, & Gross, 2012; Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018). These issues could lead to patients losing their trust in the physician's conduct which would then affect the physician-patient relationship (Chretien & Kind, 2013; Mouslim et al., 2020; Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018). As shown in Table 1.1, the existing healthcare systems do not support the integrity value for the physician on its guidelines. Integrity value means the physician must have albeit the need for ensuring data is not being shared and altered in any manner. The act of manipulating data could impact patients' trustworthiness toward a physician. For instance, a physician who would counterfeit any medical data will eventually lose the trust of his patients.

Based on Table 1.1, Halodoc (Halodoc, 2021) is the only healthcare system that provided a thumb of performance rating for the healthcare system in a form of quick response and engagement service. The ratings provided however are not for the physician. Without evaluating a direct patient's trust in a particular physician (Chretien & Kind, 2013), there is a lack of reference for any future patients that require the expertise of a physician in the domain of breast cancer. With only minimal or no details for future references being made by previous patients, new patients will not be able to put their trust in the physicians. Without a trust indicator being invoked, it is hard to obtain ethics within any system. Therefore, the trust value is an essential factor in any design of ethical guidelines.

1.3.3 Lack of patient control over their data

The manipulation of patients' data by physicians has created patients' distrust of the physicians and hospitals (Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018). In

this case, patients have a lack of control over their data specifically, the patient's medical record and communication history with the physician. Based on Table 1.1 analysis, the minimum protection and lack of confidentiality value will cause patients to lose control over their data. In addition, the patient and physician communication history records should also be within the patients' control (Passat & Israhadi, 2021; Vatikawa & Amnawaty, 2018). The interaction being held within the BSE system, between patients and physicians should always abide by the ethical guidelines (Chretien & Kind, 2013; Denecke et al., 2015; Mouslim et al., 2020).

1.4 Research Objectives

The research goal mainly focuses on proposing an ethical framework for the BSE system. The BSE system will facilitate the self-exam data and interaction between patients and physicians complying with ethics indicators. The study is focused on the BSE web-based system that could be accessed through the Facebook platform. In this study, steps to build an ethical framework for the BSE system are presented to achieve the goal. Therefore, the research objectives are as follows:

i. To identify the ethical values that influence the design of the BSE system.
ii. To identify the suitable trustworthiness factors that influence the design of the BSE system.
iii. To propose an ethical framework that is suitable for the BSE system.

1.5 Research Questions

The research questions focus on the fact that there are a lack of patient confidentiality, lack of trust in physician conduct, and lack of control over patient data. The questions emphasize identifying ethical values, trustworthiness factors, and proposed

ethical framework for the BSE system. Therefore, the research questions for this study are:

a. What are the ethical values that influence the BSE system?
b. What are the trustworthiness factors that influence the BSE system?
c. What is the ethical framework that suits the BSE system?

1.6 Research Scope

The scope of our research area focuses on the interaction between physicians and patients (females aged 18 and above) in the BSE system. Since the BSE system is a tool for early detection, the patient will be any females who are actively working and identified as an outpatient. The data collection will be conducted in Jakarta, the capital city of Indonesia due to the fact that Jakarta is the five top cities of active Facebook users in the globe (Kemp, 2018). The distribution of questionnaires was made for physicians from several hospitals and outpatient working females from Universitas 17 Agustus 1945 Jakarta.

There are seven hospitals involved which are Rumah Sakit (RS) Rayal Pragress, RS Gatot Subroto, RS Mitra Kemayoran, RS Dr.Mintohardjo Jakarta, RS Jakarta, RS Umum Pusat persahabatan, and RS Puri Indah. The ethical framework will be emphasizing the process of interconnected ethical values and trustworthiness with the BSE system as a guide to its users to conform to the appropriate ethical conduct during their interaction.

