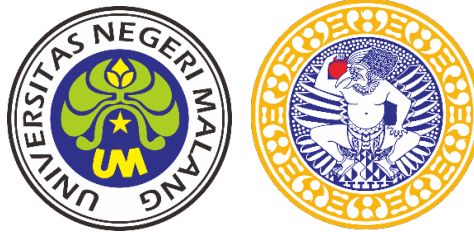# UNIVERSITY OF MALAYA

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Characterizing the Consumer's Behavior in the Adoption of Patient Social Network Systems for E-Patient Activities

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The e-patient movement and participatory medicine have risen the awareness of health literacy among the consumers, people of non-medical professionals. The consumers have been actively participating in a dedicated patient social network system (such as PatientLikeMe) to share health information and experience with others who encounter similar conditions. This patient collaboration provides valuable healthcare resources to develop an effective participatory medication among patients, caregivers, and medical professionals. This study aims to investigate what motivates the patient to participate in a patient social network system and how they engaged in e-patient activities, such participating in a discussion about a specific disease, comorbidity, or home treatment; and conducting an online consultation with medical professionals. The behavioral model is constructed based on the integration of Affective Events Theory (AET) and Self-Determination Theory (SDT). The AET is used to model the structure, the cause of affective driven behavior, and the consequences in the form of affective response. While SDT is used to model passion (i.e., engagement in patent social networks) and its relationship with behavior. The data analysis and the model testing are based on the Partial Least Square Structural Equation Modeling (PLS-SEM) using the responses of 428 patient social network users. The result indicates that the emotion of a particular event (such as medical history or past experiences) triggers the consumer's intention to participate in health information sharing and other e-patient activities. The findings from this study suggest the implementation of advanced personalization in a patient social network system to promote the consumer's participation. The advanced personalization includes emotion recognition based on the consumer's text analysis and the improvement of the patient's recommender system based on multiple parameters.

Keywords: health information sharing, behavioral model, patient network social system, affective events theory, self-determination theory

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ABSTRACT   The e-patient movement and participatory medicine have risen the awareness of health literacy among the consumers, people of non-medical professionals. The consumers have been actively participating in a dedicated patient social network system (such as PatientLikeMe, Ben's Friends) to share health information and experience to others who encounter similar conditions. This patient collaboration provides valuable healthcare resources to develop an effective participatory medicine between patients, caregivers, and medical professionals. This study aims to investigate what motivates the patient to participate in a patient social network system and how they engaged in e-patient activities, such as participating in a discussion about a specific disease, comorbidity, or home treatment; and conducting an online consultation with medical professionals. The behavioural model is constructed based on the integration of Affective Events Theory (AET) and Self- Determination Theory (SDT). The AET is used to model the structure, the cause of affective driven behaviour, and the consequences in the form of affective response. While SDT is used to model passion (i.e., engagement in patient social networks) and its relationship with behaviour. The data analysis and the model testing are based on the Partial Least Square Structural Equation Modelling (PLS-SEM) using the responses of 428 patient social network users. The result indicates that the passion and the empathy trigger the consumer's participation in patient social networks. The findings from this study also suggest the implementation of advanced personalization in a patient social network system to promote the consumer's participation. The advanced personalization includes emotion recognition based on the consumer's text analysis and the improvement of patient recommender system based on multiple parameters.

Keywords: health information sharing, behavioural model, patient network social system, affective events theory, self-determination theory

1.   INTRODUCTION

The e-patient movement and participatory medicine have encouraged consumers, people of non-medical expert, to actively participate in healthcare and to live a healthy lifestyle. A study of Pew Internet revealed that one in three adults in USA accesses the Internet to search for a diverse range of health topics and concerns (Fox and Duggarn, 2013). Another study within the Australian region suggested that 80% of the Internet users participate in health information seeking online (Mc Daid, Park, Bupa, 2010). The rising trend also applies in other regions, such as in Scotland (Moreland), French (Beck et al), and Taiwan (Fong Ching Chang). Other studies have examined health information seeking behaviour based on medical and physiological perspectives (MAchi Suka, Conell et al, Kenneth lee), consumer's characteristics (Puspitasari et al., 2015, medlock), and social context (Hayeon Song, young ji lee).