1.7 Research Contributions

The study has significant contributions to the healthcare practitioners, the body of knowledge, and the public. Among the contributions are items as listed below:

a. A comprehensive list of ethical values as a new variable that influences the BSE system. Ethical values have come up with several indicators such as interaction, integrity, confidentiality, protection, caring, and fairness.
b. Comprehensive trustworthiness indicators have been ranked based on the requirement of the BSE system. These indicators were enhanced from the existing multi-faceted trust approach. Besides trust propensity is a moderator of the relationship between trustworthiness and the BSE system.
c. A Breast Self-Examination (BSE) system prototype that integrated both trustworthiness and ethics indicators is developed.
d. An ethical framework that is designed and tested for the BSE system. The ethical framework covers four valid variables. There are ethical values, trustworthiness, trust propensity, and the BSE system.
e. The trust propensity indicator has been tested as a moderator on the relationship between trustworthiness and the BSE system. These indicators were enhanced from the existing trust model.
f. A comprehensive explanatory mixed method was applied to the validation of the ethical framework for the BSE system.
g. A comparison analysis that identifies the relationship between ethical values and trustworthiness in the fields of healthcare.

Table 1.2 explains the summary of the research objectives in detail. The review provides a clear picture of the relationship between the research objective and the research question, research problem, research gaps, methodology, as well as contribution.

Table 1.2 Summary of Research Objectives

Research Objective	Research Question	Research Problem/s	Methodology	Contribution
To identify the ethical values that influence the BSE system.	What are the ethical values that influence the BSE system?	Violation of patient confidentiality	Explanatory Mixed-Method	a) A comprehensive list of ethical values as a new variable that influences the BSE system. Ethical values have come up with several indicators such as interaction, integrity, confidentiality, protection, caring, and fairness
To identify the suitable trustworthiness factors that influence the BSE system.	What are the trustworthiness factors that influence the BSE system?	Lack of Trust in Physician Conduct on patient's data		b) Comprehensive trustworthiness indicators have been ranked based on the requirement for the BSE system. These indicators were enhanced from the existing multi-faceted trust approach. As well as, trust propensity as a moderator on the relationship between trustworthiness and the BSE system. c) Design a BSE system prototype that aims to apply trustworthiness indicators.
To propose an ethical framework that suits the BSE system.	What is the ethical framework that suits the BSE system?	Lack of patient control over their data		d) An ethical framework is designed and tested for the BSE system. The ethical framework carries four valid variables. There are ethical values, trustworthiness, trust propensity, and the BSE system. e) The trust propensity indicator has been tested as a moderator on the relationship between trustworthiness and the BSE system. These indicators were enhanced from the existing trust model. f) A comprehensive mixed-method was applied to the validation of the ethical framework for the BSE system. g) A comparison analysis was made on the relationship between ethical values and trustworthiness in the fields of healthcare.

1.8 Definition of Variables

This thesis contribution introduces four variables for the ethical framework of the BSE system. There are ethical values as independent variable 1, trustworthiness as independent variable 2, BSE system as a dependent variable, and trust propensity as moderation variable.

Ethical values are derived from the principles of biomedical ethics (Beauchamp & Childress, 2009) and AMA principles of medical ethics (Chretien & Kind, 2013). The Ethical values (IV1) carry interaction, integrity, confidentiality, protection, caring, and fairness.

Trustworthiness is derived from the multi-faceted trust model (Quinn et al, 2009). Trustworthiness is an independent variable 2 consists of honesty, reputation, competency, reliability, credibility, belief, confidence, and faith. Whereas the BSE system is derived from seven existing BSE systems. BSE system as a dependent variable that carries user account, calendar, self-exam wizard, history, chat room, forum, knowledge, location for treatment, and video tutorial.

Finally, Trust propensity is derived from the principle of the trust model (Mayer & Davis, 1995) and initial trust formation (Mcknight et al., 1998). Trust propensity is a moderation variable that carries faith in humanity and a trusting stance.

1.9 Organization of Thesis

This thesis consists of seven chapters, including (1) introduction, (2) literature review, (3) theoretical framework and hypotheses, (4) research methodology (5) analysis and result, (6) discussion, and (7) conclusion. Chapter 1 introduces the background of the study that emphasizes the research problem, research objectives, research questions, scope, and study contributions. Chapter 2 emphasizes the literature review that includes the theory of ethics, existing ethical framework, identifying ethical values, the theory of trust, analysis of choosing trust indicators, and breast self-examination systems and evaluation. Chapter 3 proposes a theoretical framework and hypotheses for the proposed study. Chapter 4 reports the research methodology. Chapter 5 explains the analysis and result, along with the interpretation of the results. Chapter 6 describes the discussion to answer the research question on the finding that is relevant to the theory and research contribution. Finally, Chapter 7 provides the conclusion that contains the objective

research summary, the implication of the study, limitations, and recommendations for future work.

CHAPTER 2 LITERATURE REVIEW

2.1 Chapter Overview

This chapter reviews the research background, theory of ethics, theory of trust, breast self-examination (BSE), review related works, comparative analysis among ethical frameworks, the research gaps in the literature, and terms definition as presented in Figure 2.1.

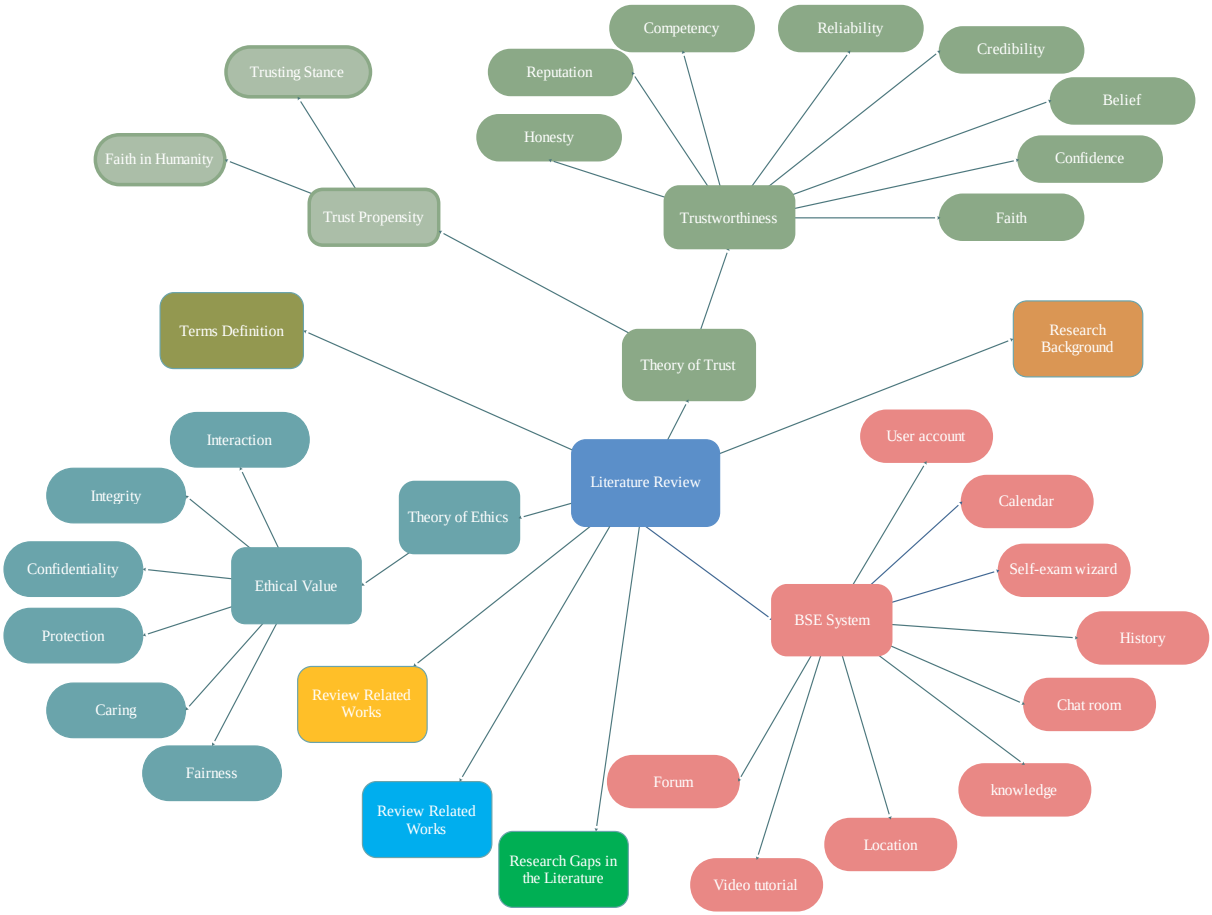

Figure 2.1 Mind map of Literature Review

The first section focuses on the chapter overview. In the second section, the study describes the research background related to ethical phenomena of healthcare on social

network sites, ethical phenomena on the existing healthcare system on Facebook, ethical phenomena on breast cancer, social media, and the conclusion of phenomena. In the third section, the explanation of the theory of ethics describes the philosophy and definition, history of ethics, the principles of ethics, differences between ethics and morals, and ethical values. In the fourth section, the theory of trust discusses in detail along with the definition of trust, the principle of trust model, the multi-faced trust model, and computational trust models. In the fifth section, there are some discussion of breast self-examination with some background on breast cancer and breast self-examination definition.