In addition to health information seeking on the Internet, the consumers also actively participate in patient social network systems (PSNS) to connect with others who encounter similar

conditions, particularly chronic health conditions. Some examples of patient social network systems are PatientLikeMe (www.patientslikeme.com), Ben's Friends (bensfriends.org), and Society for Participatory Medicine (participatorymedicine.org). The patient communities in PSNS serve as a bedrock of health education in consumer-friendly language, a platform to exchange information and experience related to disease and medication, and a facilitating system for home treatment and emotional support between consumers and families. Likewise, medical professionals have recognized the roles of patient communities in support self-management and long-term medication (Naslund et. al., 2016). They also take part in the communities to administer health-related discussions and to provide advanced medical consultation.

Consumers' engagement (both participation and contribution) delivers the benefit of a patient community. It characterizes the community and creates valuable healthcare resources to support participatory medicine between patients, caregivers, and medical professionals. Similar to other online communities, the patient's engagement in a patient social network system is voluntarily-based and defines the sustainability of the patient community. Previous studies have investigated the underlying motivation and influencing factors that drive a member to continuously engage in an online community. Participating in an online community can be encouraged by several different motivations, such as enjoyment to help others (xiao ling jin, tauschik), altruism (Ma and Chan 2014, Oh), self-development (xu and bailey, nov et al 2010), and building reputation (jiahua jin). In a study of health communities focusing on infertility, the participation includes posting support for others, that is driven by socio-emotional motivation, and receiving support from others, that is driven by informational motivation (Welbourne, Blanchard, and Wadsworth; 2013). The informational motivation further strengthens the sense of community connectedness and sustainability. Another study of knowledge sharing in social media revealed that perceived online attachment motivation, perceived online relationship commitment, and altruism have positive significant impacts on the knowledge sharing activity (Ma and Chan, 2014).

Understanding the patient motivation and examining what factors drive the consumer to engage in patient community have formed the key analysis in online health community studies. While the consumer's participation defines the community's sustainability, it is also one of the most challenging issues in the community development. In the case of patient social network systems, user affect is an important factor that motivates the patient and other members to engage in the community as these social interactions naturally occur in any social technologies. Understanding and applying health materials is perceived to be more difficult than other topics. Thus, the motivation to participate in patient community is also inspired by passion for health information sharing.

This study aims to investigate what motivates the consumer to participate in a patient social network system and how they engaged in e-patient activities. This study applies the integration of Affective Events Theory (AET) and Self- Determination Theory (SDT) (Robin and Kirk, 2016) to test how the consumer's passion for health information sharing and the user's affect influence the use of a patient social network. The AET is used to model the structure, the cause of affective driven behaviour, and the consequences in the form of affective response. While SDT is used to model the passion (i.e., engagement in patient social networks) and its relationship with the user's behaviour.

2.   RESEARCH METHODOLOGY

The consumers (i.e., patients, families, and caregivers) use the patient social network to engage in the community, such as participating in a discussion about a specific disease, comorbidity, or home treatment; and conducting an online consultation with medical professionals. This paper adopts the integration of AET and SDT approach (Robin and Kirk, 2016) to examine the contributing factors that influence the use of patient social networks. The first step of research activities was constructing the research model based on the AET and SDT integration, as shown in Figure 1. According to AET, the user affect has a direct impact on the use of patient social network. While SDT supports the linkage between the user's passion and the use of patient social network. Participating in a patient community carries a heavy burden. As the content contributor, consumers

must ensure they provide and share only reliable and accurate health materials. In addition, before applying the materials they received from the community, the consumers are required to do double checking to avoid misunderstandings as it may cause severe consequences (Puspitasari, 2017). Thus, it requires a strong passion to participate and to contribute in a patient community. Participating and conducting an activity based on the passion may generate a variety of emotion, one of them is the empathy. Empathy refers to the aptitude to understand and to feel what others are experiencing, thus inducing the desire to help them (Bellet and Maloney, 1991; Pijnenborg et. al., 2012). Empathy encourages the members of a patient community to extend their best effort because they share the same experiences and emotions pertaining to specific health conditions. This discussion leads to the following hypotheses.