In the sixth section, there is a description of the review related to works on the existing ethical framework review, the analysis of chosen suitable trust model, the existing breast self-examination system review, and the comparative analysis among ethical frameworks. In the seventh section, discussion on the research gaps is presented and in the final section, there are terms' definitions on ethics and social media.

2.2 Research Background

According to the AMA code of medical ethics (AMA, 2001), the interaction between physician and patient either offline (face to face) or online (web-based or social media) should be ethically performed. However, there are a lot of issues on the ethical aspect in the healthcare system such as violation of patient confidentiality, inappropriate online communication, misconduct by the physician, profanity, and so on. The research background describes points based on several phenomena such as ethical phenomena of healthcare in social media, ethical phenomena on the existing healthcare system on Facebook, healthcare phenomena on breast cancer, internet usage of breast cancer

patients, and ethical phenomena conclusion. These studies are concerned with ethical phenomena that exist in the healthcare system. A lot of ethical issues exist in the healthcare system as presented in Table 2.2. Thus, our research will be emphasized on the BSE system under a web-based/internet platform.

2.2.1 Ethical Phenomena of Healthcare in Social Media

Social media can effectively be used by engaging the public in communicating critical public health messages. In the study by Brown et al. (2014), a survey on 1500 physicians' use of social media was carried out. Overall participants were 187 physicians, 19.4% participants received a friend's request from a patient, 30.5% communicated with the patient through email, 48.1% physicians offered patient information through electronic media, **21.2% communicated with a patient through Facebook or Twitter**, 60.8% accepted the fact which patients looked at their profiles before the consultation, and **65.8% were reluctant to use social media fully due to worries of protection on public access and legal concerns** (Brown, 2014). The nature of social media for collaborative use between people, participation, and openness has created concern for privacy, confidentiality, information sharing, and personal boundaries (Decamp, 2015).

Table 2.1 shows that the annual data presenting the violations of patient confidentiality discloses unethical aspects as the main concern on Facebook. These phenomena show the annual violations of patient confidentiality and the misconduct of physicians. The violation of patient confidentiality shows 13% from 130 participants in 2009, 47.8% - 65% out of 68 in 2012, and 79% out of 70 in 2013. Whereas data for the year 2018, 2019, 2020, and 2021 are not exactly in the form of data survey but only the claiming of violation happens. Even though the way of doing the survey is different but

the trend of increase is present in the cases of violation of patient confidentiality (Beltran-Aroca et al., 2016; Noroozi et al., 2018).

Table 2.1 Ethical phenomena on social media

Author	Violations of patient confidentiality	Depiction of intoxication	Profanity	Frankly discrimination language	Sexually suggestive material
(Chretien et al., 2009)	13%	39%	52%	48%	38%
(Kind et al., 2012)	-	74%	-	98%	97%
(Fisher & Clayton, 2012)	47.8%	-	-	-	-
(Greysen et al., 2012)	65%	-	-	-	69%
(Greysen et al., 2013)	79%	73%	77%	60%	-
(Vatikawa & Amnawaty, 2018)	Present	-	-	-	-
(George & Bhila, 2019)	Present	-	-	-	-
(Shakriah et al., 2020)	Present	-	-	-	-
(Passat & Israhadi, 2021)	Present	-	-	-	-

Based on a survey on 130 participants conducted by Chretien et al. (2009), 13% of respondents has claimed of patient violations of confidentiality. The violation action did such as posting patients' pictures related to their disease, sharing patients' information with other colleagues without any consent from the patient, and misbehaving with the patient. Those medical students received training on ethical codes and disciplinary action was given to those who avoid the ethical code. On the other hand, Greysen et al. (2012) did a survey of 68 executive medical directors that found 65% of violations came from a physician based on the reports from patients and patients' families. This report has brought disciplinary action from the US medical licensing authority such as license restriction, suspension, or revocation (Chretien et al., 2009; Greysen et al., 2012).

The fact is the unprofessional character of a physician such as posting inappropriate content, credentials misrepresentation, posting incorrect information, and false advertising or claims (Chretien et al, 2011). According to Lagu et al. (2008), out of 271 medical blogs, 11% of physicians have published healthcare product authorization for

commercial purposes. Moreover, the survey of 68 medical directors provided violation reports on online professionalism to state medical boards such as 69% on inappropriate online communication reported by the patients, 63% published on the improper practice of internet use, and 60% on online misrepresentation of credentials (Greysen et al., 2012). Therefore, the venue of interaction in the healthcare system between patients and physicians should abide by ethical guidelines (Chretien & Kind, 2013; Denecke et al., 2015; Mouslim et al., 2020).

2.2.2 Ethical Phenomena of Existing Healthcare System on Facebook

The ethical phenomena on social network sites have proven the violation of patient confidentiality and the unprofessional character of the physician in the previous section. This section will describe and synthesize the ethical phenomena in the existing healthcare system that exists on Facebook which is presented in Table 2.2.

The ethical phenomena in the healthcare system have brought the principles of biomedical ethics (Beauchamp & Childress, 2009) and the AMA principles of medical ethics (Chretien & Kind, 2013) to address the ethical aspect. This ethical principle has been derived from several ethical values such as interaction, integrity, confidentiality, protection, caring, and fairness. The existing healthcare system in Facebook will evaluate the system guidelines or policy based on the ethical values indicators.

Table 2.2 Existing Healthcare System on Facebook

Healthcare System in Social Network Sites	Aims	Media/Tool type	Function	Features	Guidelines/ Policy/Law	Patient's Informed consent	Physician Conduct Measurement	Control of Patient's Data	Ethical values
Memorial Healthcare System (MHS, 2021)	To be a premier clinically integrated delivery system providing access to exceptional patient-and family-centered care	Facebook page, Twitter, Instagram, LinkedIn, Mobile apps, and Web-based	Online chat for consultation with the physician for oncology, cancer, AIDS, etc.	• Find a physician • Location & Directions • Medical Services • Healthcare pricing	Present on: 1. Social media policy 2. Website & Mobile Apps a. Privacy and security b. HIPAA Privacy Notice c. IT security policies and videos d. Privacy policy for Foundation	One Time Approval	Absent	Hospital Database	1. Social media Policy **Exist of values** confidentiality, protection, and fairness. **Absent the values of** interaction, integrity, and caring. 2. Website & Mobile **Exist of values** confidentiality, protection, and fairness. **Absent the values of** interaction, integrity,& caring
Genesis Healthcare System (GHS, 2021)	An integrated healthcare delivery system that provides compassionate and quality healthcare	Facebook page, Instagram, Twitter, LinkedIn and web-based	Online appointment for a consultation with the physician for heart & vascular, lung care, cancer care, orthopedics, etc	• Find physicians • Search services • Request an appointment	Present on: 1. Privacy 2. Terms of Use 3. Discrimination is Against the law 4. HIPAA Notice	One Time Approval	Absent	Hospital Database	Website and Social media **Exist of values** confidentiality, protection, and fairness. **Absent the values of** interaction, integrity, and caring
Bunda Medik Healthcare System (BMHS, 2021)	To become a leading hospital in private health services in the field of Indonesian mothers and children, especially in Jakarta with	Facebook page, and web-based	Online chat for several diseases consultation	• Find a physician • Physician Schedule • Medical Facility	Absent	One Time Approval	Absent	Hospital Database	Absent the values of interaction, integrity, confidentiality, protection, caring, and fairness