H1: Empathy educed by the passion for engagement in a patient community positively impacts the use of patient social networks.

H2: Passion for engagement in a patient community is positively related to the empathy elicited by an event (i.e., e-patient activities in patient social networks).

H3: Passion for engagement in a patient community positively impacts the use of patient social networks.

Previous studies suggest that emotional factor is likely to amplify the passion for an activity that may result in more extensive affective behaviour. Thus, it is expected that the stronger the passion of engagement in a patient community, the more extensive the use of patient social network. However, this relationship is administered by the level of empathy and adds the following hypothesis.

H4: Empathy elicited by an event moderates the effect of passion for engagement on the use of patient social networks.
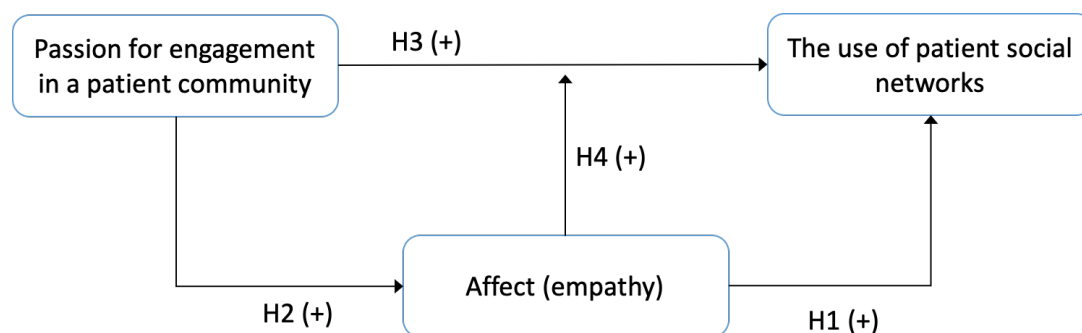

Figure 1: The research model.

The next activity was collecting the data using online questionnaire. The questionnaire enquired the demographics profile and the behavioural characteristics based on AET and SDT instruments. The behavioural questions were measured using 6-point Likert scale, i.e., strongly disagree (1), disagree (2), somewhat disagree (3), somewhat agree (4), agree (5), and strongly agree (6). The criteria for the recruited respondents were a member of any patient social network, aged 18 years and over, and had experiences of participating in at least one patient community. The data analysis and the model testing were based on the Partial Least Square Structural Equation Modelling (PLS-SEM) using the evaluation of the measurement model and the evaluation of structural model. The collected data was tabulated to characterize the respondents' profile and answers. The measurement model evaluation tested the validity and the reliability of the constructs, i.e., passion for engagement in a patient community (event), empathy (user affect), the use of patient social networks, and the moderating effect of empathy in the relationship between passion and the use of patient social networks. The structural model (inner model) evaluation tested the acceptance of the proposed hypotheses. The last activity was the discussion of the results obtained and the implications pertaining to the use of patient social networks.

3.   **RESULT**

3.1   Sample and Demographic Profiles

The number of minimum samples for the data collection was calculated based on the following Slovin's formula (Ryan T):

$$n = \frac{N}{1 + N(e)^2} \tag{1}$$

n = minimum sample size
N = population size
e = margin of error

The population size for this data collection was 670,000, the total member of PatientsLikeMe (www.patientslikeme.com) and Ben's Friends (bensfriends.org). The margin of error was set to 0.05, resulting in 399,761 ≈ 400 respondents as the minimum sample size.

A total of 450 respondents participated in the data collection, but only 428 respondents were successfully completed the questionnaire. Hence, the data analysis and the model testing were based on 428 valid responses. The majority of the respondents engaged in patient community on behalf of oneself as the patient (61.45%). Most respondents reported using the patient social networks weekly (36.21%) and monthly (34.35%). More than half of the respondents were aged between 41 and 50 years. The gender profile also confirmed prior study about the role of female in the family and society healthcare (Birdman 2015). The complete demographics profile of the respondents is presented at Table 1.

Table 1: Demographics Profile of the Respondents.

Category	n (%), N = 428
Age group (in years)	
18 – 30	46 (10.75)
31 – 40	113 (26.40)
41 – 50	174 (40.65)
51 – 60	79 (18.46)
> 60	16 (3.74)
Gender	
Male	181 (42.29)
Female	247 (57.71)
Role	
Patient	263 (61.45)
Family	121 (28.27)
Caregiver	44 (10.28)
Frequency of use	
Daily	36 (8.41)
Weekly	155 (36.21)
Monthly	147 (34.35)
As the need arises	90 (21.03)

1.1   The Measurement Model

The measurement model tests the validity and the reliability of the proposed constructs. A sufficient validity construct consists of a convergent validity test and a discriminant validity test. The results in Table 2 shows that the loading factor for all indicators exceeds 0.7 and the average variance

extracted (AVE) for all constructs is more than 0.5, indicating a favourable convergent validity (Fornell Lacker, Chin 1998).

Table 2: Construct, Measurement Item, Loading Factor, and AVE.

Construct	Indicator	Measurement Item	Loading Factor	AVE
Passion for engagement in a patient community	P1	I join patient social networks because I have a passion for helping other patients who share similar conditions with me.	0.887	0.625
	P2	I am interested to share my experience and knowledge about specific health topics to others.	0.931	
	P3	I am willing to do extra efforts to participate in patient social networks.	0.736	
Affect (empathy)	E1	I can feel the distress of other patients who recently have been diagnosed with a disease.	0.840	0.731
	E2	I am willing to share my detail experiences to cope with a disease to support other patients.	0.884	
	E3	I open more myself to others in patient social networks.	0.712	
	E4	I enjoy participating and having good discussions in patient social networks.	0.790	
	E5	It feels good to know that my contribution benefits others in patient social networks.	0.712	
Use of patient social networks	U1	I frequently use patient social networks.	0.775	0.606
	U2	I would like to continue to use patient social networks.	0.823	
	U3	My willingness to use patient social networks is high.	0.735	

The results in Table 3 demonstrates a satisfied discriminant validity as indicated by the cross-loading of each variable is larger than 0.7 and the square root of each construct's AVE is larger than its correlations with other constructs (Chin, 1998; Pavlou et. al.; 2006). The reliability test evaluates the internal consistency, one of the methods is calculating the composite reliability. The reliability test is considered acceptable since the composite reliability of each construct in Table 3 exceeds 0.7 .

1.2   *The Structural Model*

The structural model tests the relationship between constructs in the model. The results reveal that passion for engagement (β=0.870, *p*<0.001) and affect (empathy) (β=0.503, *p*<0.001) have positive impacts on the use of patient social networks, thus supporting H1 and H3. Similarly, there is a positive relationship between passion for engagement and the empathy (β=0.870, *p*<0.001), which confirmed H2. Lastly, the moderation effect of empathy to passion for engagement on the use of patient social networks demonstrates a significant impact (β=0.169, *p*<0.01), hence verifying H4. The structural model results are summarized in Figure 2.

Table 3: Discriminant Validity Test and Reliability Test.