	high-quality services								
Halodoc (Halodoc, 2021)	To provide a good service in helping patients with better treatment	Facebook page, Instagram, Twitter, Mobile Apps, and web-based	Online chat and appointment with a physician for diabetics, heart, stroke, breast cancer, etc	• Find a physician • Medicine Shop • Find Physician • Book an appointment	Present on Rules and regulation (syarat dan ketentuan)	One Time Approval	Present based on the thumb of performance	System Provider	Absent the values of interaction, integrity, confidentiality, protection, caring, and fairness
MAKNA (Makna(LUDIc), 2017)	To fight cancer and reduce related pain, morbidity, and the suffering that cancer patients undergo	Facebook page, Mobile apps, and web-based	Self-exam guidelines, practice, and recording into the system	• Calendar • Self-exam wizard • Knowledge • Location • Video tutorial	Absent	Absent of Approval	Absent	System Provider	Absent the values of interaction, integrity, confidentiality, protection, caring, and fairness
The Breast Control (BC, 2021)	To save millions of lives and the health of women who will avoid breast cancer with your help	Facebook page, Mobile apps, and web-based	A self-exam guidelines and practice	• Use account • Calendar • Tutorial • Instant help	Absent	Absent of Approval	Absent	System Provider	Absent the values of interaction, integrity, confidentiality, protection, caring, and fairness
Keep-A-Breast (Mendoza, 2021)	To reduce breast cancer risk and its impact globally	Facebook page, Mobile apps, and web-based	A self-exam guidelines and practice	• Calendar • Self-exam wizard • Information	Present on the website privacy policy	One Time Approval	Absent	System Provider	Website and Social media **Exist of values** of protection and fairness. **Absent the values of** confidentiality**,** interaction, integrity, and caring

As mentioned in Table 2.2, the memorial healthcare system (MHS) provided guidelines for social media and web site. The MHS's social media policy has declared that the guidelines do not follow the HIPAA act, are not used for professional medical advice, used for medical diagnosis or treatment, are not responsible for the patient's data, and no physician-patient relationship is established through information exchange, patients' own risk while accessing MHS social media. It is protected only to remove any posting at its sole discretion and remove any posting related to offensive material. The opportunity for violation of patient confidentiality exists, due to the responsibility of confidentiality that is not on the system but on human monitoring. Based on the above information, the MHS's social media policy identified several ethical values being followed such as protection and fairness. However, the ethical values of interaction, confidentiality, integrity, and caring are not fully supported.

The MHS's website and mobile apps have stated the guidelines on data privacy and security by not sharing information with others. Under HIPAA privacy notice, patient privacy, protect the confidentiality of patients' personal medical information and disclose patients' medical information for treatment, payment, healthcare operations, incidental disclosures, appointment reminders, and treatment alternatives. On the other hand, patients' rights to their medical information stated the right to inspect and copy, right to amend, right to an accounting of disclosures, right to request restrictions, and right to request confidential communications. The MHS's website and mobile apps guidelines have existed with several ethical values such as interaction, confidentiality, protection, and fairness. However, the ethical values of integrity and caring are not supported. Thus, MHS's social media policy, website, and mobile apps guidelines have brought several ethical values except for interaction with social media, integrity, and caring values. On the

other side, the room of authorization access under confidentiality value on informed consent from the patient is not available in each request section. Meaning that the confidentiality approval once to cater the access to the rest of the patient's data. The physician selection is not based on the patient's recommendation. The opportunity of patient confidentiality violation will occur in the system, due to patient data being fully controlled in the hospital and a lack of trust in physicians. Therefore, MHS is not an ethical healthcare system.

The genesis healthcare system (GHS) has declared the policies of social media while websites have covered the policy of privacy, terms of use, discrimination against the law, and HIPAA notices policies. The policy of privacy emphasizes the protection of patients' health information from unauthorized access. Disclosures of protected health information on medical treatment about a patient to providers such as physicians, nurses, technicians, and medical students are compulsory in a one-time declaration on the website (GHS, 2021). This policy is against the principles of ethics on confidentiality that patients must get informed concerns while using their personal health information. On the other hand, the terms of use policy emphasize the use of the public internet provided by genesis. It is supporting the principles of ethics on protection. The policy of discrimination is against the law that emphasizes no discrimination based on race, color, national origin, age, disability, or sex. It is supporting the principles of ethics on caring and fairness. The policy of HIPAA notices has emphasized the uses and disclosures of protected health information such as disclosures for treatment, disclosures for payment, and so on. The genesis website and social media policies have supported several ethical values such as confidentiality, protection, and fairness. However, the ethical values of integrity, caring, and interaction are not supported. In conclusion, the genesis website and social media