	Passion for engagement in a patient community	Affect (empathy)	Use of patient social networks	Composite Reliability
Passion for engagement in a patient community	0.855			0.890

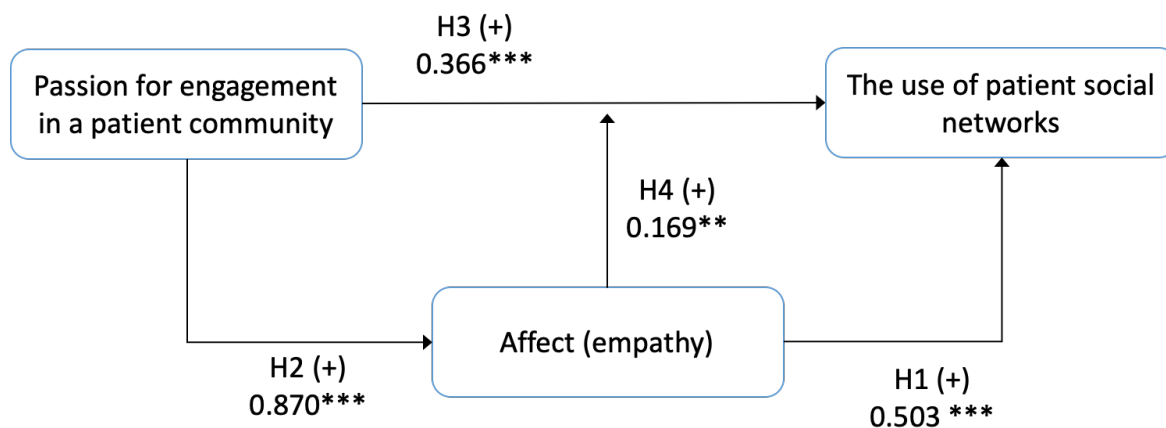| Affect (empathy)	0.840	0.790		0.892
Use of patient social networks	0.625	0.645	0.778	0.821

Figure 2: Structural model results. Note: * *p<0.05*, ** *p<0.01*, **p <0.001*.

4.   DISCUSSION

This study explores the contributing factors that affect the consumer to use patient social networks for e-patient activities based on the integration of AET and SDT. The positive correlation between empathy and the use of patient social networks in H1 shows that empathy motivates the consumer to engage in e-patient activities, particularly as the contributor. Experiencing a disease, especially a life-threatening disease, causes major impacts on a patient's life, such as the change in the physical and physiological conditions, the adjustment of aspiration, lifestyle, and work. In most cases, patients and even family members develop psychiatric disorder following a chronic disease diagnosis. This situation is perceived to be distressing, hence it could generate the feeling of empathy toward others who recently have been diagnosed with a chronic disease. This empathy emotion triggers the desire to help others that is demonstrated by the consumer contribution and continued efforts in patient social networks. This finding is also consistent with previous studies that reported empathy as one of the motivational factors to contribute health materials (information, answers to questions, knowledge, and experience) in patient online communities (Zhao et.al., 2013, Sanghee Oh, 2011).

The support of H3 suggests that the passion affects the use of patient social networks. Composing and contributing health materials in patient communities involves a meticulous research and a comprehensive understanding of specific health topic by expertise or by experience. It requires an intense cognitive effort, especially for nonmedical professionals, to produce reliable and accurate health materials. The passion to help others may encourage the consumer to do such intense cognitive effort using patient social networks. This finding is in line with prior studies in community of practice (CoP) that suggest the passion is one of the key factors of the CoP sustainability (Oliver Serrat 2017, Tseng and Kuo, 2013). The passion drives the learning process and knowledge sharing among its members.

Consistent with hypothesis H2, the results indicate that the passion for engagement in a patient community intensifies the empathy experienced by the users. The presence of passion and empathy may amplify the consumer motivation to participate in patient social networks.

Technical Implications and Future Research

In view of the rising e-patient movement and health information sharing using patient social networks, this study offers significant contribution in the consumer's behavioural study. The contributing factors that affect the use of patient social networks can be investigated further to be addressed in the future patient social network systems updates or new versions. The consumer's passion to participate in the patient community can be enhanced by adding acknowledgement features and incorporating user experience design. Another system improvement is an advanced personalization to connect patients with similar conditions. This feature is beneficial to promote the consumer's participation and to support the consumer's empathy while participating in patient social networks. The advanced personalization includes emotion recognition based on the consumer's text analysis and the improvement of patient recommender system based on multiple parameters.

Despite the conformity of the results and findings to the goals of this study, future works are required for further validation. It is advisable to investigate the moderation effect of other variables, such as gender, age groups, and educational attainment. Future study could also incorporate other physiological theories, such as protection motivation theory (PMT) or Health Belief Model, to refine the behavioural model.

5. CONCLUSION

This study examines the consumer's behaviour in the adoption of patient social network systems for e-patient activities. The consumer's behaviour is defined based on the contributing factors that motivate the consumer to participate in online patient communities. Passion for engagement in a patient community as well as the consumer's empathy affect the use of patient social networks. These factors are expected to amplify and to sustain the consumer's participation since contributing in health-related communities as non-medical professionals requires intense cognitive efforts. The results and findings from this study offer recommendations to further promote the consumer's participation in patient social networks, such as incorporating user experience design, adding acknowledgement features and advanced personalization tools.

Table 4: Structural model evaluation

Hypothesis		Path-coefficients (β)	P-value	Results
H1:	Empathy educed by the passion for engagement in a patient community positively impacts the use of patient social networks	0.503	0.000	supported
H2:	Passion for engagement in a patient community is positively related to the empathy educed by an event (i.e., e-patient activities in patient social networks).	0.870	0.000	supported
H3:	Passion for engagement in a patient community positively impacts the use of patient social networks.	0.366	0.000	supported
H4:	Empathy educed by an event moderates the effect of passion for engagement on the use of patient social networks.	0.169	0.00012	supported

Table 1: Title of Example Table.

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Micrasterias denticulata Brébisson ex Ralfs	Freshwater	200mM NaCl or 200mM KCl	Cell viability ↓, change in morphology, F_v/F_m ↓, ROS ↑
Tetraselmis suecica (Kylin) Butcher *Nitzschia* sp. *Alexandrium minutum* Halim *Prorocentrum lima* (Ehrenberg) F.Stein	Marine	5-35psu	Photosynthesis and growth were affected under low salinity. *T. suecica* showed the highest tolerance.

Tables and figures should be placed close after their first reference in the text. All figures and tables should be numbered with Arabic numerals. Table headings should be centred above the tables. Figure captions should be centred below the figures.
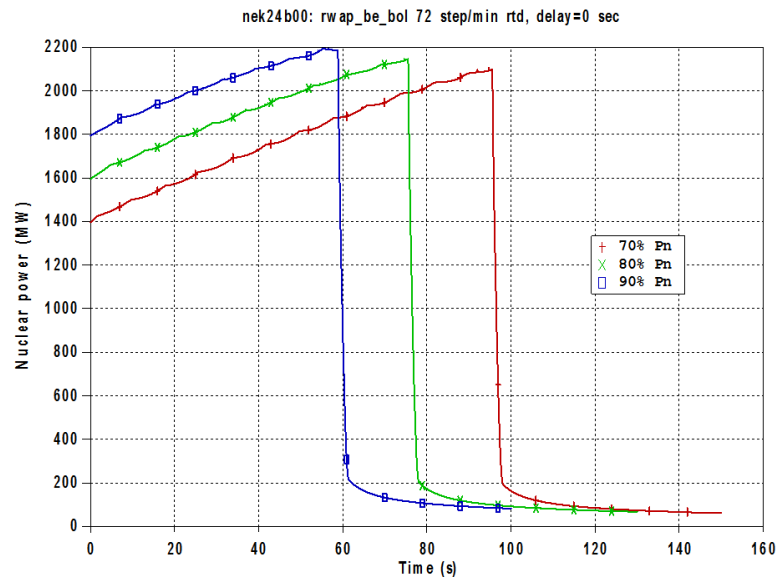
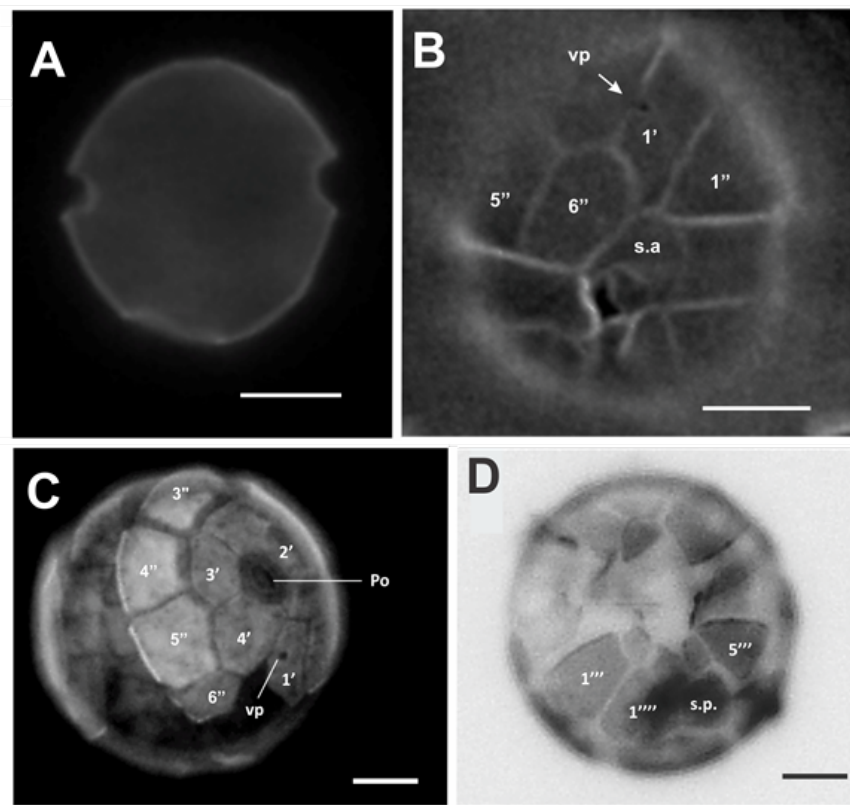**Figure 3**: Example of figure for the full paper.

Figure 2: Example of figure for the full paper.

1.1 Equations

Each equation should be presented on a separate line from the text with a blank space above and below. Equations should be clear and expressions used should be explained in the text. The equations should be numbered consecutively at the outer right margin, as shown in Eq. (1) and (2) below. Here is one example. The number of different ways that a specified component can fail with *(k-1)* other components in a group of *m* similar components is:

$$\binom{m-1}{k-1} = \frac{(m-1)!}{(k-1)!(m-k)!}$$

(1)

Thus, the total failure probability, Q_t, of component in a common cause group of *m* components is:

$$Q_t = \sum_{k=1}^{m}\binom{m-1}{k-1}Q_k^{(m)}$$

(2)

1.2 Reference

References should be listed in alphabetical order and appear at the end of the manuscript. **APA Style.** See also examples in the REFERENCES section of this template.

1. CONCLUSION

Conclusions should state concisely the most important propositions of the paper as well as the author's views of the practical implications of the results. The conclusion is intended to help the reader understand why your research should matter to them after they have finished reading the paper. A conclusion is not merely a summary of the main topics covered or a re-statement of your research problem but a synthesis of key points and, if applicable, where you recommend new areas for future research.

2. ACKNOWLEDGEMENT

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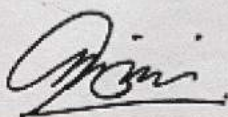
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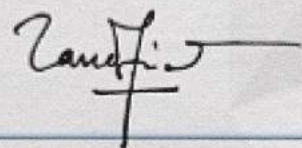## IRA PUSPITASARI

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